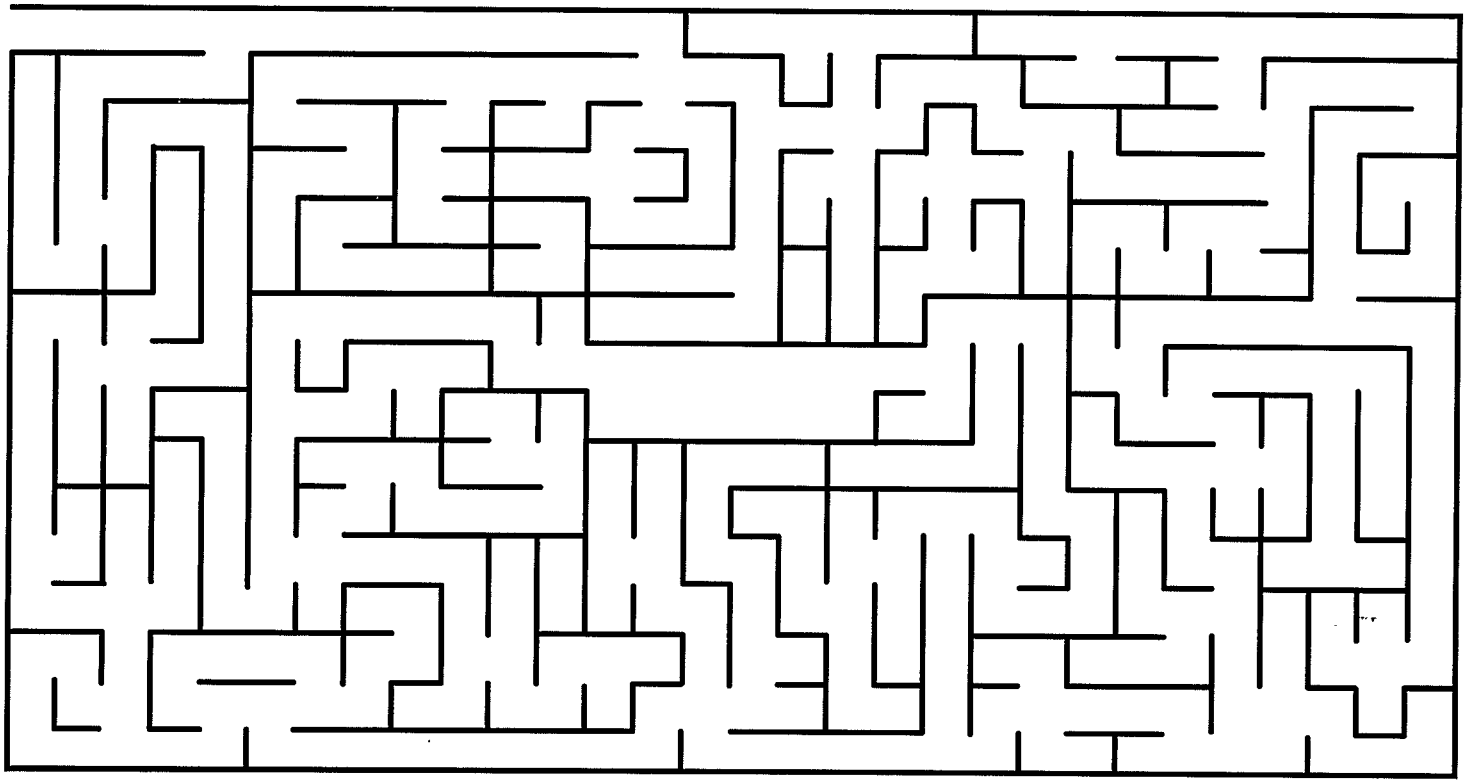
NATIONAL CENTER FOR HEALTH STATISTICS

Proceedings of the 1991 Public Health Conference on Records and Statistics

The 1990's: A Decade of Decisions for Vital and Health Statistics



Mayflower Hotel • Washington D.C.
July 15-17, 1991

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
Centers for Disease Control

CDC
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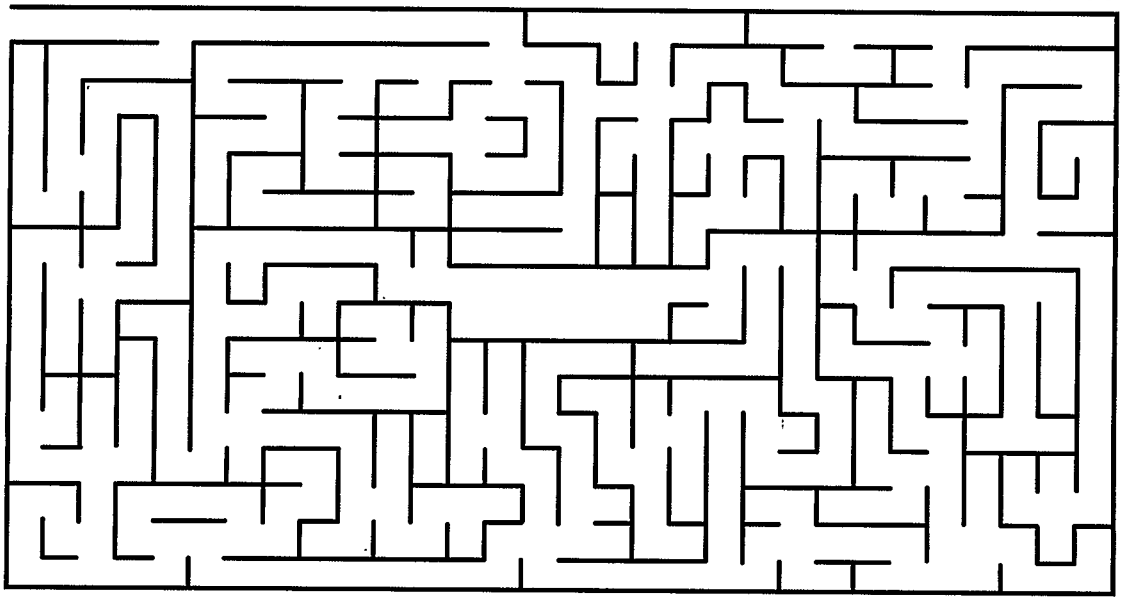

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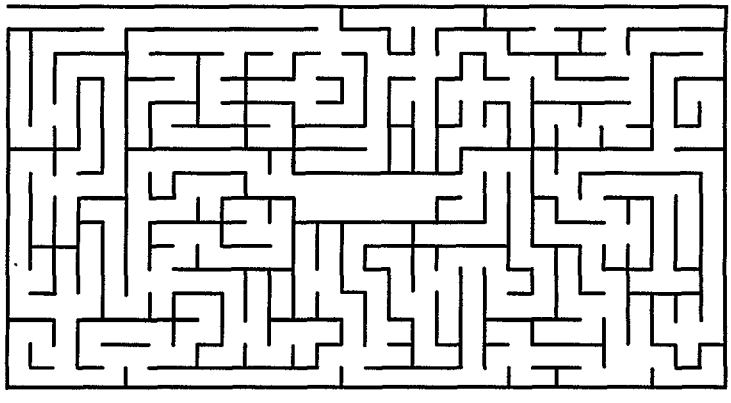
Each article has been prepared by the author.



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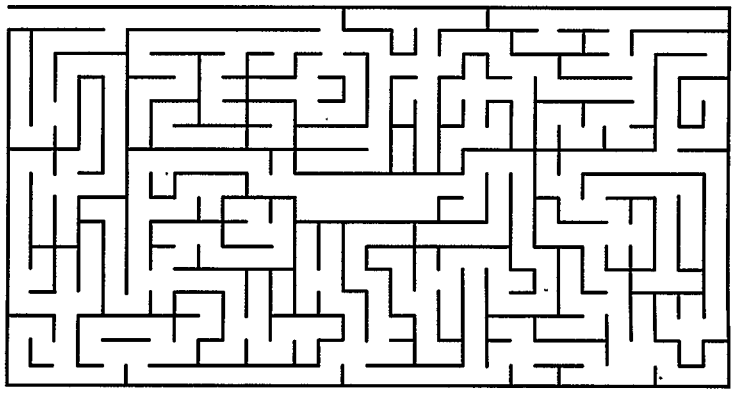
First Plenary Session

Opening Ceremony

Data Sytems for the Nation's Health Agenda



A DECADE OF DECISIONS FOR VITAL AND HEALTH STATISTICS

Dr. Manning Feinleib, National Center for Health Statistics

It is a pleasure to officially call to order the 23rd National Meeting of the Public Health Conference on Records and Statistics. It is also a pleasure to welcome all of you, to thank you for coming, and to wish you a most successful and interesting meeting.

Over 1,000 participants are pre-registered for the conference making this one of the largest PHCRS meetings. Many of you have attended previous public health conferences. A number of you, however, are new to this meeting. Perhaps some you are even new to the effort to produce and utilize vital and health statistics to improve the Nation's health. We welcome you and hope that you will provide a new perspective to our deliberations.

According to the Conference theme we are in a "Decade of Decisions for Vital and Health Statistics." I don't have to remind most of you about that.

At the Federal, State and local levels, health officials are making critical decisions on how to fund, provide and deliver services.

In the public health sector, we are deciding on the best methods to prevent disease, encourage good health practices, and prolong life with healthy, productive years. Additionally, we are trying to improve the health of our citizens, their communities, and our society by reducing violence and conflict.

That's where data come into the picture. We need reliable, timely, and relevant statistics to help achieve those goals. This Conference, with its focus on the interaction between the Nation's health agenda and data, provides a unique forum for exchange. From the opening session to the final workshop, we will have many opportunities to learn about the application of new methodologies, concepts and approaches to the complex health and health data issues we face.

This conference is a diverse gathering where the varied backgrounds and responsibilities of participants enrich the discussion and the results. We have tried, and I believe succeeded, in obtaining speakers and workshop leaders who can offer valuable insight.

YEAR 2000 HEALTH OBJECTIVES

You have already heard something about the Year 2000 Health Objectives this morning. Throughout this conference, you will hear more about the health promotion/disease prevention strategy that is the framework for public health at the National, state and local levels. And you will hear a good deal more about Objective 22 -- Surveillance and Data Systems. CDC, and specifically NCHS, has the lead responsibility to work with agencies at all levels of government to produce the data needed to monitor progress in reaching the 300 main objectives for the Year 2000.

RELEASE OF THE HEALTH STATUS INDICATORS

The 300 main objectives I have mentioned, as well as 220 sub-objectives, will be monitored at the national level. Many will be monitored at the state level. However, not all can be tracked at the Federal, state and local levels. To ensure that a central set of objectives could be followed at all levels of government, a core set of health status indicators has been identified.

The Year 2000 objectives came out of a process that involved thousands of professionals from many disciplines as well as health advocates and consumers. The process of developing the Health Status Indicators also drew upon the expertise of a wide range of individuals in the public and private sectors.

I would like to review that process with you. The effort was headed by a group called Committee 22.1, because the Health Status Indicators were called for in the first objective of Priority Area 22. Committee 22.1 consisted of health officers, researchers from academia, and representatives from the American Public Health Association, the Association of State and Territorial Health Officers, the National Association of County Health Officers, the U.S. Conference of Local Health Officers and the Public Health Foundation.

ASSISTANCE TO STATES

We're in this together: Federal, state and local agencies; public and private researchers and planners. The data needs of the Year 2000 objectives offer an excellent opportunity to strengthen the health statistics infrastructure. Let me mention a few key projects that are underway:

NCHS has developed a newsletter on statistical support for the Year 2000 objectives -- "Surveillance and Statistics for the Year 2000". This will feature:

-- updates on statistical techniques

-- summaries of new methodological approaches and

-- news of developments in Federal, state or local vital and health statistics agencies of importance to the Year 2000 objectives.

It will frequently be supplemented with a technical presentation on a specific surveillance or statistical methodology. We will seek contributions and news from all of you and welcome your suggestions for topics to cover. The first issue will be out this fall.

A new program of short training courses -- a new Applied Statistics Training Institute (ASTI) -- is underway. Three courses on measurement of the Year 2000 objectives at the state and local level have been developed and conducted. We began with an introduction to epidemiology and descriptive biostatistics. If planned resources are available, we expect this effort to expand to about 10-15 courses each year, given nationwide, and often drawing upon State and local health departments and universities for the instructors as well as the participants.

Working through the Public Health Foundation, NCHS will provide support for a selected number of states to do analyses of data for the Year 2000 objectives, involving minority populations and using the health status indicators.

HIGHLIGHTS OF THE CONFERENCE PROGRAM

I would like to take a moment now to give you a preview of the conference program. Each morning there will be a session addressing the major themes of the conference; Data Systems for the Nation's Health Agenda, Community Assessment, and New Concepts for the Decade of the 1990's.

There are 26 concurrent workshops and over 100 presentations on aspects of data development, analysis and use. I would like to draw your attention to a special session on "Release of Vital Statistics Data: Privacy and Data Utility". This session will provide a dialogue with data users on the issues of privacy and data availability.

We have an expanded exhibit area, with information on health programs from agencies focusing on the Year 2000 objectives. This year the exhibit area will feature a number of demonstrations of new NCHS electronic data products, including CD-ROMS and data diskettes. There are demonstrations of the WONDER and PC WONDER data retrieval programs. The exhibit area will also feature the new NCHS video "Monitoring the Nation's Health".

The conference logo is a maze. To me, that symbol depicts not confusion nor doubt, but the array of choices we face. This conference offers the opportunity to define those choices, select our paths, and begin our travels through the decade of decisions.

The Committee also relied upon input from the Data Streamliners (a group advising the Assistant Secretary for Health), as well as staff throughout the Centers for Disease Control, the Public Health Service and the Department of Health and Human Services. A conference of almost 200 participants was convened in early April to gather more information on what could and should be used to indicate health status.

On behalf of the Centers for Disease Control we are ready today to announce the Health Status Indicators for the Year 2000, published in the Morbidity and Mortality Weekly Report (MMWR) for July 12, 1991 (appended). We could choose no better forum for their release and discussion than this Public Health Conference on Records and Statistics.

Eighteen health status indicators have been chosen. These measures are not intended to replace any measure implied by the 300 plus objectives for the Year 2000. Neither are they intended to provide a priority subset. Rather, these indicators give a focus, among priority health areas, to measures which are feasible to produce, which are understandable, and which give general measures of health status within the community.

Other indicators were discussed and could have been selected. Indeed, there are several critical areas, such as environmental and occupational exposure, access to care, and use of preventive services, where data are not available to the extent and in the detail necessary to be used as indicators nationwide. In fact, recommendations were made for data improvement in these areas so that adequate measures can be obtained in the future. The details of the Indicators will be presented at a session this afternoon.

NATIONAL SURVEILLANCE ACTIVITIES

In addition to focusing our attention on the most important aspects of public health, the Year 2000' process focused our attention on data and data needs. We have worked to identify the core components of existing data, but are also working to expand the data available for the nation and in each community. Through national data systems we will be tracking and monitoring objectives and working with lead agencies in other government agencies. Some 40 percent of the Year 2000 objectives rely on data from NCHS; another 20 percent from the other CDC programs; and the rest other sources in PHS, DHHS, other government programs, and the private sector.

The availability of data and the central role of data in the Year 2000 objectives is in stark contrast to the health promotion and disease prevention objectives of 1990. Relevant and reliable data were identified and used in the 1990 process, but many of the objectives lacked a quantitative base to set a meaningful goal and to really measure progress.

CDC

July 12, 1991 / Vol. 40 / No. 27

MMWR

MORBIDITY AND MORTALITY WEEKLY REPORT

Health Objectives for the Nation

Consensus Set of Health Status Indicators for the General Assessment of Community Health Status — United States

Healthy People 2000 establishes a framework for the development of an explicit prevention program for the nation (*1*); the Year 2000 Health Objectives Planning Act* provides legislative support for such a program. To address both the requirements of that act and Objective 22.1 of *Healthy People 2000*, a consensus set of 18 health status indicators has been developed to assist communities in assessing their general health status and in focusing local, state, and national efforts in tracking the year 2000 objectives (Table 1). Priority in selecting the indicators was given to measures for which data are readily available and that are commonly used in public health.

The set of health status indicators was developed by a committee† established to implement Objective 22.1 through a consensus process involving local, state, and federal health officials and representatives from academic institutions and professional associations. The health status indicators are intended to ensure data comparability and facilitate use by public health agencies at all levels of government. These indicators are *not* intended to supersede specific measures suggested in *Healthy People 2000*; however, they will provide a broad indication of the general health status of a community.

In addition to this consensus set of health status indicators, modifications to existing data collection systems have been recommended to emphasize additional measures of outcomes, risk factors, and processes that will be helpful for planning prevention programs devoted to achieving the year 2000 objectives (Table 2). This additional list includes data needs for indicators of selected chronic diseases, access to medical care, and environmental exposures or behavioral risks.

Reported by: National Center for Health Statistics; Epidemiology Program Office; National Center for Chronic Disease Prevention and Health Promotion; Public Health Practice Program Office; Office of the Director, CDC.

Editorial Note: The need and rationale for a consensus set of health status indicators has been described previously (*1,2*). Development of this initial set of indicators involved broad input by policy and technical experts representing all levels of public health practice in the United States.

As public health priorities change and other data sets become available, the list of indicators will be modified through similar public consensus processes. CDC encourages both the immediate adoption of this list of health status indicators in public health practice and the development of the new and/or modified data systems recommended by the committee.

References

1. Public Health Service. Healthy people 2000: national health promotion and disease prevention objectives—full report, with commentary. Washington, DC: US Department of Health and Human Services, Public Health Service, 1990; DHHS publication no. (PHS)91-50212.
2. Institute of Medicine. The future of public health. Washington, DC: National Academy Press, 1988.

*Public Law no. 101-582 (42 USC § 246 [1990]).

†Committee members and representations: *American Public Health Association*—T. Colton, Ph.D., Boston University School of Public Health; D. Rice, Sc.D., University of California, San Francisco. *Association of State and Territorial Health Officials*—L. Novick, M.D., New York State Department of Health; R. Eckoff, M.D., Iowa Department of Public Health. *National Association of County Health Officials*—M. Luth, M.P.H., Washington County Health Department; F. Guerra, M.D., San Antonio Health Department. *Public Health Foundation*—L. Olsen, M.D., Delaware Division of Public Health; O. Shisana, Sc.D., District of Columbia Commission of Public Health. *United States Conference of Local Health Officers*—R. Biery, M.D., Kansas City Health Department. The committee was convened by CDC.

TABLE 1. Consensus set of indicators* for assessing community health status and monitoring progress toward the year 2000 objectives — United States, July 1991

Indicators of health status outcome

1. Race/ethnicity-specific infant mortality, as measured by the rate (per 1000 live births) of deaths among infants <1 year of age

Death rates (per 100,000 population)† for:

2. Motor vehicle crashes
3. Work-related injury
4. Suicide
5. Lung cancer
6. Breast cancer
7. Cardiovascular disease
8. Homicide
9. All causes

Reported incidence (per 100,000 population) of:

10. Acquired immunodeficiency syndrome
11. Measles
12. Tuberculosis
13. Primary and secondary syphilis

Indicators of risk factors

14. Incidence of low birth weight, as measured by percentage of total number of live-born infants weighing <2500 g at birth
15. Births to adolescents (females aged 10–17 years) as a percentage of total live births
16. Prenatal care, as measured by percentage of mothers delivering live infants who did not receive prenatal care during first trimester
17. Childhood poverty, as measured by the proportion of children <15 years of age living in families at or below the poverty level
18. Proportion of persons living in counties exceeding U.S. Environmental Protection Agency standards for air quality during previous year

*Position or number of the indicator does not imply priority.
†Age-adjusted to the 1940 standard population.

TABLE 2. Priority data needs* to augment the consensus set of health status indicators

The measures in the following areas either do not exist or are incomplete. The committee† identified them as measures that could be obtained with minor modifications to existing data-collection systems.

Indicators of processes

- Proportion of children 2 years of age who have been immunized with the basic series (as defined by the Immunization Practices Advisory Committee)
- Proportion of adults aged ≥65 years who have been immunized for pneumococcal pneumonia and influenza
- Proportion of assessed rivers, lakes, and estuaries that support beneficial uses (fishing and swimming approved)
- Proportion of women receiving a Papanicolaou smear at an interval appropriate for their age
- Proportion of women receiving a mammogram at an interval appropriate for their age
- Proportion of the population uninsured for medical care
- Proportion of the population without a regular source of primary care (including dental services)

Indicators of risk factors (age-specific prevalence rates)

- Cigarette smoking
- Alcohol misuse
- Obesity
- Hypertension
- Hypercholesterolemia
- Confirmed abuse and neglect of children

Indicators of health status outcomes

- Percentage of children <5 years of age who are tested and have blood lead levels exceeding 15 µg/dL
- Incidence of hepatitis B, per 100,000 population
- Proportion of children aged 6–8 and 15 years with one or more decayed primary or permanent teeth

*Position of the indicator does not imply priority.
†Convened by CDC to interpret Objective 22.1 of the year 2000 health objectives (*1*).

OPENING CEREMONY

Audrey Manley, M.D.
Department of Health and Human Services

(Not available for publication)

HEALTH STATISTICS AND HEALTH DECISIONS: A MARRIAGE WHOSE TIME HAS COME

Carlessia A. Hussein, District of Columbia, Commission of Public Health

It is my pleasure to welcome all of you to the Nation's Capitol.....The theme for this year's Public Health Conference on Records and Statistics is very timely and appropriate. "The 1990's a Decade of Decisions for Vital and Health Statistics", echoes not only the overall challenge that faces the profession that is public health, but also the growing "threat" to the health of the people of this great nation.

What makes up this challenge? What are its antecedents? What are the problems? How can we frame the issue for analysis and decision? Who makes the decisions? These are some of the process objectives of this conference, and over the next three days we must develop recommendations, through exploration of the session topics, that will provide a framework for action for all attendees.

In the District of Columbia, like many other communities throughout the nation, the problem faced by public health and health statistics is simply stated; health data systems are not keeping pace with the needs of the health delivery system, officials are making decisions that directly affect the health of the population without accurate health information, and the assessment function, the core governmental obligation in public health is ineffective.

Health expenditures are continuing to rise with the spread of new technology, introduction of costly major medical equipment and the declining health insurance coverage for the population. At the same time, health interventions remain focused primarily on acute episodic care for the major causes of illness and death and the "new morbidities" associated with violence. These dynamics demand large outlays of funds and drain available resources for developing needed data systems at the national, state and local levels; data systems that are critical to evaluating the health system and determining the most cost effective program components which should receive a share of limited funds. As a result, area health care systems "lumber" along, well intended, but in a costly hit-or-miss pattern.

Increasingly, officials are making decisions that affect the allocation of health resources and thus the health of the population, absent timely and accurate information on health status, health program productivity and correlates for improved health. These decision-makers not only include health professionals but also include elected legislators, mayors, governors, budget controllers and others who need health data presented in a simplified understandable manner that is responsive to their broader policy concerns. Public health policy development often is severely hampered by an inability to respond to policy questions in a timely, accurate and usable manner.

The core functions of public health agencies at all levels of government are assessment, policy development and assurance as articulated in the Institute of Medicine's publication "The Future of Public Health". An understanding of the determinants of health and of the nature and extent of community need is a fundamental prerequisite to sound decision-making and implementing effective and cost-saving programs for the public's health. Accurate information, reality-based interpretation and expert forecasting serves for more efficient use of finite resources. Assessment, the determination of need, is therefore the core governmental obligation in public health. This function, carried out by top public health professionals, should have participation of direct service providers, statisticians, researchers, administrators and the public and the availability of meaningful health information.

Communities across the nation look to the leadership of the National Center for Health Statistics, and its sister agencies, to provide technical assistance and statistical support in establishing and maintaining effective area health statistics systems. Objective 22 in Healthy People 2000, promotes the development of surveillance and data systems to provide a baseline for health objectives.

The people of our nation, on the other hand, face a far more serious threat to their health status as the health delivery system becomes more costly and yet less capable of increasing the years of healthy life and decreasing health disparities among the population. Health promotion and disease prevention programs are on the decline as jurisdictions retrench services to adjust to major budget deficits. Health education and illness followup in the home and community are becoming non-existent as outreach staff diminishes. Change in the makeup of households and neighborhoods has resulted in the absence of an experienced health advisor, a role that elderly relatives or neighbors often filled. The interplay of drugs and violence throughout communities have left many citizens barricaded in their homes and children at risk for abuse and neglect. The public health practice of today does little to address these problems and health data providers few insights for intervention.

A framework for effective action is critically needed at the national, state and local levels, if this nation is to avert a major collapse of the health system with attendant soaring morbidity and mortality statistics among population subgroups. I challenge this August body to address the following recommendations as you deliverate the next few days:

- Assist state, local and rural authorities to set up early warning systems that identify pending epidemics: make public health statistics dissemination timely and understandable to decision-makers and the public;
- Assist states in establishing centers for health statistics that addresses the major health problems in their communities: reorder the funding and technical assistance priorities in order to provide more direct and measurable assistance to local communities;
- Place priority on the development of baseline data that will enable tracking of progress on selected health objectives across the nation; and

- Develop strategies to aid states in identifying population groups who are at high risk for premature death, disease and disability and implementing interventions that reduce the major health disparities among Americans: improve the coding of racial and ethnic groups to provide a reliable knowledge base for health status; place greater emphasis on prevention and health maintenance.

The District of Columbia's Health profile contains a list of totally unacceptable health status indicators for the population. The city tops the nation's list in areas of infant mortality, HIV/AIDS infection, cancer, homicide, sexually transmitted diseases, and heart disease. This community, like many others across the nation, need a concerted and effective effort by professionals gathered here and the public and private organizations represented to meet these challenges in this decade.

Let me close with this little saying I find myself mumbling frequently in recent years while I listen to the decision-makers deliberate health programs:

When heresay meets heresay,
The higher authority has the final say,
And the people suffer and the people
die....

BETTING ON OUR NATION'S HEALTH POLICY: WITH AND WITHOUT DATA

Daniel M. Fox, Milbank Memorial Fund

Two words describe the history of major reform in United States policy for financing medical care: dormant and imminent. When Mary Grace Kovar and Peter Hurley invited me to give this talk it was dormant; since then it has become imminent. That is some sort of record: four months. Usually the cycle of dormancy and imminence is measured in years.

Earlier this year the uninsured and the underinsured were still a problem. Now they are once again a political opportunity, at least according to the Democratic leadership of the Senate, the Director of the OMB, the Editor in Chief of the AMA, and the New York Times.

What has happened? As everyone here knows, the same data systems have been offering up superb information pertinent to the nation's health agenda before and after the beginning of this year. Similarly, the media have been for years giving us stories about people who are poorly served by our health policy. Big industry and what's left of big labor have the same interests they did last year and ten years ago; so, on the other hand, do small employers. Everybody I know over the age of 40 can tell you a horror story about managing medical care for an elderly member of his or her family. Even the public opinion polls have not, to my knowledge, suggested a change in the political salience of health policy reform or the political fortunes of the national Democratic Party.

The publicly stated odds on the likelihood of national health policy reform therefore seem to be changing again without any significant changes in data about health status, costs or political preferences. This happens routinely in American political history. It happened unambiguously in 1915, 1934, 1945, perhaps in 1955, certainly in 1965 and in 1976. The only time the earth moved, however, was in 1965, when we achieved Medicare, Medicaid and, depending on whom you listened to, informed opinions that national health insurance was either imminent or impossible.

What explains this curious political history of health policy reform in the United States? How do social scientists account for this cyclical changing of odds on bets that hardly ever pay off?

There is an extensive literature that attempts to explain this phenomenon. The contributors to this literature have usually posed the question differently: why has the United States failed to achieve national health care financing that resembles that of Western Europe or Canada? That is, why do we persistently maintain a medical care financing system that is perversely expensive, inefficient, and inequitable?

For more than half a century, from about 1920 to the late 1970s, my predecessors and colleagues in contributing to this literature generally agreed that the explanation, reduced to one word, was interests. Reduced to two words the explanation was interests and political structure.

You are familiar with the interests argument because like so much social science it has passed from common sense to sophisticated analysis and back again to common sense. The preeminent interest group in thwarting health policy reform has been, according to the literature, the medical profession. Organized medicine prevented reform in order to protect its income and its autonomy. Most of the time doctors found allies among businessmen who were, for practical and ideological reasons, dubious about more government regulation. As a result of the growth of voluntary, employment-based health insurance since the 1940s, a private and non-profit insurance industry was created that had a stake in preserving things as they were or, at most, in gradual changes that would take account of their institutional self-interest.

The political structure explanation tries to account for the ability of these interest groups to prevent health policy reform after the 1950s, when--for the first time--a substantial majority of Americians, according to surveys, were in favor of it. The structural explanation is as follows: Our politics are fragmented. At best we have national political parties in election years. Neither of our national parties has unambiguously represented the interests of what other countries call a working class. The executive and legislative branches of government are often in functional stalemate. Legislatures are run by committees that are obsessed with turf and tightly linked with executive agencies and interest groups in what is called an iron triangle.

I have caricatured both the interest group and political structure explanations. They are more nuanced and sophisticated than my summaries suggest. Now I caricature a competing explanation for the failure of major reform in health policy, one that has gathered more adherents over the past decade. That explanation emphasizes the power of beliefs and values, operating independently of and shaping interests

and political structure. In some variants, this explanation makes interests and structures results of beliefs and values.

Two sets of beliefs and values are pertinent. One set is about health and health care. The other is about politics and community. I remind you again, as a contributor to this literature, that I am caricaturing in order to communicate.

First, health and health care. Most people in Europe and North America have placed great faith in the power of medical science in the twentieth century. In the United States, this faith has been deeper and more fundamentalist than elsewhere because of our national tradition of belief that material and spiritual progress is inevitable and that, since 1776, we have been in the vanguard of the world's progress. Moreover, Americans have great faith in science and its applications. Only an American Congressman could have said, as a leading Republican actually did in 1960, "The NIH is our national health insurance."

Here's how our faith in medical science and progress has prevented major reforms in health care financing. Until the 1970s, most people gave unusually high credence to claims made by doctors about their knowledge and authority. High, that is, by international standards.

Americans have been persuaded to accept medical authority by positive data about scientific achievements and improvements in health status and have generally ignored or rationalized contradictory evidence. Hardly a week has gone by in this century without prominent headlines about scientific breakthroughs in the fight against some disease. We know that we have been living longer, that children--except among the poor--have been healthier than in the past. Most Americans who have been alive in the 20th century had or have vivid personal memories of illness that could be cured or death that could be prevented by medical intervention.

For most of this century, it has not been hard for many people to believe that the American health care system was doing pretty well and getting better. Sure there were problems. Sure some people did not have access to adequate care. But weren't the number of people who were covered by health insurance increasing each year? Wasn't the breadth of coverage increasing?

Thus the belief in progress, and especially in medical progress, produced a level of political comfort with health policy and with the people who opposed efforts to reform it.

I turn now to the second set of beliefs that had a similar political impact: beliefs about the political community.

In the past decade or so it has been inescapable that an effective majority of Americans have political preferences that are right of center. That is, an effective majority distrusts government and values liberty over equality. Uncle Sam, having been coopted by the New Deal and Liberal Republicanism, has been replaced at home and abroad by the Marlboro Man.

This should not have been a surprise. I recently did some arithmetic, knowing that I would be addressing the members of this conference. Since the beginning of the century, there have been 1087 months in which the members of the United States Congress have received paychecks. By my count, a center-left coalition that could make major changes in domestic policy has led the Congress for no more than, at most, 50 of those months: the first three years of the New Deal, and just over a year in the Johnson Administration, beginning in January, 1965. A lot happened in those 50 or fewer months: Social Security, unemployment insurance, aid to dependent children, the national labor relations act, Medicare, Medicaid, and federal aid to elementary and secondary education to name just a few.

I'm not, of course, saying that reform legislation did not pass in other years. I know better than that. What I am arguing is that much of the history of health and social policy reform agitation in the past half century has been an effort to restore the lost golden ages of those relatively few months of center-liberal glory. Most reformers have assumed that change will happen as a result of a center-left coalition.

The evidence says, however, that the American people are only rarely in a center-left mood. The political norm turns out to be the center-right. This has been abundantly clear in the past dozen years. But it should have been clear to political analysts and reform strategists for most of this century.

One more controversial point before I turn from an explanation of the past to some conjectures about what could happen in the near future. That point is that it is impossible to disentangle the normal political preference of Americans for the center-right from the issue of race, either historically or at the present time. American opinions about what is proper health and social policy are frequently coded opinions about what is proper policy for helping or containing the aspirations of people of color. This coding makes it easier to deal with the

contradictions between what we profess to believe about liberty and equality and our strong feelings about race, feelings that depending who and where you are, are central to our individual political preferences.

I have taken you through a complicated discussion of American history and politics. I will recapitulate it and then move on. I started by saying that major reform in health policy has recently been talked about as once again imminent. I implied that I was skeptical about what would happen because all of us have been there before. Then I took you on a tour of the literature that explains why our health financing policy is the anomaly among industrial nations.

On this tour, I first stopped at the explanations that social scientists gave from 1920 to the 1970s. According to these explanations, American health policy was different as a result of interest groups and political structures. I then said that in recent years, explanations have stressed that beliefs and values--about individualism, government and race--have seemed to provide more profound explanations for our national aversion to spending our health dollars in ways that considerable data suggest would be more equitable, more efficient and more effective.

Now it should be clear that the older explanations were the optimistic ones. It is hard to change interests and political structures. But it is much easier to change them than it is to change beliefs and values. Interests change in response to changes in the characteristics of economies and of populations. There is much historical evidence for that. But beliefs and values change slowly, if at all.

In the past generation we have watched American politics accommodate to a number of shifts in interests. For example: the growing numbers and political activity of the elderly; geographic population shifts from the East and the Midwest to the South and the West; changes from an industrial to a service labor force; the growth of a home-owning suburban population at the expense of center cities; the growing political power of black, Hispanic and Asian working and middle class voters in cities and older industrial suburbs.

But these shifts in interests have occurred in the larger context of an overall center-right majority. Moreover, that majority has been more effective in national affairs since 1980 than at any time in the previous half century.

With this background, I can restate the problem I have posed for you: How can health financing reform be imminent if it has, for so long, not had an effective interest group coalition (except for the elderly acting in their own interests)? How can health financing reform be imminent if its opponents can find strength in the center-right values that dominate American politics?

It is now time to place bets on the future using the only data that we have: data about political behavior in the past. The safest bet is that major reform in health financing policy is not imminent. According to this bet, we will continue to have large numbers of people who lack proper access to medical services, we will continue to have inadequate long term care, and we will continue to have large differences among the states in the availability of health services to people whose incomes are below the poverty level. It is safe to bet on stalemate, perhaps safest.

There may, of course, be some beneficial incremental changes that do not cost very much money in tax appropriations. Such changes might include mandates for basic coverage combined with structural changes in the insurance industry, and some reform in Medicaid. Make your own list. This is a very good bet because it extrapolates the incrementalism of the past: for example, the expansion of Medicare to persons covered by Social Security Disability Insurance in 1972 and the changes in Medicaid mandates over the past decade. It also pays attention to the incremental reforms that have been made or proposed in several states to increase access to health insurance. Thus it is not wildly radical to bet on incrementalism.

If you place either of these bets, on stalemate or on incrementalism, you are implicitly making the following interpretation of the current talk about the imminence of health policy reform. The Democrats need a domestic policy for the 1992 election. The Administration has to acknowledge that there are problems of access to medical care, expecially for the poor and especially for children and infants. The American Medical Association has, over the past twenty years, gradually been converted to the view that national health financing reform is the best way to protect physicians' target incomes. The AMA is, therefore, happy to advocate reforms that, at least in the short run, increase per capita health care costs.

Solutionists, my label for smart people who have schemes to reform health care financing, have been standing by since 1932 waiting for moments like this. Not the same people, of course, but there has been an high replacement rate among

left and center solutionists during the past six decades.

Our contemporary solutionists are familiar to most people who earn their living in health affairs. The Journal of the American Medical Association last year advertised a contest for solutions to the problems of medical care finance and in mid-May published the winners, after holding a press conference in Washington to say that reform is imminent and necessary. The New York Times then ran a series about the problems of health care finance, discussed the solutions proposed by the winners in the AMA contest in an editorial and the next day picked its favorite solutionist. Congressional Committees have ordered their employees to design and make cost estimates of alternative packages of benefits.

If you placed your bet on stalemate or on incrementalism you may safely predict that the publicity accorded to solutionists and their supporters will increase during the next year. Activity is a good surrogate for action, especially in the media and especially in an election year.

But there may be grounds for placing bolder bets, bets against longer odds. Such bets are discomforting because political analysts almost never know that an array of interests or a set of beliefs have changed until after the fact. The most astonishing recent example is the failure of political communism in eastern and central Europe. Most experts missed its timing and its velocity, however strongly they either hoped for it to happen or wished that it would not.

The most interesting example of an unanticipated realignment of interests in recent domestic politics may have been the passage of the Americans with Disabilities Act in the summer of 1990. As recently as March 1990, many well-informed people were betting against the ADA and in favor of the interests arrayed against its passage.

Some of you who are still with me are probably muttering that health financing reform will be a great deal more difficult than passing the ADA. Perhaps. The politics and the potential impact of the ADA are for later discussion.

Now as I move toward a conclusion, I want to suggest three rational bets, bets that could be placed as private citizens by the smart and highly disciplined people who manage our nation's health data systems. The first bet is that even if a major change in health financing policy does not happen by 1994 it will occur within a decade. The second bet is that the successful reform coalition will be a center-right alliance. The third bet is that the reformed system will be pluralistic (that is, both private and public), that it will be inequitable (that is, that some will still do much better than others) and that it will demand more accountability from patients, providers and payers.

Obviously the bets are related. They are bets, I repeat, not predictions. Moreover, they are not bets in a game: they are political bets which means that I would be pleased to influence the outcome if I could.

Taken together the three bets assume that there will be financing reform sooner rather than later, that we will have a distinctively American solution, one that bears little resemblance to any other country's, and that, in the American way, the pain of reform, will be broadly distributed. Thus my three bets on 1) reasonable imminence, 2) pluralism, and 3) shared burdens.

Why should anyone who is smart, disciplined and aware of how American politics works place these bets? Here are several reasons:

--The first is that, especially in hard economic times, the burden of paying for our existing health financing system is becoming more onerous to employers and to state governments and their taxpayers. More people want to spend less and to spend better; this year and next more than thirty states are required by their constitutions to do precisely that.

--The second is that there are many signs that the national faith in inevitable material progress and in the benign advance of medical science has been eroding for more than a decade. More people agree that economic growth will not solve the problem of health insurance coverage and that biomedical research will not lead inexorably and rapidly to techniques to prevent and cure disease.

--The third reason is that data about the flaws in our financing system are becoming hard personal experience for more people. More people are identifying, because of their personal experience, with what the people who array and assess data professionally have known for years. It is easier to understand the problems of the frail elderly living alone when you are one or the adult child of one. It is easier to appreciate the problems of managing chronic disease when you have been forced out of the workforce, or cannot work at your full capacity, or do not have insurance that covers personal assistance.

It is easier to want to help families with a child who has one or several severe disabilities when it is your family or one close to you. The problems of adequate access to medical care for the poor and the uninsured are more meaningful when solving them could have an effect on your state and local taxes or on a wage-earner in your family.

You know better than I do the enormous difficulties of translating data into policy. Data are, of course, evidence taken from the experience of individuals and arrayed in meaningful patterns. When these patterns, effectively when the data themselves, become part of voters' personal awareness, the patterns of data become sources of political energy. This happened in the past with data about unemployment. It happened with data about economic insecurity in old age. Recently it happened with data about the number of people with disabilities and the impediments to their participation in work and community life. Will it happen with data about the distribution of illness and its disabling consequences, about the barriers to access to health services, about the effectiveness of medical interventions, and about what we get in return for what we spend on medical services? Place your bet. Perhaps place several. If you ask me privately I'll tell you where my money is.

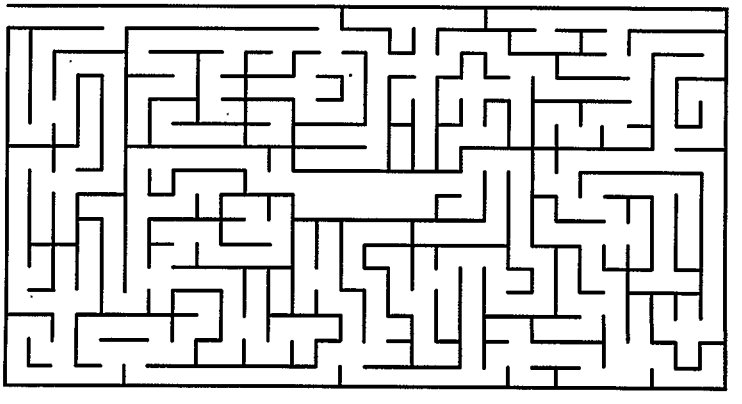
HOW MUCH IS ENOUGH? BUILDING STATE CAPACITIES FOR HEALTH DATA

Kristine M. Gebbie
Washington Department of Health

(Not available for publication)

Session A

Year 2000 Surveillance and Data Systems– Health Indicators



Year 2000 Surveillance and Data Systems Health Status Indicators
Dr. Manning Feinleib, National Center for Health Statistics

The groundwork for this session was established by the PHS-wide effort known as 'Statistical Support for Healthy People 2000: National Health Promotion and Disease Prevention Objectives'. For the specific implementation of Priority Area 22, seven objectives were defined for surveillance and data systems. They are --

- health status indicators,
- national data sources,
- comparable data collection procedures,
- gaps in health data,
- periodic analysis and publication of data,
- data transfer systems, and
- timely release of national data.

This session deals with the first, Objective 22.1 - Health Status Indicators. Other sessions at this Conference will deal with comparable data collection procedures, and future conferences will report on the remaining objectives.

From the Institute of Medicine Report, The Future of Public Health, came the recommendation that "A uniform national data set should be established that will permit valid comparisons of local and state health data with those of the nation and of other states and localities and that will facilitate progress toward national health objectives and implementation of Model Standards: A Guide for Community Preventive Health."

In response, Congress passed Public Law 101-582 Section 5.1, which directs: "The Secretary, acting through the Director of the Centers for Disease Control, and in consultation with the states, shall -- (1) develop a set of health status indicators appropriate for Federal, state, and local health agencies to measure health status...and establish use of the set...", in the closing days of its' 1990 session.

There then came a clear mandate from the Department that CDC was to give highest priority to this objective and to move quickly on it, since the set of health indicators would guide initial efforts for Healthy People 2000 and help focus activities for States and localities. Channels of communication were quickly established both within the Department and with outside groups. This included the CDC Health Data Policy Group, the Assistant Secretary's Data Streamlining Group, and the State Centers for Health Statistics. But key to these activities was the formation of a special working group dealing specifically with Objective 22.1, and named therefore, Committee 22.1.

Five key organizations concerned with data issues at the State, County, and Federal levels, were represented. Many of the members (see below) are on today's panel,

Committee 22.1
Convener: Manning Feinleib, M.D., Dr.P.H.
Director, National Center for Health Statistics

Members

APHA	Theodore Colton, Sc.D.	Boston U. S.P.H.
	Dorothy Rice, Sc.D.	U.C.S.F. Schl. of Nursing
ASTHO	Ronald Eckoff, M.D.	Iowa H.D.
	Lloyd Novick, M.D., M.P.H.	New York State H.D.
NACHO	Fernando Guerra, M.D., M.P.H.	San Antonio Metro H.D.
	Mary Luth, M.P.H.	Washington County H.D.
PHF	Lyman Olsen, M.D., M.P.H.	Delaware Division P.H.
	Olive Shisana, Sc.D.	D.C. Dept. of Human Svcs.
USCLHO	Richard Biery, M.D.	Kansas City H.D.

but I would also like to acknowledge the contributions of those unable to attend. In particular, Olive Shisana, then with the District of Columbia Department of Human Services, who has returned to her native South Africa to work in their health statistics unit. Additional thanks go to Charlie Schade of APHA, whose reports on the activities of the committee via articles in the Nation's Health brought in a number of valuable comments from around the country. However, the committee's zeal to respond to the mandate to move quickly, forced Charlie to point out that the articles in the Nation's Health were always behind.

The committee met three times. Initially, as a small group. Then in April 1991, as a large, working conference involving more than 200 Federal, state, local, academic, and other public health workers. Finally, it reconvened as a small group to digest all of the input and make final recommendations. These were reviewed by the NCVHS, the HHS Health Data Policy Committee, and by all of the PHS agencies. Dr. William Roper, Director of CDC, approved the publication of the Indicators in the MMWR issue of July 12, 1991.

Many agencies at all levels of government, and their respective health data systems, provided a rich resource of data to meet the Year 2000 National Health Objectives. The committee first had to review the 300 objectives spelled out in Healthy People 2000, in order to

determine a set of indicators to select from, and define an array of other suggested indicators. The set of indicators had to meet certain objectives:

- be a small number of measures,
- allow a broad measure of community health,
- include general measures of community health,
- include specific measures of community health, and
- contain a subset that would be consistent at the Federal, state, and local levels.

Criteria for inclusion were then developed for the indicators. Each one had to be readily and uniformly understandable and acceptable, and be measurable using data currently available or readily obtainable. Further, each indicator should also imply specific interventions compelling action, and be outcome oriented. It should be stressed that the indicators would be an initial set of items to begin to achieve comparable data sets across jurisdictions. They are NOT intended to supplant any measure or data item identified in Healthy People 2000, or any of the state adaptations in Health Communities. The absence of a measure on the recommended list of indicators does not mean that the topic was not discussed, but generally, that it did not meet the criteria, particularly with regard to the current availability of data at state and local levels.

As selected, the health status outcome indicators included nine measures of mortality and four measures of incidence of specific diseases. The specific mortality measures are --

- all causes of death,
- infant mortality,
- deaths from motor vehicle accidents,
- work-related deaths,
- suicides,
- homicides, and
- deaths from lung cancer, breast cancer, and cardiovascular disease.

Indicators of disease incidence would include --

- acquired immune deficiency syndrome,
- measles,
- tuberculosis, and
- primary and secondary syphilis.

Five indicators of risk factors have also been selected. Three of them -- low birth weight, births to adolescents, and lack of prenatal care -- rely on information obtained from birth certificates. The two remaining indicators -- children in poverty, and the proportion of people living in counties with poor air quality -- are more general measures of economic and environmental risk.

As previously mentioned, many important potential indicators did not make this initial list because of the lack of data. This troubled the committee to the point of introducing a list of additional indicators they felt should be given the highest priority when developing appropriate data sources. The list encompassed three broad categories of indicators -- processes, risk factors, and outcomes.

Additional recommended indicators of processes are --

- proportion of 2-year-olds immunized,
- proportion of 65 and older immunized for pneumonia and influenza,
- percentage of viable rivers, lakes, and estuaries,
- women receiving Pap smears,
- women receiving mammograms,
- percent uninsured for medical care, and
- percent without a regular source of primary care (incl. dental).

Recommendations for indicators of risk factors took into account three major goals. The first was aimed at tracking the initiation and discontinuance of cigarette smoking and alcohol misuse, by collecting their age-specific rates. The second would estimate prevalence rates for the major risk factors for coronary heart disease, specifically obesity, hypertension, and hypercholesterolemia. The third goal was to strive to estimate the prevalence of child abuse.

Among the many choices for indicators of health status outcomes, three were chosen. They are --

- percentage <5 years with high blood lead levels,
- incidence of hepatitis, and
- proportion of children (ages 6-8 and 15) with decayed teeth.

It should be noted that during the next

few months and years, CDC will be working with the states and their localities to identify appropriate data sets, provide standard definitions and statistical procedures, and disseminate the information effectively.

Although this list of indicators is the result of a 'first cut', and will be reviewed periodically, it sets the stage for a decade long process to achieve useful, comparable data sets to monitor changes in the health of the American people.

In closing, I would like to thank all the panelists in today's program, all the other members of Committee 22.1, and all of those that assisted with comments and reviews of the recommendations. This was a daunting task which required not only substantive professional expertise, but a great deal of political savvy in balancing a wide variety of interests and priorities, while having an eye to the practical realities of implementing these indicators. In particular, I want to thank the members of the CDC Health Status Indicators Work Group; Doug Williams, Gary Hogelin, Donna Stroup, Tom Richards, and Bob Irwin, who worked so effectively in supporting the committee's activities.

Ronald D. Eckoff, Iowa Department of Public Health

Dr. Biery has described some of the specifics regarding the Environmental/ Occupational/Injury Control area. I would like to add a few comments about the process. The committee had a formal set of objectives and criteria for the selection of health status indicators. After I had been away from the process for a time, I wrote down what I thought were the most important factors. I think there was a pretty close match between the formal criteria and my informal thoughts. The first key is to have indicators which are reasonably understandable and meaningful to non public health professionals. They must be something I can discuss with the Governor, the board of health, a county supervisor, a reporter or my neighbor. In a brief conversation I must be able to explain what the indicator is and what it means.

The second key is to have indicators with reasonably good data available at the local level. There were many indicators with good national data and perhaps good state data but which could not be used because of lack of local data. We probably did not discuss as much as we should have the minimum population base for local data. In Iowa we have a number of counties with populations of 5,000 to 10,000 and very few over 50,000. I suspect that even though many of our public health jurisdictions are smaller, we need to use data based on at least 50,000 population.

It is important that we recognize that this is intentionally a very short list of indicators and it does not include all important measures or measures for all important program areas. Just because something is not on the list does not mean it is not important or a high priority. The Table 2 list of measures which require additions or modifications to existing data collection systems represent a very important part of the committee's work. I am very hopeful it will soon be possible to routinely obtain this data and add many of these measures to the original list.

One of the interesting experiences in this process was to note that there were groupers and splitters among us. The groupers want to put two, three or more different measures together. This allows us to be more comprehensive and have larger numbers. However, it may be more difficult to explain and may create problems with the definition of the population at risk. The splitters want to separate the measures down to precise separate items. This allows us to be very precise and perhaps attach more specific meaning to the measure. However, the numbers may be very small and the focus very narrow. There probably was more tendency toward such fine distinctions when the discussants were highly expert in the area.

Another lesson which was clear in this process was that public health professionals need to become more aware of and make more use of data sets which are not considered traditional public health data sets. Data regarding various types of violence, occupation related information and certain types of environmental data come immediately to mind.

This has been an interesting and educational experience for me and I have appreciated the opportunity to participate in it.

YEAR 2000 SURVEILLANCE AND DATA SYSTEMS--HEALTH INDICATORS

Other Panelists:

Richard M. Biery
Kansas City Health Department

Theodore Colton
Boston University School of Public Health

Fernando A. Guerra
San Antonio Metropolitan Health District

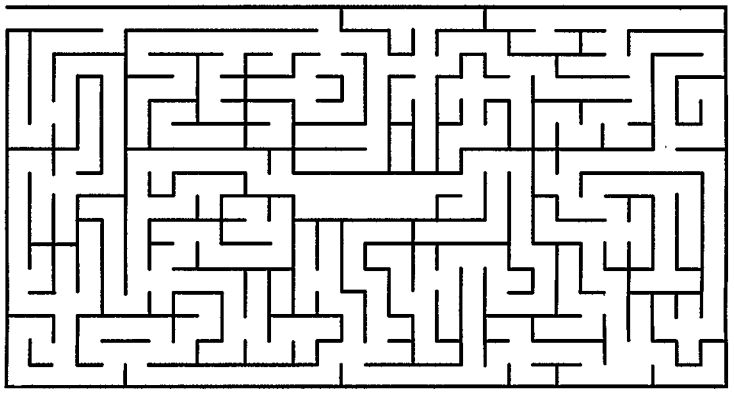
Lyman J. Olsen
Delaware Division of Public Health

Dorothy P. Rice
University of California

(Not available for publication)

Session B

Longitudinal Data Systems



A LARGE, LONGITUDINAL DATABASE OF PRIVATELY-INSURED FAMILIES

A. Michael Collins and Kathe P. Fox, MEDSTAT Systems, Inc.

Our purpose is to describe briefly the content, structure, and some of the uses of a large, longitudinal database of the healthcare experience of privately-insured families. This database is available for use by researchers. We will discuss some of the challenges of building and maintaining such a database, lessons we have learned in the course of our work, and some of the paths we intend to take in the near future.

Fifty-four percent of the population have employment-based medical coverage, yet until the construction of the MEDSTAT research database it was difficult to study this population's use of healthcare services, because there has not been a readily accessible database that describes their cost and use. MEDSTAT Systems, Inc., is a publicly held healthcare information company that provides databases, analytic software and consulting to America's largest private and public employers. The MEDSTAT research database currently tracks the healthcare experience of 6.5 million Americans, who are employees and dependents of large private and public employers. All of the persons in the principal MEDSTAT research database are under 65, and 31% are under 18. The population is diverse in its geographic distribution, as well as by industry.

MEDSTAT DATABASE STATISTICS

- 235 million medical claims from over 100 payers
- 6.6 million privately insured individuals (no Medicare, Medicaid, Workers' Compensation)
- $7.8 billion -- 5.7% -- of annual employer healthcare expenditures
- Wide population distribution

Geographic:	Northeast Region	19%
	South Region	30%
	North Central Region	34%
	West Region	17%
Age Group:	Under 18	31%
	18 - 34	25%
	35 - 44	19%
	45 - 54	14%
	55 - 64	11%
Industry Group:	Durable manufacturing	32%
	Nondurable manufacturing	23%
	Communications/Utilities	19%
	Service/Financial	11%
	Retail	10%
	Mining/Energy	5%

The MEDSTAT database contains longitudinal data beginning in 1987; it is continuously updated, and data are available in the database about a year after the date of service. The foundation of the MEDSTAT database is data from paid medical claims. We receive claims data from over 100 claims processors. The *sine qua non* of our technical function is that we integrate these data into standardized databases, where fields and values are consistently defined. This is conceptually simple but technically difficult. To give an example, the payment field is always the total amount paid to the provider from all sources, and includes deductible, copay, and coordination of benefit amounts, but is net of any network or provider discounts.

Data standardization and updating require a continuous, close working relationship with our data sources. Data structures and formats change constantly, and changes must be incorporated in every quarterly update. We have dedicated conversion programming teams that work with the claims processors; healthcare data are a rapidly moving target, and just keeping track takes a significant investment.

Database Contents

The MEDSTAT database uses claims and other data to maintain the following types of information:

- Unique patient identification. Scrambled identifiers are used to protect patient confidentiality. The identity of data sources and claims processors is also protected.
- Patient demographic information -- age, sex, location, employment status (active/retiree, hourly/salaried), industry.
- Clinical information -- diagnoses, procedures, lab and x-ray tests, drugs.
- Financial information -- facility and physician charges and payments, copay and deductible amounts, coordination of benefits and cost containment savings.
- Provider information -- hospital identification, physician identification and specialty.
- Benefit plan and cost management program information -- copay, deductible, stoploss, PPO participation, presence of utilization review, second surgical opinion, case management, special mental health and substance abuse treatment provisions, etc.

The database is growing 40-50% per year, as we add new data sources. In 1989 it contained almost $8 billion in expenditures, representing about six percent of corporate healthcare expenditures and 1.1% of all U.S. healthcare spending. Currently, the database contains data from all types of medical practice except staff-model HMOs; HMO data will be added in the near future.

EXAMPLES OF DATA ELEMENTS

Patient
- ID (scrambled)
- Age
- Sex
- Location
- Employee/spouse/dependent
- Active/retired
- Hourly/salaried
- Industry

Benefit Plan
- Copay level
- Deductible level
- Stoploss
- Cost containment information

Clinical
- Diagnosis
- Procedure
- Diagnosis Related Group
- Major Diagnostic Category

Provider
- Hospital ID
- Physician ID and specialty
- Date, type and place of service

Financial
- Charge amount
- Payment amount
- Deductible
- Copayment
- Coordination of benefits amount
- Per admission charge and payment detail -- hospital, physician, room and board, ancillary

Data Enhancements and Analytic Capabilities

One of the strengths of this database is that we pre-aggregate claims data into meaningful units, while at the same time maintaining the detailed information necessary for many types of analysis. For example, inpatient claims are aggregated into episodes describing discrete admissions. Some of the capabilities that are built into the database include:

- Patients can be followed over time and across sites of care. Individuals may also be linked to their families.

- Patient cohorts can be constructed on the basis of any value in any field. For example, for the Agency for Health Care Policy and Research's urinary incontinence practice guidelines panel we constructed a longitudinal database of persons with any of four diagnoses related to incontinence.

- Inpatient episode construction. Information from inpatient facility and professional claims are merged together to make a single inpatient admission or case. A series of algorithms is used to determine which claims constitute the beginning and end of an admission. Once this has been determined it is possible to include all services which occur during the time window of the admission, even if the claim is missing other information, such as place of service.

- Inpatient Major Diagnostic Categories. MDCs can be assigned to any claim which has an ICD-9 diagnosis code. In addition, this information can be assigned to some inpatient claims without diagnostic codes once they have been constructed into cases.

- Inpatient Diagnostic Related Groups. DRGs are assigned to inpatient cases based on information from facility and professional claims. Constructing a case merges information from the facility and professional claims and allows all of this information to be considered when constructing the DRG. Having professional information improves the accuracy of surgical DRGs, a common problem when only hospital claims are used to assign DRGs.

- Outpatient Major Diagnostic Categories. All outpatient claims are assigned an MDC if they have a diagnosis code. The logic developed for inpatient assignment is duplicated in the outpatient setting allowing consideration of common MDCs across place of service.

- Outpatient Procedure Groups. The majority of outpatient claims have CPT-4 procedure codes since they are the basis for payment for the majority of carriers. Similar CPT-4 codes are grouped into outpatient procedure groups for ease of analysis, though the initial code is retained on every claim.

- Ambulatory Surgery Procedures. We have developed ambulatory surgery procedure groups for those procedures most commonly included in ambulatory surgery programs by our clients. These groups combine all of the payments made on the date of service for an ambulatory surgery: surgeon, anesthesiologist, operating room, laboratory, radiology, etc. The intent is to develop a unit of analysis that is comparable to an inpatient admission. Ambulatory surgery procedure groups allow one to test such questions as savings associated with setting and absolute rate of procedures regardless of setting.

- Payment detail. Payment reductions such as copayments, deductibles, coordination of benefits, and provider discounts are attached to individual claims, not treated as bulk adjustments.

- At-Risk Populations (denominator data). Employers submit population information in a variety of formats, including payroll data tapes, spreadsheets, and carrier eligibility files. The result, regardless of the input, is population matrices -- quarterly counts of the at-risk population, with breakdowns by age cohort, sex, employee relation, employment status and class, location, and industry. Population counts are linked to every claim, so that any sample of the claims (numerator) data can be linked to the proper denominator, making rate-based analysis of health care utilization possible.

- Data linkage. Both hospitals and physicians are identified in the database, and these identifiers may be used to link the claims data to other sources of information, such as Medicare cost reports, AHA and AMA databases, etc.

Database Structure

The MEDSTAT research database consists of four linked files. Patient and family identifiers provide the file linkages. This capability allows the complete healthcare experience of one family member to be compared to the complete experience of other family members. The files are:

1. The Inpatient Case File stores summary information on cases constructed for each inpatient episode by a patient. There is one record per inpatient admission.

2. The Inpatient Service File stores information about individual services performed during a patient's hospital stay. There is one record for each service.

3. The Outpatient Claims File stores information about individual claims resulting from services provided in an outpatient setting. There is one record per claim.

4. The Populations File indicates the number of persons who were eligible for coverage in each population-supported field.

Research Using the MEDSTAT Database

The MEDSTAT research database contains exceptionally strong financial, clinical, and utilization information. In addition, the database is structured to facilitate a variety of research approaches and methodologies.

FRAMEWORK FOR MEDSTAT DATABASES

- Patient or claim as unit of analysis
- Health services research model

Dependent Variables = Independent Variables + Intervening Variables

Price	Benefit Levels	Geographic Location
Use	Provider Characteristics	Workforce Demographics
Quality	Administrative Arrangements	Industry Type

In the three years that the research database has been available, it has been utilized for a variety of clinical, economic, and policy-related studies, including the following:

- Richard G. Frank, Ph.D., D.S. Salkever, Ph.D., and S.S. Sharfstein, M.D. -- "A New Look at Rising Mental Health Insurance Costs," *Health Affairs*, Summer, 1991. Frank et al. tracked the experience of a population over four years and documented changes in mental health and substance abuse costs and utilization.

- Bruce J. Hillman, M.D., et al. -- "Frequency and Costs of Diagnostic Imaging in Office Practice -- a Comparison of Self-Referring and Radiologist Referring Physicians," *New England Journal of Medicine*, December 6, 1990. Hillman et al.'s study utilized a unique method of creating episodes of outpatient imaging treatment, based on diagnosis, procedures, physician specialty, and duration of treatment.

- Employee Benefit Research Institute -- Using a database of persons in the Los Angeles metropolitan area, William F. Custer, Ph.D. tracked the effects of benefit plan design features on plan costs.

- Health Care Financing Administration -- Medicaid Quality of Care Study. We provided private sector comparative data for evaluating the quality of care received by Medicaid patients.

- University of North Carolina School of Public Health and the Harvard School of Public Health -- With a grant from the Robert Wood Johnson Foundation, researchers are utilizing MEDSTAT data to study the effectiveness of healthcare cost management programs.

- National Institute of Alcohol Abuse and Alcoholism -- A longitudinal database of alcohol and drug abusers and their families is being used for research.

Future Development

As the healthcare delivery system changes and information systems evolve, both the form and content of longitudinal databases must also change. Maintaining the link between earlier and later data formats is a major challenge. New delivery systems (such as managed care) collect different types of data and use data in varying ways. In addition, changes in classification systems (DRG versions, ICD-9 revisions) require maintaining the underlying detail necessary to translate between old and new versions.

As the utility of additional data sources increases, we are expanding the variety of data we maintain in the database. Our near-term plans include:

- Integration of HMO and other managed care data into the research database.
- Addition of detailed pharmaceutical data.
- Integration of additional work-related employee information, such as workers compensation, short-term disability, and health risk appraisal data.

Another development priority is to make available smaller databases for exploratory data analysis. These databases, which will be available to researchers for on-line, interactive analysis. One database will be a representative sample of the whole, while others will focus on clinical issues, benefit design, or regional experience.

Lessons

We have learned many lessons about maintaining large longitudinal databases. Some of the most important are:

- Longitudinal database maintenance requires strong incentives and a sustained investment. It is important to define the objectives of data collection and the potential uses of the data.

- The form, content and quality of the data change constantly. Extensive testing and benchmarking will always be necessary.

- One must understand the entire "lifecycle" of the dataflow in order to ensure meaningful research results.

- Database use and quality are proportional; the more the data are used, the better their quality tends to become. Put differently, only through intensive use can all data problems be revealed and repaired.

- The healthcare experience of the population is a constantly moving target; database designs rapidly become obsolete.

- The movement away from fee for service transactions greatly complicates database design. Maintaining the link between utilization and reimbursement will be increasingly difficult.

LINKING MEDICARE DATA WITH SURVEILLANCE, EPIDEMIOLOGY, AND END RESULTS (SEER) PROGRAM DATA

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This paper describes a project being conducted jointly by the Health Care Financing Administration and the National Cancer Institute. The project links Medicare data with tumor registry data obtained from the National Cancer Institute's Surveillance, Epidemiology, and End Results Program, or SEER program. The purpose of the link is to combine clinical information on cancer cases at the time of diagnosis with information on the use and costs of services related to cancer treatment. The data bases are being linked on an individual basis to create a merged data base that will contain extensive Medicare utilization and cost information for up to several years following a diagnosis of cancer. This paper describes the new data base and presents some preliminary findings on trends over time in Medicare charges attributable to cancer patients.

The SEER program involves the reporting of uniform data to the National Cancer Institute by 9 geographically distinct, population-based, tumor registries. The program contains information on all incident cancer cases occurring among residents of the 9 geographic areas. These areas cover close to 10 percent of the U.S. population. The SEER areas are not statistically representative of the U.S. population, but they have been used as the best source of data for national estimates of cancer incidence and survival. Reported data include month and year of diagnosis, site of cancer, stage at diagnosis (indicating extent of disease), histology, and first course of therapy.

We developed an algorithm to link the SEER and Medicare files, based on variables common to both data sets. The algorithm was derived from the criteria used by the National Center for Health Statistics to link the National Death Index to other data bases. We primarily used name, Social Security Number, date of birth, and sex to establish matches.

So far, data from the Medicare Statistical System have been linked to SEER data from 8 of the 9 registries through 1986 (Table 1). In total, over 400,000 cases were matched; this represents 86 percent of elderly SEER cases. There are over 50,000 matched cases for each of the major cancer sites, including cancers of the prostate, lung, colon, and breast. We are currently preparing to update the linked data base to incorporate SEER data through 1989.

Table 1

Number of matched SEER-Medicare cases 1973-1986

All sites combined	438,024
Lung and bronchus	57,684
Colon and rectum	76,494
Bladder	24,171
Breast	53,824
Prostate	61,429

Although SEER data go back to 1973, most of the Medicare data are available only for 1984 and later. Summary data on all Medicare claims are available from 1984 on, as well as detailed information on all inpatient hospital stays. Detailed information on physician and outpatient services are currently available for only a 5 percent sample of beneficiaries beginning in 1985. Because many cancer treatments are now performed on an outpatient basis, the 5 percent limitation is very significant. The updated linkage will add a significant number of new cases for which we will have detailed information on physician and outpatient services. Limited data are also available on a 5 percent sample of Medicare beneficiaries going back to 1974.

The linked data base will have a great many uses. We will study the short and long term costs of cancer care, by stage at diagnosis. These cost estimates will be useful in studying the cost effects of certain cancer screening and treatments. We will study changes in cancer care costs over time, including the implications of shifts from inpatient to ambulatory care. We will be able to describe existing patterns of treatment for various cancers, and the outcomes associated

with those treatments. Outcome data will include mortality, and may include such things as recurrence of cancer or complications of treatment. Variations by demographic characteristics and by geographic areas will also be examined. We will also study the incidence of comorbidities and their impact on outcomes and costs.

Next, I want to present some preliminary findings on trends over time in Medicare covered charges attributable to breast cancer and colorectal cancer patients. We used the Continuous Medicare History Sample file, or CMHS. This file contains cost, charge, and utilization data on a 5 percent sample of Medicare beneficiaries going back to 1974. Records of beneficiaries who die are retained on the file and new beneficiaries are added on an ongoing basis. Cost, charge, and utilization data are available for all types of Medicare covered services, but are summarized by calendar year. By linking this file to SEER data we were able to examine costs incurred around the time of diagnosis by type and stage of cancer, at different points in time.

For our analysis we defined as our dependent variable Medicare charges in the calendar year of diagnosis. We were interested in how charges in the calendar year of diagnosis changed over time, and specifically whether they increased faster than Medicare covered charges in general. We chose charges rather than Medicare reimbursements because changes in Medicare reimbursement rules over time could introduce changes in average reimbursements that do not reflect changes in services used. Because of limitations in the CMHS we examined total charges in the calendar year of diagnosis. That is, we could not distinguish charges for cancer treatment from other charges, nor could we look at time frames other than a calendar year.

Table 2 summarizes the increase in Medicare charges for breast and colorectal cancer patients between 1976 and 1986. The percent increase in average Medicare charges for all aged beneficiaries is also given in the first row for comparison. The first row shows that Medicare charges in general increased by 241% on a per enrollee basis. Average charges for breast cancer patients increased by 185% and charges for colorectal cancer patients increased by 144%. Thus, average charges for breast and colorectal cancer patients did not increase as fast over this time period as Medicare charges in general. Charges for these cancer patients did rise at a somewhat faster rate than the Medical Care Component of the Consumer Price Index, which increased 134%.

Table 2

Percent increase 1976-1986

	Percent increase
Average Medicare covered charges in calendar year - all aged	241.2%
Diagnosed with breast cancer	185.3%
Diagnosed with colorectal cancer	144.3%
Medical Care component of CPI	133.5%

Figure 1 contains data on the growth in charges in the calendar year of diagnosis for breast cancer and colorectal cancer patients, by year of diagnosis. The graph shows the growth in charges from 1976 to 1986. It is based on about 1,800 observations for the breast cancer group and 2,800 for the colorectal cancer group. In order to show the relative growth in charges over time, we divided the average charges for breast cancer patients in each year by the average charges for breast cancer patients in 1976. We plotted those ratios on the y axis of the graph. The same was done for colorectal cancer patients. Similarly, the top line in the graph describes the growth in average Medicare charges for all aged enrollees.

As the graph indicates, average charges for colorectal cancer patients have risen substantially, but have not risen as fast as average Medicare charges in general. The growth in charges for colorectal cancer patients particularly slowed after 1983, and even reversed in 1984 and 1985. For breast cancer patients, average charges increased at about the same rate as overall Program charges until 1981, after which average charges for breast cancer patients grew more slowly.

Figure 2 shows the growth in Part A charges over time. Part A covers primarily inpatient hospital services. For colorectal cancer patients, Part A charges increased at a slower rate than average charges for all aged beneficiaries,

Figure 1

AVERAGE CHARGES IN CALENDAR YEAR OF DIAGNOSIS

indexed to 1976

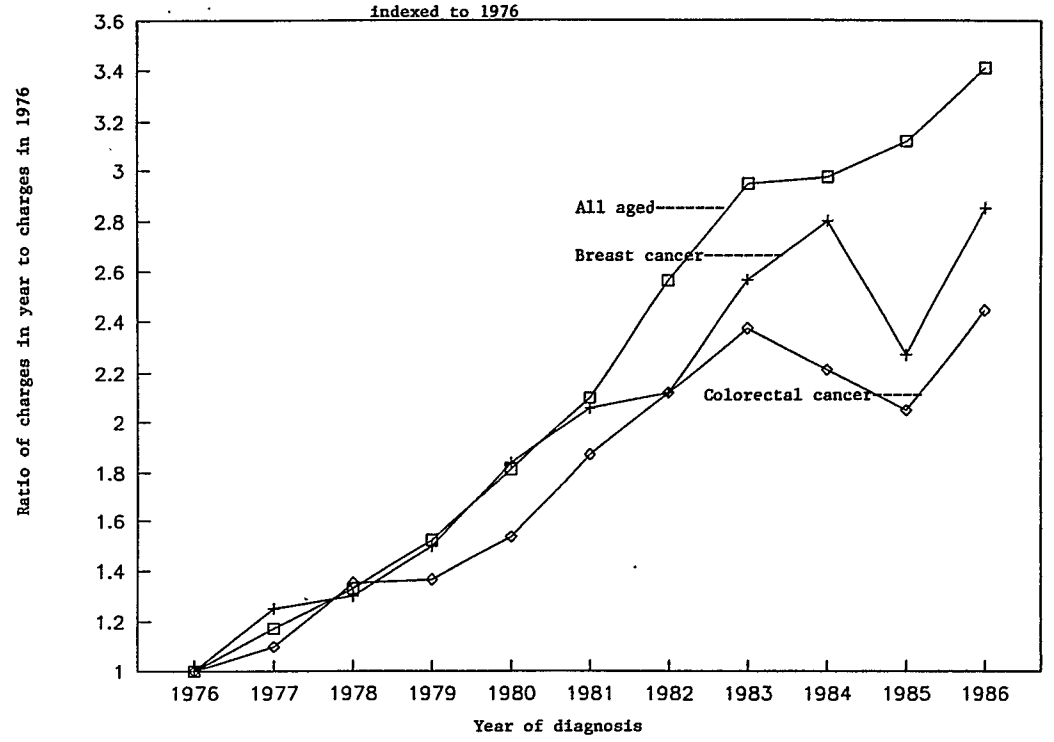


Figure 2

AVERAGE PART A CHARGES IN CALENDAR YEAR OF DIAGNOSIS

indexed to 1976

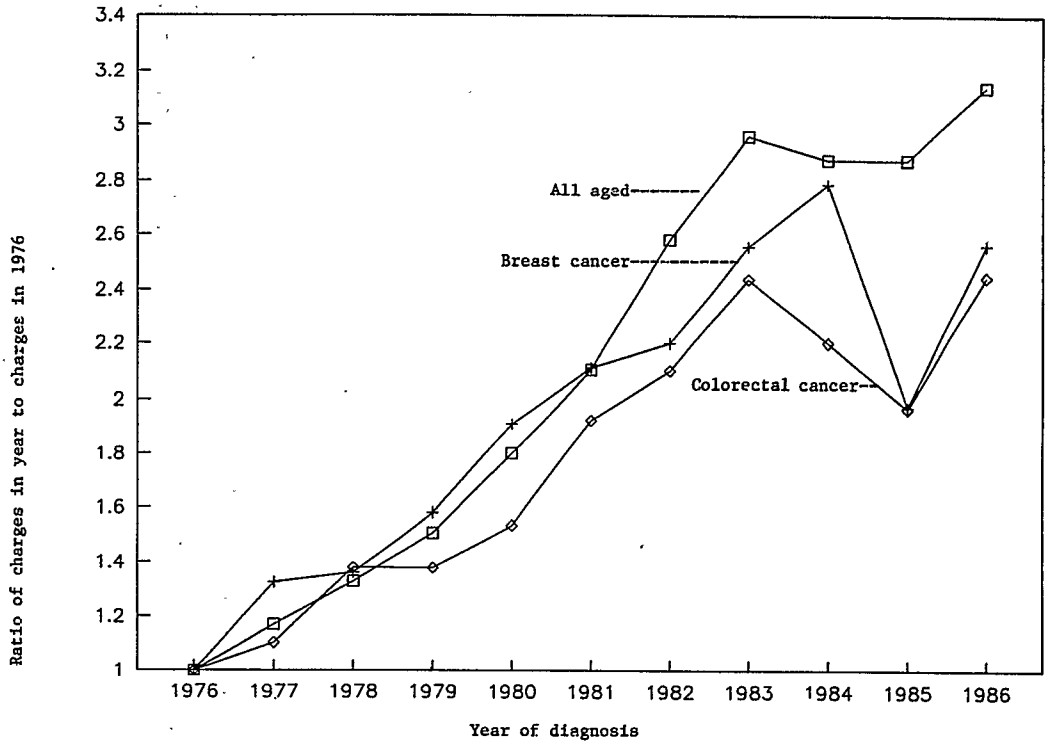
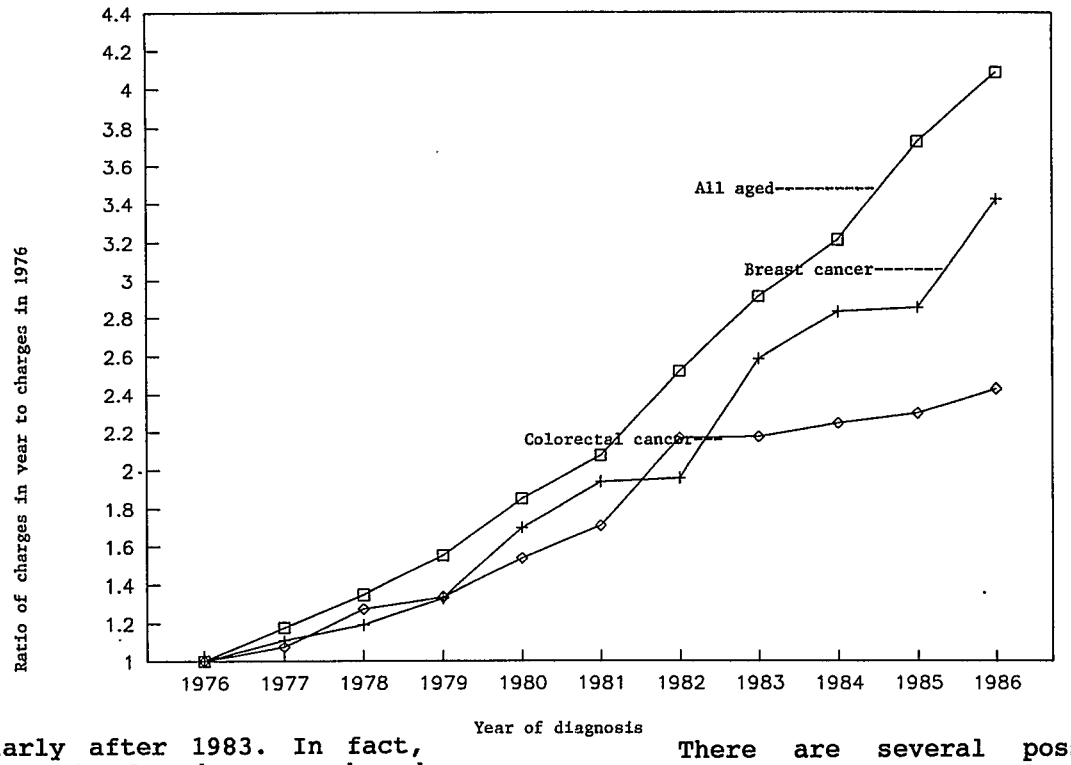


Figure 3

AVERAGE PART B CHARGES IN CALENDAR YEAR OF DIAGNOSIS

indexed to 1976



particularly after 1983. In fact, average Part A charges showed absolute declines in 1984 and 1985. These declines may be related to the introduction of the prospective payment system for hospitals in 1984. For breast cancer patients, average Part A charges rose at approximately the same rate as charges for all aged beneficiaries through 1984, then declined sharply in 1985.

Figure 3 shows the relative growth in Part B charges. Part B covers primarily physician and outpatient services. Again, the top line shows the growth in Medicare Part B charges on a per enrollee basis. For the colorectal group, average charges increased each year in absolute terms, but at a relatively slow rate. Part B charges rose especially slowly after 1982, which was a time during which overall Part B charges rose very rapidly. Part B charges for breast cancer patients grew somewhat more slowly than Part B charges for all aged beneficiaries throughout the time period of the study.

In summary, the figures suggest that for elderly breast and colorectal cancer patients, charges in the calendar year of diagnosis have not grown as fast as average Medicare charges for all aged beneficiaries. This finding holds for both Part A and Part B services.

There are several possible reasons for the relatively slow growth in charges for breast and colorectal cancer patients. According to oncologists at the National Cancer Institute, there has been an increasing emphasis on outpatient treatment that has lessened the need for lengthy inpatient stays. This emphasis on outpatient treatments may explain the relative decline in Part A charges over the period of the study. Much of the surgery now performed on breast and colorectal cancer patients is less radical than that performed previously, which may result in lower overall charges. Another likely explanation is that treatment for conditions other than cancer have become very technology intensive and expensive. For example, coronary artery bypass surgery, and major joint replacements have become common. Expensive new technologies like these may have increased Medicare charges in general at a much faster rate than charges for cancer treatments specifically. As we study treatment patterns in more detail we hope to form more specific hypotheses about the reasons for trends in Medicare charges for elderly cancer patients.

A NATIONAL EXPOSURE REGISTRY: A LONGITUDINAL DATABASE

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BACKGROUND:

More than 32,000 hazardous waste sites are listed in the Environmental Protection Agency's (EPA) national hazardous waste site inventory. The public health and environmental impact of hazardous waste sites are the focus of the Comprehensive Environmental Response, Compensation, and Liability Act of 1980 (1), also known as CERCLA or Superfund. Congress designated EPA as the lead agency in implementing CERCLA and created the Agency for Toxic Substances and Disease Registry (ATSDR) to implement health-related sections of the Act.

One of the program elements in ATSDR is the National Exposure Registry, which is a listing of persons exposed to hazardous substances at selected sites. The primary purpose of the Registry is to aid in assessing long-term health consequences of exposure to Superfund-related hazardous substances.

METHODS:

The methodology used to establish the Registry involves identifying persons from different sites who have been similarly exposed to a specific environmental contaminant of concern. The selection criteria for choosing primary contaminants, sites, and potentially exposed populations are detailed in the Policy and Procedures for Establishing a National Registry of Persons Exposed to Hazardous Substances (2).

A new chemical-specific subregistry is created with the selection of a primary contaminant. Baseline interviews are conducted with potentially exposed persons to verify exposure and answer a questionnaire. The questionnaire addresses demographic, occupational, health, smoking, and basic reproductive health histories. After the baseline interview, Registry members are contacted by phone annually to update the information.

To date, there are four subregistries. The trichloroethylene (TCE) subregistry has over 4,800 members. The dioxin subregistry has over 225 members. Sites are still being considered for the benzene and chromium subregistries. Development of the subregistries is an ongoing activity.

The size of a particular subregistry (number of participants) is determined by a statistical power calculation that estimates the sample size needed to detect a change in the incidence of the suspected health effect (or a difference between the health outcomes reported by Registry members and those reported in other national health surveys). In general the smaller the difference to be detected, the larger the sample size. The benzene and chromium subregistries will eventually contain approximately 5,000 registrants each.

PREVENTION/INTERVENTION TOOL:

Of particular concern in considering environmental health issues is the lack of information on the effects of low-level exposures of long duration. This is the type of exposure typically found in persons living near hazardous waste sites. The Registry directly addresses these types of "real life" exposures.

Registry members' answers to the health status questions will be compared with answers to other national health surveys, including the National Center for Health Statistics (NCHS) Health Interview Survey (3). Due to the longitudinal nature of the data, a trend analysis will be conducted to determine if there are any changes over time in reports of adverse health outcomes.

The Registry will be a valuable tool in addressing the potential health outcomes of environmental exposures to hazardous substances. Facilitating environmental epidemiologic studies is the major goal of the Registry. The data files will be of value in research related to known adverse health outcomes (hypothesis testing) and in identifying unknown, undetermined adverse health outcomes (hypothesis generating) should they exist.

CONCLUSION:

The human health effects of many hazardous substances are largely unknown. The National Exposure Registry represents a valuable tool in the detection of excess adverse health conditions related to environmental exposures and hence the development of prevention strategies and early intervention programs. The Registry provides a tool for assisting in meaningful evaluations of major public health questions.

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PITFALLS OF PANEL DATA: THE CASE OF THE SIPP HEALTH INSURANCE DATA

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I. Introduction

Survey data are inevitably imperfect. First, finite budgets imply that we sample only a (very small) fraction of the population--inducing sampling error. Second, and more pernicious, are a range of non-sampling errors. In simple cross-sectional surveys among the important non-sampling errors are *non-response bias*--some people in the original sample are not found or refuse to respond, and *recall bias*--some people forget that events occurred or mis-date them.

This paper, prepared for the session on "Longitudinal Data Systems", considers corresponding problems in longitudinal (or panel) survey efforts. Corresponding to non-response bias, we have *panel attrition* -- some people who answer the first interview can not be located or refuse to respond to some (or all) later interviews. Corresponding to recall bias, we have *seam bias* -- when asked when events occurred, some people respond that their status changed immediately following their previous interview.

Using the health insurance data from the Survey of Income and Program Participation (SIPP) as an example, this paper explores these two non-sampling error issues for panel data. We describe under what conditions the biases are likely to be important, propose simple methods for identifying if the biases are present, suggest work-arounds for imperfect data, and sketch formal parametric methods for estimation in the presence of these longitudinal non-sampling biases.

II. Background

The United States is the only major western country without a system of universal national health insurance. Instead, receipt of health care and corresponding payment mechanisms are a patchwork quilt of private and government programs. A long term trend towards increasing levels of health insurance coverage reversed over the last decade, leaving about fifteen percent of the non-elderly population without health insurance coverage (Swartz, 1984; Ries, 1991). This trend reversal, the high levels of lack of insurance coverage, and the rapidly increasing cost of health care have stimulated political efforts to ameliorate the problem.

These trends have also focused attention on the survey sources for the underlying estimates of the levels of health insurance and focused attention on the survey efforts underlying the estimates themselves. Some of the controversy about the levels of health insurance coverage are due to inconsistencies between data sources and over time in a sequence of related surveys (Moyer, 1990; Swartz and Purcell, 1991; Ries, 1991).

The work which we report here uses the SIPP, a multi-purpose longitudinal survey conducted by the Bureau of the Census. It is designed to provide policy makers with more accurate and comprehensive information about income and participation in public programs (including Medicare and Medicaid) of persons and household in the United States, and about the principal determinants of income and program participation (Jabine, 1990, p. 5). As such it collects monthly data on demographics (age, marital status, state of residence), labor market status, health insurance coverage, and participation in receipt of income from government programs.

The basic survey design is a rotating panel. A new panel of households is introduced at the beginning of each year and interviewed seven times (eight times for the 1984 panel) at four month intervals. Thus, each panel is followed for 28 months. The sample size for each panel has varied. The sample sizes have been cut several times in mid-panel for several of the waves. Overall, the sample eligible to complete all seven interviews has been about 13,000 households. The first panel was begun in late-1983. The work reported here uses the 1984 (started in late-1983), 1985, 1986, and 1987 panels.

In the work which follows, we use a subset of the full file. The work on attrition uses the 1196 black males 18-64 at the start of the 1984 panel with positive panel weight who were not cut in the sample reduction. The work on seam bias uses individuals from all four panels who are 18-64 at the first interview and less than 65 in the month to which the data refers. Some people younger than 18 at the start of the panel will reach age 18 during the period of the panel, so we are missing some people who reached majority during the panel.

III. Attrition Bias

In a cross-sectional survey, non-response bias is a problem when not all of the sampled individuals actually respond *and* the non-respondents are different from the respondents. For example, if people with health insurance are more likely to be located and/or less likely to refuse to be interviewed, then the health insurance coverage rates computed from the respondents will be higher than the true rates in the population.

Attrition bias is the panel survey equivalent of simple non-response bias. At its first interview, the interviewed population is likely to be similar to the population which is successfully interviewed in cross-sectional surveys and the computed coverage levels are likely to be similar. At subsequent interviews, however, panel surveys continue to have trouble locating individuals and refusals can become more common as respondents realize the burden of participating in a longitudinal survey. Conditional on having answered the initial interview, when the non-respondents to subsequent interviews differ from respondents at subsequent interviews, attrition bias is present. In our case, the concern is that the non-respondents would be less likely to have health insurance. If so, then even if health insurance coverage levels were stable in the population, coverage levels in the panel would appear to be rising. Although the rates in the population are (by the assumption of the example) unchanged, the *respondents* are composed increasingly of the insured.

Such biases are a common concern in the analysis of panel data. A recent review of longitudinal data collection efforts listed among the disadvantages of longitudinal data (Subcommittee on Longitudinal Surveys, 1986):

> *Beginning refusal rates may be comparable to those of cross-sectional surveys, but the attrition suffered over time may create serious biases in the analysis.*
> *Longitudinal surveys are often improperly analyzed, not taking into account longitudinal characteristics or attrition.*

In this section, we use a worst case scenario, black males from the 1984 Panel to assess the empirical importance of attrition bias.

There is no doubt that attrition is a non-trivial problem for this population. Only 65 percent of the black males in our sample completed all eight interviews. Aside from the loss of sample size for longitudinal analyses, this is not a major problem if panel non-respondents are similar to panel respondents.

That criteria, that panel non-respondents be similar to panel respondents, suggests a simple test for the presence of attrition bias. If non-respondents at subsequent interviews are like respondents at subsequent interviews, then their health insurance status at the first interview should be the same. Rates of coverage at the first interview are not the same across the sub-samples completing and not completing all of the interviews. Individuals who complete all eight interviews are 11.4 percentage points more likely to be insured at the first interview than those who are interviewed at the first interview, but not subsequently (73.4 percent vs. 62.0 percent).

The requirement of the previous paragraph is what Little and Su (1989, citing Little and Rubin) call *missing completely at random.* One possible cause of the divergence between the two groups is selection on observables -- what Little and Su call *missing at random.* Attriters tend to be younger. The young are less likely to be insured at the initial interview. We can reweight the two sub-samples so that they each separately sum to the population control totals for age. Doing so explains some of the difference between the two populations, but not much -- about 20 percent. The reweighted coverage levels still differ by 8.9 percentage points (73.2 percent vs. 64.3 percent).

The other possibility is selection on unobservables. Given observationally identical individuals (i.e., they have the same age), the ones without health insurance are less likely to be interviewed at successive interviews. One way to formalize this is to say that individuals have some underlying time-invariant *propensity* to have health insurance and to be interviewed and these two propensities are negatively correlated.

If we are interested solely in the trend in health insurance, we could analyze only those individuals who complete all of the interviews. Such a procedure holds the distribution of the propensities fixed through time. However, since those completing all the interviews are more likely to be insured at the first interview, this procedure gives a biased estimate of the levels. A simple correction would therefore be to take the percentage point difference between the full sample and the sample completing all the interviews at the first interview (in our case 4.4 percentage points) and add that difference to our estimate of the percentage insured computed from the sub-sample completing the entire set of interview.

The model in Klerman (1991) embeds that idea in bivariate generalization of the panel probit model's permanent transitory structure (Butler and Moffit, 1984):

$$I_i = X\beta_i + \mu_i\eta_i + \varepsilon_i$$
$$I_h = X\beta_h + \mu_h\eta_h + \rho\mu_i\eta_i + \varepsilon_h$$

where the I's are the indexes to probit functions for being interviewed and having health insurance respectively, X is a vector of observed covariates affecting the probability of being insured (in this example age), η is the time invariant unobserved propensity, ε is a period-specific shock, and ρ represents the correlation between the propensities to be insured and to be interviewed. The η's are treated as random effects with a unit normal distribution. The μ's serve as a factor loadings and ρ estimates the correlation between the two unobserved propensities. All of the parameters (the regression coefficients, β; the factor loadings, μ; and the correlation parameter ρ) are estimated jointly by maximum likelihood. The data are the binary outcomes: was the individual interviewed? and did the individual have health insurance?

When the whole model is estimated as a system, the *rising* trend in health insurance coverage among the sample of people who are interviewed in a given month is replaced by a *falling* trend in coverage rates. Even for this worse case of black males, however, the magnitude of the effects are not large (a 2.4 percentage point increase, vs. a 0.7 percentage point decrease).

Thus, the effect on the level of health insurance coverage of using those individuals who were interviewed in that month distorts the estimates of the trend, and in later months the level of health insurance. Even in this worst case population, the effects are small. For the population as a whole, where attrition rates are lower and in a survey which is as well run as the SIPP, the problems are negligible. For other surveys with less energetic follow-up of non-interviews and higher attrition rates, the problem could be more severe.

Ex-post comparing the interview 1 behavior of those completing all of the interviews and those not completing all of the interviews provides a simple test for the importance of attrition bias. Using the difference between the month 1 behaviors of the two populations to adjust the trend estimate computed from the population completing all of the interviews provides a simple way to correct for the attrition bias. The model of Klerman (1991) provides a formal way to incorporate this correction.

IV. Seam Bias

The previous section described using the SIPP to measure levels of health insurance each month. This could be done using a sequence of cross-sectional surveys. Panel surveys like the SIPP are uniquely suited to collecting dynamic information on changes in health insurance coverage.

Such information on changes in status can be collected in cross-sectional surveys using retrospective questions. In retrospective data collection, at a single interview, respondents are asked both about their current status and their status at some earlier date (e.g., last month, last year), or when they were last in some other state (asking uninsured people when they last had insurance). Alternatively, a longitudinal survey can reinterview individuals at regular intervals, ascertaining health insurance coverage status at each interviews.

As opposed to asking retrospective questions, asking about contemporaneous status at two points in time is generally considered to yield higher quality data (Sub-Committee on Longitudinal Data, 1986; Bailar, 1989). The corresponding disadvantage of longitudinal data collection is cost. A longitudinal survey interviews each respondent multiple times. Since the cost-per interview usually dominates survey costs, longitudinal surveys are considerably more expensive to field.

Longitudinal surveys must choose two frequencies First, survey sponsors must choose a frequency at which to attempt to record the data. Do they want to know health insurance each day? each week? each month? Second, survey sponsors must choose the frequency with which to interview the respondents. The more frequent the interviews, the smaller is the problem of recall bias, but the higher is the cost and the greater is the respondent burden.

Most longitudinal surveys balance the two considerations. They choose an inter-interview interval which is longer than the frequency of the data concepts to be collected. The difference is made up by asking respondents to describe changes in outcomes during the period since the last interview.

In the SIPP, interviews are conducted every four months. Health insurance information is collected retrospectively for a monthly frequency. Employment information is collected retrospectively for a weekly frequency.

The recall error induced by these retrospective responses has been documented, and it is systematic. Changes in status are more likely to occur across two periods which are reported at *different* interviews. This problem is known as *seam bias.*

One simple explanation for this seam bias is propagation (see Young 1989, who calls this constant wave response). Respondents tend to propagate their current status back through the entire reference period for the current interview. This appears to occur because respondents forget that a transition occurred. Instead, they report their current status for the entire reference interval for this interview. Thus, it appears that the transition occurred the day after the previous interview.

This problem has been widely noted in the SIPP. Jabine (1990, pp. 57-61) summarizes the SIPP specific literature. The problem is overwhelming. To equalize interviewer load, each SIPP interview is given to a quarter of the sample each month. Thus, even if the rates of transition were seasonal (e.g. more people change jobs between December and January), the percentage of changes in health insurance status occurring on the seams should be constant. It is not. The percentage of people with employer provided health insurance in the first month of the four month reference period who report not having health insurance in the second month of the reference period is 0.37. The figures for month 2 to month 3 and month 3 to month 4 are respectively 0.57 and 0.63. The figure for month 4 of one interview to month 1 of the next interview is 14.98. The ratio of transitions at the seam to the mean (which would be 1.00 if there was no seam bias) is a convenient summary measure of the degree of seam bias. For this example, there are 3.62 times as many transitions at the seam as there should be if transitions were reported evenly distributed across reference months. The corresponding figure for transitions from no health insurance to health insurance is 3.51. Alternatively, we can consider the percentage of transitions occurring across the seam. If seam bias was absent, the figure would be 25 percent. For the SIPP health insurance data the percentages are 90.51 and 88.00 (from insured to uninsured and from uninsured to insured)

Part of the problem is the SIPP health insurance question battery. It is:

> *24a. During the 4-month period, did ... have group or individual health insurance in ...'s own name?*
> *24b. Was ... covered by a health insurance plan in somebody else's name?*
> *24c. Did ... have this health insurance plan during the entire 4-month period?*
> *24d. In which months did ... have the plan?*
> *24e. Did ... have a health plan provided through an employer or union (or through a former employer or pension plan)?*

Note that these questions on health insurance assume no change in status. The respondent must expend the effort of saying that there was a change in status before being probed for when the change occurred. Respondents to panel surveys may learn that answering yes to anything induces an additional set of questions.

The comparison with labor force status is informative. Labor force status is more important to the SIPP (and to other Census surveys like the Current Population Survey) than is health insurance status. The SIPP interview more carefully explores labor force behavior:

> *24d. In which months did ... have this plan?*
> *2b. Please look at the calendar. In which weeks was ... looking for work or on layoff from a job?*
> *6a. Please look at the calendar. In which weeks did ... have a job or business?*

The questions do not assume no change in status. They use a weekly, rather than a monthly, reference period. Finally, a physical calender on a card is used.

Thus merely because of interview structure, we would expect to see more seam bias in the health insurance questions than in the employment questions. The fact that employment is likely to be a more salient status than health insurance status reinforces the expectation that the employment data would show less seam bias than the health insurance data.

In fact, seam bias is less important in the employment data. The ratio of seam to mean transitions for employment to non-employment is 2.70. For non-employment to employment, the ratio is 2.38. The percentage of transitions occurring across the seam tells a similar story. For employed to not employed, the percentage is 67.67. For not employed to employed, the percentage is 59.52. Thus even with the more careful employment battery, over half the transitions occur on the seam.

The effect of this seam bias is clearly visible in discrete time hazards for length of time with or without health insurance, and length of time with or without a job. Both the distribution functions and the hazards show heaping at 4, 8, 12, ... months.

Thus, although the questionnaire would lead one to think that one could estimate the duration of spells in monthly (or for the labor force status, weekly) time units; in fact, we can only reliably investigate transitions at the frequency of the interviews -- four months. For many phenomenon, this is too long to address the substantively important questions. Young (1989) describes some models which allow one to recover the true distribution of spell lengths. With appropriate assumptions, those models allow one to jointly model the probability of a seam response and the true distribution of spell lengths.

Comparing transitions on and off the seam provides a simple test of the presence of seam bias. Unlike attrition bias, where even for a worst case, the effects were small; the seam bias dominates the data. The approach of Young provides a formal solution to the problem. There are, however, so few non-seam transitions that it seems necessary to simply ignore the off-seam responses. Thus, if a survey truly requires monthly data, monthly interviews -- with the much higher costs -- may be necessary. Relying on retrospective answers, even over seemingly short intervals (four months in the SIPP) appears to yield unsatisfactory data.

V. Conclusion

This paper has investigated two forms of non-sampling bias in panel data: attrition bias and seam bias. We noted that they are the panel data counter-parts to non-response bias and recall bias. We gave simple tests for the presence of the two types of bias and noted that more complicated procedures exist which specify conditions under which one can jointly model the true behavior and the probability of the non-sampling error.

We considered the empirical importance of the two problems for the SIPP health insurance data. For the worst case, black males, ignoring attrition and analyzing the sample completing each interview yields some bias (about 4

percent) in the levels and the conclusion that levels of health insurance coverage are rising. Correcting for attrition bias, yields a small decrease in health insurance coverage. Analyzing only those who complete all of the interviews yields the correct trend, but the wrong levels. The magnitude of each of these effects is small, even on this worst case sub-population. Attrition bias does not appear to be a major problem.

Seam bias is, however, a major problem. While only a quarter of the transitions should occur on the seam, over half of them do. These seam transitions dominate the estimates of the distribution of spell lengths. Despite the fact that the questions are asked for monthly insurance status, the data are nearly useless for any analyses below the interview frequency -- every four months.

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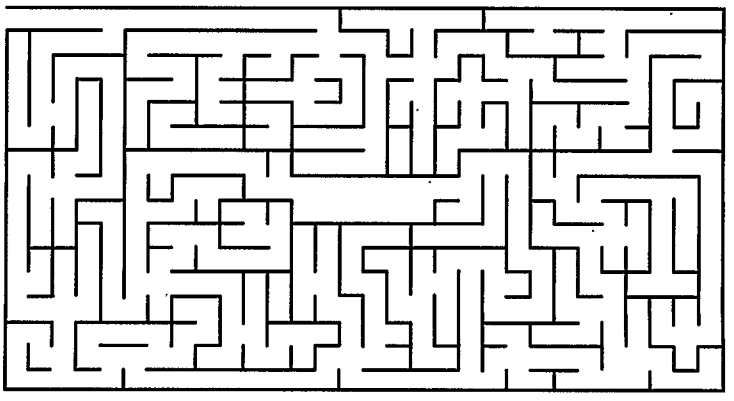
Session C

Alternative Sources of Health Care



MEASURING HMO PERFORMANCE: AN EVALUATION OF HMO DATA REPORTING CAPABILITIES

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Health maintenance organization (HMO) enrollment nationwide now exceeds 30 million. The explosive growth in HMO membership over the last twenty years has resulted in large part from federally mandated incentives, specifically the HMO Act of 1973 and the Tax Equity and Fiscal Responsibility Act of 1982, and from widespread interest and support of the HMO concept by U.S. industry and labor unions. Although perhaps not reaching the 25% national penetration rate once predicted for 1995, HMO membership still is expected to increase 15 to 20 percent annually in the near term.

Many healthcare purchasers, however, are beginning to demand information from HMOs to determine whether the increasing proportion of their health care expenditures going toward these plans represents an effective allocation of resources. When confronted with employer requests for data, many HMOs have been unable or unwilling to respond.

In an effort to improve their information on managed care alternatives, several large U.S. corporations turned to MEDSTAT Systems to design a decision support system capable of monitoring the utilization, quality and cost patterns of their employees enrolled in HMOs. As part of this development process, MEDSTAT Systems conducted a review of historical HMO data collection initiatives.

Our examination of HMO data collection initiatives revealed that attempts to obtain information were underway in multiple sectors, including the federal government, state agencies, individual corporations, business health coalitions and research groups within universities and think tank organizations. The eclectic mix of organizations devoting attention to gathering information from managed care plans has resulted in a correspondingly wide array of projects whose only commonality is the desire to understand the process and cost of caregiving in health maintenance organizations.

The data currently collected generally fall into one of several categories: descriptive information, financial statements, utilization statistics or quality of care measurements. Some organizations are simply assembling databases of descriptive information on HMOs for purposes of comparison; premiums, benefit coverage, administrative procedures and access issues are incorporated into these databases. Government agencies are routinely collecting financial statements, frequently on a common reporting instrument, the "Health Maintenance Organization Financial Report of Affairs and Conditions." Utilization data are of high interest to many requesters, but to date have not been widely sought at the level of specificity present in indemnity claims databases; with notable exceptions, organizations have confined their request to a group-specific level of detail. Finally, design of quality of care assessment measures is in a dynamic phase, with efforts ranging from third-party administration of enrolle satisfaction surveys to think tank research into establishing universally applicable protocols for HMO quality assessment.

Another fact which emerged in reviewing HMO data collection efforts was the variation in plans' willingness and ability to respond to information requests. Some HMOs have flatly refused to respond to information requests from the private sector, while others have been willing to work with healthcare purchasers to meet their data needs. In some cases, HMOs have required assistance in converting raw data into value-added information; individuals experienced in obtaining data from HMOs cited the need for flexibility and a willingness to work creatively with the information available. Even when the data exist, data reporting in paper format appears to be more common than the use of computer-readable formats, placing the burden of computerizing the data for purposes of analysis on the data requester.

In June 1988, MEDSTAT Systems set out to develop and implement a decision support system designed to monitor the use, quality and cost of care provided by HMOs. The key developmental objectives of this initiative were to:

- initiate a consistent flow of HMO data;
- develop an on-line interactive database;
- create new analytical tools for use with HMO data; and
- establish data standards

During the first phase of this initiative, MEDSTAT Systems designed an HMO data reporting process that balanced the information needs of healthcare purchasers with the data reporting capabilities of the HMO industry. Numerous interviews with healthcare purchasers to understand their decision support requirements were combined with site visits to over 30 HMOs from across the country.

Site visits to individual HMOs were intended to serve two major purposes. The first was to assess present data reporting capabilities of the HMO industry. Meetings with systems experts at these HMOs revealed what information was being collected and to what extent it was currently automated. Second, these site visits afforded HMOs with the opportunity to influence the design of the HMO database and analytical software system. Plan executives were asked to identify what they believed were the most appropriate measures for evaluating HMO performance.

Between October 10, 1988 and May 3, 1989, 34 HMOs were visited. The 34 plans were located in 12 states and included 14 IPA Model, 10 Network Model, 7 Group Model, and 3 Staff Model HMOs.

Site visit surveys were mailed to HMOs in advance of the visits. The survey covered a variety of topics, including hardware configuration, current HMO software applications, data reporting capabilities for selected data elements, and coding conventions. During the site visits, HMO representatives also were asked to identify what they believed to be the most appropriate measures for evaluating HMO performance.

The remainder of this paper summarizes the findings from our site visits to HMOs, focusing on the types of

management information systems in place at HMOs, and on the data reporting capabilities of the HMOs we visited.

Management Information Systems

HMOs reported using a wide array of computer systems for their electronic data processing, ranging from minicomputers to IBM mainframes. Of the 28 plans that completed the site visit survey, 32% ran their basic system applications, including billing, membership and utilization tracking, on internally developed software. The rest (68%) used commercially-developed software packages. Fourteen percent had Jurgovan and Blair Incorporated (JBI) systems, while 18% of the HMOs used systems installed by Comtec. Eleven percent use Blue Cross Blue Shield parent organization systems to support their management information systems' requirements. The remaining plans (25%) used other vendors including Electronic Data Systems (EDS), Digital Insurance Systems Corporation (DISC), and Unisys.

Most information systems were found to be in a state of evolution. In order to respond more effectively to internal and external requests for data, 29% of the plans reported they were implementing system replacements or upgrades. All of the plans visited indicated the ability of producing data on magnetic tape.

Data Reporting Capabilities

The site visit survey also asked HMOs to indicate whether selected data fields were currently being captured by their automated MIS. The thirty-one data fields, proposed for HMO data reporting, were divided into four major groups:

- Demographic
- Clinical
- Provider
- Financial

On average, the HMOs we visited automated 85% of the data fields for inpatient services. IPA/Network Model HMOs, on average, were able to provide 91% of these data fields, while Group/Staff Model HMOs were able to provide 79% of the data. Differences existed primarily in the ability to provide Provider and Financial data: more IPA/Network Model HMOs collected these data than Group/Staff Model HMOs.

The HMOs automated, on average, 79% of the data fields for outpatient services. IPA/Network Model HMOs, on average, were able to provide 86% of these data fields, while Group/Staff Model HMOs were able to provide 71% of the data. Again, the difference was due primarily to more routine collection of Provider and Financial data by the IPA/Network Model HMOs. In contrast, Group/Staff Model HMOs reported certain Demographic and Clinical data fields more routinely than the IPA/Network Model HMOs.

Several opportunities for improving reporting capabilities were observed. Some of the more general problems frequently encountered were:

- Demographic Fields:

  Forty-eight percent of the plans did not maintain the employee's Social Security Number as the subscriber record key on the system; HMOs indicated, however, that it is possible to cross-match the social security number to the data records of HMOs using a data tape provided by the employer.

- Clinical Fields:

  Principal Diagnosis for outpatient procedures were not maintained by 27% of the plans; these plans either had capitation arrangements with primary service providers in which no detailed level data are passed back to the HMO for processing, or own their own outpatient facilities and compensate their physicians on a salaried basis. Nevertheless, two IPA model plans, which had capitation arrangements with ancillary service providers, did require encounter data.

- Provider Fields:

  Thirty-four percent of the plans did not maintain the Primary Care Physician ID on their system; most of these plans instead designated primary medical care groups or primary care centers.

- Financial Fields:

  On average, only 44% of the proposed financial fields were maintained by Group/Staff Model HMOs, while 82% of these fields were maintained by the IPA/Network Model plans. The low number of captured financial fields by the Group/Staff Model HMOs can be explained by differences in financing and delivery systems.

Of the plans visited, 79% appeared to appreciate purchasers' need for data, and 71% seemed willing to provide data and participate in an initiative to create an HMO decision support system. Twenty-nine percent of HMOs appeared hesitant to provide data. Twenty-one percent actively expressed an interest in a collaborative effort in the evaluation of HMO data.

Key Findings

Standard Data Format

Construction of a test database confirmed the finding made during site visits to HMOs, that while most HMOs maintain key membership, provider and utilization data, they vary extensively in the manner in which these data are collected and stored within their MIS systems.

In order to achieve a uniform database structure that allows comparability between HMOs and comparison of HMO to indemnity experience, MEDSTAT Systems recommends continued use of a standard data format in data collection.

Tracking Utilization Experience for Subcontracted Services

As evidenced by absence of Mental Health and Substance Abuse data in several HMO datafeeds, HMOs frequently subcontract various services such as psychiatric and substance abuse care or diagnostic laboratory services

to outside vendors. The HMO may receive information on subcontracted services in hard-copy format but generally electronic data are maintained by some third-party vendor.

MEDSTAT Systems recommends that healthcare purchasers work with HMOs to obtain utilization data from all sources, including third-party vendors, where appropriate, in order to develop a comprehensive healthcare utilization database.

Data Quality

Certain data quality problems were consistent among all HMOs participating in this initiative. Common data problems included poor coding of last date of service on inpatient cases, the absence of discharge status for inpatient cases, and less than optimal diagnosis and procedure coding in outpatient data. Greater use of HMO data can be expected to drive improvements in HMO data quality.

CHARACTERISTICS AND SHORTCOMINGS OF ALCOHOL AND OTHER DRUG TREATMENT DATA SYSTEMS

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Sharon Brooks

The focus on treatment services to respond to the Nation's drug crisis has raised numerous questions about the nature and scope of services available, as well as their geographic distribution and quality. This paper summarizes and critiques the principal data system in place to address the needs of services researchers, managers and policy makers.

A large system of over 8,000 outpatient and inpatient treatment units, most outside traditional health care settings such as hospitals, physicians' offices and mental health centers, has developed over the last 20 years to address the specialized needs of persons with alcohol and other drug problems. The major data system to collect information about this unique service system is the National Drug and Alcohol Treatment Unit Survey (NDATUS), which has reported periodically on treatment units. The survey has been administered by the National Institute on Drug Abuse (NIDA) with support from the National Institute on Alcohol Abuse and Alcoholism (NIAAA).

The 1989 NDATUS reports 734,955 drug abuse and alcoholism clients in treatment on the September 30, 1989, point prevalence reporting date in the 7,759 treatment units responding. More than one-half of the clients in treatment were between the ages of 25 and 44 in both inpatient and outpatient programs. Fourteen percent of all clients were inpatients on the point prevalence date.

Eighty-three percent of the responding units estimated the annual unduplicated count of clients served in the 12-month period. There were an estimated 2,446,246 clients served, with 59 percent reported as clients being treated for a primary problem of alcoholism and the balance had a primary problem of drug abuse.

Total financial support of $3,988,616,000 was reported by 6,706 units. The funds were about equally divided between drug and alcohol clients.

The following is the treatment unit orientation and the percentage of all clients on the point prevalence date:

Hospital	12.3%
CMHC	15.0
Correctional Facility	1.9
Halfway House	2.5
Other Residential	7.0
Outpatient	51.2
Other	10.0

Hospitals account for 12.3 percent of the clients, but represent 17.6 percent of all reporting units.

Hospitals are the only reporting units for which there is a data base to determine the extent to which the NDATUS survey is congruent with other data. This provides a measure of the integrity of the NDATUS survey in representing the hospital sector of the drug and alcohol treatment system.

The other source of hospital data is the comprehensive 1989 American Hospital Association's (AHA) Annual Survey of Hospitals which asks whether a hospital has a designated and distinct section for "alcoholism/chemical dependency" (A/CD) treatment.

The results show that 41 percent of the 1,892 AHA hospitals with the A/CD designation were included in the NDATUS. Of these, 1,282 of the AHA A/CD survey hospitals had inpatient beds and 47 percent of those with inpatient beds were reported in the NDATUS survey.

Thus, data from less than one-half of the specialty alcoholism/chemical dependency units in hospitals are available.

The average number of beds in the AHA hospitals with alcoholism/chemical dependency inpatient units reported in NDATUS and not in NDATUS were similar. There were an average of 30.0 A/CD beds in AHA hospitals in NDATUS and an average of 27.7 A/CD beds in non-NDATUS AHA hospitals. There were 18,054 A/CD beds in the AHA/NDATUS hospitals and 18,837 beds in the non-NDATUS AHA hospitals.

There are NDATUS respondents that classified themselves as hospitals, but were not located in the AHA file. They accounted for 572 NDATUS responding units. This may be due to self-designation as a hospital although not meeting AHA criteria, or they were satellite units not matched in the study with the hospital unit.

The universe to which questionnaires are sent is maintained by NIDA and is updated on an ongoing basis using information submitted by treatment programs and State drug and alcohol agencies as well as from listings submitted by staff. Prior to a survey, State agencies are provided a printout and are asked to make additions, deletions or corrections in the master list. Subsequently, the face page of each questionnaire is preprinted with identifying information for each facility in the universe.

Some weaknesses in this process may arise when State agencies do not have responsibility or an interest. NDATUS is a voluntary periodic point prevalence

survey of drug and alcohol treatment and prevention programs. Thus, if personnel are not available for the updating activity, the facilities for which the State has no fiscal responsibility would be the lowest priority for assuring inclusion.

State interest and availability of personnel for NDATUS survey followup also play an important role in the response rate. States have the opportunity to include transmittal letters and survey supplements when distributing the Federal questionnaires. The relative interest and/or State resource support is illustrated by the following data:

Distribution of State Response Rates (including Puerto Rico and District of Columbia)

Percentage	No. of States
Under 60	9
60 to 70	10
70 to 80	15
80 to 90	6
90 through 100	+12
	52

Overall response rates for the 12,330 active treatment and prevention units was 77.9 percent indicating that larger States had better response rates on average than smaller States. The importance in services research of State-by-State comparisons requires improving low response rates.

In order to correct these wide State-to-State variations in response rates, it is recommended that a minimum level of 85 percent be established for each State. Federal contract personnel would contact programs directly to secure data from nonresponding programs.

Secondly, minimal data from nonresponding facilities would be assembled from State licensure or program promotional material. Such core data would enable the development of estimated data for nonrespondents based on the characteristics of similar responding facilities.

Two recent Institute of Medicine reports, one on treatment of alcohol problems and the other on treating drug problems, utilized NDATUS survey data and made recommendations or observations about NDATUS.

The alcohol report urged that "NDATUS should be redesigned to reflect actual practice more accurately and to identify clearly which types of treatment are being provided."

The drug report advised "several cautions are in order...estimates of treatment delivery and funding are conservative."

As the Nation's only comprehensive effort to gather data on the specialty drug and alcohol treatment sector, NDATUS survey methodology should be improved to incorporate a complete listing of service units, pretesting of questionnaires, improved response rates, and synthetic estimates for nonreporting units in order to provide complete estimates on the national treatment effort.

For publicly-supported facilities, the new Minimum Data Set reporting requirements established by NIDA/NIAAA should improve information about the number and demographic characteristics of clients in treatment. However, the improved survey administration suggested will require additional financial and personnel resources at both the State and national levels. The importance of this data to administrators and policy makers at the State and Federal level bode well for the implementation of such survey improvements.

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THE FEASIBILITY OF COLLECTING DATA IN A NATIONAL SURVEY OF AMBULATORY SURGERY

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Since 1965 the National Center for Health Statistics (NCHS) has collected and published annual statistics on use of medical and surgical care by hospital inpatients. These data are collected through the National Hospital Discharge Survey (NHDS). It has been apparent since the late 1970's that the NHDS was unable to provide comprehensive statistics on many common surgical procedures because advances in technology have increasingly enabled these procedures to be performed outside the hospital inpatient setting. Data from the American Hospital Association, SMG Marketing Group, and HCFA, for example, have confirmed the rapid growth in numbers of facilities providing surgery programs for outpatients and in the number and variety of surgical procedures performed in these settings. However, no comprehensive national data are available on the characteristics of the patients and the surgical care received in outpatient settings.

Valid data about medical and surgical care provided in hospital based and freestanding ambulatory surgery centers (ASCs) are necessary to make national and local decisions for the allocation of resources and training of medical manpower, to aid efforts to control medical care costs, and to plan for the provision of future medical and surgical care. Currently ASCs provide a wide variety of surgical treatment, including tonsillectomy, myringotomy, lens procedures, D & C of the uterus, hernia repair, laparoscopic tubal ligation, arthroscopic surgery, as well as a variety of diagnostic procedures ranging from biopsy and endoscopic examinations to cardiac catheterization.

Although there is an obvious need to collect data on ambulatory surgery in hospital and freestanding ASCs, it is unclear how best to survey such facilities for these data. Further, the costs of conducting such a survey will depend on a number of factors, such as whether different methods are needed for surveying freestanding versus hospital based ambulatory surgery. Thus, a feasibility study was needed to identify problems, test methodologies for overcoming these, and demonstrate a feasible approach for collection of valid data on ambulatory surgery performed in these settings.

Feasibility Study Design

The objectives of the feasibility study were to provide detailed recommendations concerning the design of a national survey of ambulatory surgery, including the definitions of the universe of facilities and of surgical visits within facilities to be sampled. The feasibility study would also provide recommendations as to the data set to be collected, the methodology to be employed, and the estimated costs for a national survey. A principal focus of the study was to assess the extent to which the present methods used for the NHDS could be adapted to a national survey of ambulatory surgery, although alternative methodologies should be investigated. Thus, as a starting point we were to examine the feasibility of a two stage sampling process. First, the facilities, then surgical cases. The study consisted of two phases:

Phase 1. Survey Design

a. Define the universe of ambulatory surgical facilities (hospital based and freestanding) to be included in the sampling frame.
b. Provide a working definition for identifying surgical cases to be included/excluded from the sampling frame within hospitals.
c. Identify the data elements to be collected for selected ambulatory surgical cases and develop operationally useful definitions for each.
d. Develop protocols, data collection forms, and administrative procedures for the conduct of a field test of survey content and methods.
e. Prepare the ASC facilities sampling plan, develop and produce survey materials for the field test.

Phase 2. Demonstration, Analysis, and Recommendations

a. Field test systems and procedures for the sampling and collection of ambulatory surgery visit data, including provisions for data quality control. The test will be performed in approximately 90 ambulatory surgical facilities, both hospital and freestanding.
b. Analyze the response of the sampled facilities and the problems encountered in sampling of surgical cases, data collection, and data quality control.
c. Assess the potential for alternative data collection methods.
d. Develop recommendations for a national survey design.

An expert technical advisory panel consisting of representatives of professional and trade associations interested in ambulatory surgery is providing advice on technical issues. The panel reviewed the design for the feasibility field test prior to its execution, the findings from the field test, and assisted in formulating recommendations for a national survey.

Findings

1. Preparation and Maintenance of a Facilities Sampling Frame

In order to sample ASCs it is first necessary to define those to be included in the sampling universe, then collect and maintain a complete inventory of the eligible facilities. To avoid potential duplication in sampling with the National Ambulatory Medical Care Survey (NAMCS) which presently is limited to a sample of office based physicians and patient visits to their private offices, a way to distinguish between freestanding ASCs and physician private offices was needed. Another concern was whether to include specialized facilities which add little to projections of national ambulatory surgery statistics, deal exclusively with procedures not commonly performed in the operating rooms of hospital based or other regulated ASCs, or for which access to such a specialized facility's records would be much more problematic than would be likely for a hospital (e.g., dental surgery clinics, abortion clinics, freestanding diagnostic imaging centers, etc.). Similarly, it was necessary to develop recommendations as to whether to include specialized facilities in which surgical procedures may occasionally be performed, but which are incidental to the primary purpose and services of the facility (e.g., a family planning clinic which performs a vasectomy, or a freestanding birthing center in which obstetric procedures classified as surgical procedures are occasionally performed).

A physician may designate his private office as an ambulatory surgery facility in most states without any special facility license. Such a facility, is treated by the state and third party payers as any other physician's private office and is unregulated, although the physician owner/operator must be a licensed physician. The self-designated ambulatory surgery facility will not receive a facility fee from Medicare or Medicaid when surgical procedures are performed on their beneficiaries. Other third party payers may also deny payment of a facility fee to the unregulated self-designated ASC, although some payers do contract with selected physicians for specific in-office surgical procedures at reimbursement rates which reflect the inclusion of facility costs as well as the surgeons' fee.

Because of the need to exclude physician in-office surgery from the planned new survey of ambulatory surgery, and building upon the findings and recommendations of an earlier study of differentiating characteristics of regulated versus self-designated ASCs, it was recommended that the present feasibility study be restricted to the survey of "regulated facilities" in which surgery is performed on an outpatient basis (e.g., state licensed and/or Medicare certified hospitals or ASCs). Further, special purpose facilities licensed as an ASC in some states, but for which surgical procedures were incidental to the primary purpose of the facility (e.g., a birthing center), which were limited to procedures not customarily performed by a physician (e.g., oral surgery centers), or which were unregulated in many states or for which access by survey staff would be problematic (e.g., abortion clinics) were recommended for exclusion.

The questions to be resolved through the field test related to the completeness and validity of readily available lists of regulated facilities performing ambulatory surgery. Sources to be evaluated were:

- The HCFA Provider of Services (POS) file.
- The American Hospital Association (AHA) list of hospitals and freestanding ASCs published in the AHA Guide to the Healthcare Field.
- Lists available for purchase from the SMG Marketing Group, Chicago.
- Trade and professional organization lists of their membership.
- Lists of state regulated facilities obtained from the licensing and certification agencies within the state government.

Hospitals and freestanding ASCs were identified in each of 6 primary sampling units (PSUs) selected for the feasibility study. The resulting lists were then unduplicated and facility contact and outpatient surgery information compiled on each identified facility. A sample of the hospitals as well as all freestanding ASCs were then contacted to assess the accuracy of the information and to screen them for possible inclusion in collection of data on a sample of surgical outpatient visits.

Findings indicated that there was little to differentiate the AHA, POS, and SMG lists as sources of information on hospitals. However, among freestanding ASCs there is a substantial turnover and lists rapidly become obsolete. Further, no single source for freestanding ASCs fully substitutes for collection of the most recent data directly from the state licensing and certification agency. The findings for freestanding ASCs is as follows:

- POS file - Some freestanding ASCs choose not to be Medicare certified, thus the POS file excludes about 10 percent of regulated ASCs. An ASC may elect not to be Medicare certified because it does not treat many Medicare patients, or because it is authorized to bill Medicare using the POS certification number of a parent facility (usually a hospital).
- AHA list - The most recent list includes some ASCs which are not regulated or which are owned/operated by hospitals and not separately regulated, and excludes a number of separately

regulated ASCs, both hospital owned and those completely freestanding.

- SMG list - Because the SMG list of freestanding ASCs excludes many of those which are hospital affiliated, the list is incomplete as to all facilities separately licensed and/or Medicare certified. The extent of this omission varies widely from state to state, depending on how licensing of ambulatory surgery facilities owned by hospitals but located off the premises is handled (New York, for example, requires that all such ASCs be licensed under the category of "hospital extension clinics", while Louisiana only requires a separate license for a hospital owned ASC located more than 50 miles from the hospital. Hospital ASCs which are Medicare certified as "separate part facilities" are also omitted from the SMG list, whether separately licensed or not. For those ASCs included in the SMG list, this was the best source of data on volume and specialty of ambulatory surgery, although the data were seriously in error for a few percent of the ASCs.
- Trade and Professional Association lists - These were found to provide no additional regulated facilities not found on SMG or AHA lists. Moreover, a substantial proportion of all regulated ASCs do not appear on any such list (excluding the AHA list of hospitals).
- State licensing and certification lists - Except when a facility was newly licensed or certified, or discontinued its licensed status since the creation of the list, these lists were complete, by definition. However, because 12 states did not have an ASC licensing law as of mid-1989, ASCs which do not serve Medicare patients, which are unregulated, but which would be licensed if located in a different state have been identified through the SMG and AHA lists.

We conclude that the most recent SMG freestanding ASC list, together with either the SMG or AHA hospital list, provide a vehicle for identifying between 90 and 98 percent of separately regulated ASCs. The HCFA POS file can be used to identify hospital affiliated but separately certified facilities. If hospital affiliated but separately licensed ASCs which are not separately certified are to be reliably identified, either the state licensing agency must be contacted for licensing information, or the hospitals must be directly contacted to identify any such separately licensed affiliated facilities.

At this time we are unable to measure the extent to which SMG and AHA lists reliable identify ASCs not separately regulated because they are located in states without an ASC licensing law. None of these states were included in our sample of PSUs for the feasibility study. Further, it is not clear what criteria and sources can be used to provide a complete listing in such states for comparison with SMG and AHA lists. Although there is overlap between the AHA and SMG lists of freestanding ASCs in states without ASC licensing, there are facilities listed in each which do not appear on the other list.

Because some states exclude from licensing certain types of facilities (e.g., facilities limited to pregnancy termination procedures), we must either identify all such facilities in those states not requiring licensing, or be able to screen them out among licensed ASCs in other states. Based on contacts with licensed ASCs and comparisons with data available on the SMG list, we conclude that the SMG list can be used to screen out most, but not all such licensed facilities. Information available from state licensing agencies can also be used to screen out most, but not all, such special purpose regulated ASCs.

2. Definition and Identification of Surgical Cases Within a Facility

Once an ASC has been identified, the problem remains as to which patient visits represent outpatient surgical visits. Definitions of surgical procedures tend to be very broad, including cutting, suturing, injecting, and, in some cases, endoscopic procedures using naturally occurring body orifices. The inclusion and exclusions are particularly important in large medical centers. Historically most hospitals have used their own definition of "outpatient surgery". For example, since GI subspecialties usually fall under the department of medicine, many hospitals do not consider GI colonoscopies as outpatient surgery. Endoscopic special procedures rooms are often separate from the OR and are used for those patients for whom the procedure can be performed without general anesthesia. Such patients and the procedures usually do not fall within the hospital's definition of ambulatory surgical patients and procedures. Patients receiving general anesthesia for an endoscopic procedure will be treated in the operating suite, although often in an OR dedicated to endoscopy.

Other questionable areas include those radiologic procedures involving dye injection which may be performed in the radiology department on outpatients, while in another institution it may be done in the operating room. Cardiac catheterization performed in the Cardiac Catheterization Laboratory may also be done on an outpatient basis is some hospitals. Inclusion of osteopathic manipulation as a surgical procedure is another example for which there is no clear answer.

Options include:

- Use a prepared list of surgical procedures.
- Base the determination on the clinical characteristics (e.g., anesthesia was administered, the procedure was invasive, or the procedure required post-operative observation).

- Use reimbursement as a guide (e.g., the procedure warrants an ambulatory surgery facility charge by most payers, it appears on the HCFA list, etc.).
- Identify qualifying administrative arrangements (e.g., if the procedure was performed in a special procedure room, was scheduling and responsibility under the administrative control of the OR department?). This might be further refined to limit the procedures to those which would be appropriate to perform in an OR (or, conversely, to exclude those which can generally be performed in a physician's private office, or in an examination or special procedure/diagnostic procedure room in the hospital).

The issue is critical both for the interpretation and validity of national estimates resulting from any future survey of ambulatory surgery, and for the ease and reliability of assembling lists of such patients to serve as a sampling frame within a hospital. Our field test employed a broad definition of surgery which included all patient visits to operating rooms, dedicated endoscopy units, cardiac catheterization labs, minor procedure rooms within the OR, or special rooms in other locations which were primarily used for laser surgery (e.g., ophthalmologic procedures). Specifically excluded were the hospitals' ERs, general purpose examination and diagnostic rooms, or radiologic procedures rooms not part of the OR. Thus, our test used as a sampling frame all patient visits to certain geographic locations within the ASC, sorting out and excluding those which represented inpatients at the time they entered the surgical unit (regardless of whether they were subsequently discharged without staying over night) and specifically retaining those who entered the surgical unit as outpatients, even if they were admitted as inpatients subsequent to surgery.

Findings from the field test indicate that hospitals found this definition overly broad and that it greatly increased the costs and complexity of data collection to include patients treated outside of the main OR and other operating rooms under the control of the OR department. This was exclusively a problem in the larger hospitals. Our definition was not a problem for the freestanding ASCs. Time required during the initial visit to a hospital with multiple locations for surgery (especially, those with endoscopy units remotely located from the operating rooms and those which performed any cardiac catheterization on an outpatient basis) was nearly twice that for uncomplicated hospitals with all qualifying surgery under the OR department's control. Time to compile lists and to draw the sample was also about twice as long in those facilities with qualifying surgical units not under the OR department.

3. Data Elements for Collection

Table 1. lists the data elements included in the field test. This list was distilled from a more comprehensive list initially compiled from a wide variety of sources (e.g., the NHDS data elements, the Uniform Ambulatory Care Data Set recommended by the National Committee on Vital and Health Statistics, and recommendations from interested professional, trade, and governmental agencies). The list of data elements tested is more comprehensive than will be possible with a national survey, but the test was necessary to permit specifying the costs and data quality measures for each potential data element. Medical abstract forms were developed for recording the data elements for each selected surgical visit. Definitions and instructions as to where the item is customarily found in the medical record and how to classify the record information within allowed response categories were provided.

In each of the test facilities about 20 surgical visits were sampled, using a proportional sampling scheme with randomized starting points to include all lists of qualifying surgical visits. After the list of patient visits for abstracting was selected, the medical records for these patients were retrieved and the records abstracted. A total of 1642 abstracts were collected from 84 participating facilities (51 hospitals and 33 freestanding ASCs).

Findings discussed here are limited to those data elements for which a problem or special concern was identified.

A. Patient Identification

5. Social Security Number - This item was indicated as "not available" in the medical record for 12 percent of the sample and the item was incomplete for an additional 4 percent.

B. Patient Characteristics

8. Age - 97 percent of the sample provided date of birth. One third of those abstracts without date of birth provided age.
10. Race - Was not available or incomplete for 39 percent of the abstracts.
11. Ethnicity - Was not available or incomplete for 86 percent.
12. Marital Status - Was not available for 14 percent of the abstracts. The reason for interest in this item is that whether or not a patient has someone at home to provide transportation and to assist during the 24 hour post-surgical period has a bearing on suitability for ambulatory surgery.
13. Expected Payment Source - Incomplete for 8 percent.

14. Discharge Status/Disposition - 94.9 percent of freestanding ASCs and 93.3 percent of hospital ambulatory surgery patients were routine discharges to home. Transfer or admission to a hospital for inpatient care was reported for 0.6 percent of freestanding ASC patients and 2.7 percent of hospital ASC patients. The remainder represented incomplete or missing documentation.

C. Surgical Visit Data

15. Was Surgery Cancelled/Terminated - This item was included to determine is collection of data on cases terminated after the ASC has invested in preparing the patient, but before the actual cutting begins. Because such patients do not reliably appear in the surgery lists from which we sampled, the item will produce unreliable statistics.
16. Place Of Service - This item was indicated as not available, or was left incomplete for 6 percent of abstracts.
17. Visit Type - Ambulatory surgery is almost always done on an elective basis (97 percent of FSASC cases and 93.7 percent of hospital cases were so listed, with most of the remainder identified as the item "not available").
18. Time Periods - Pre-op time was not available in 20 percent and incomplete for another 13 percent. Operating room time was not available for 9 percent and incomplete for 5 percent of the abstracts. Recovery room time was not available or incomplete for 19 and 9 percent, respectively. Discharge times were not available or incomplete for 11 and 4 percent, respectively.
19. Total Charges - Charge data were seldom readily available in the hospital medical record departments, and available in the records departments of freestanding ASCs for less than 50 percent of the abstracts.

D. Medical Data

20. Type Anesthesia - This item was not stated in 4 percent and incomplete for another 4 percent of abstracts.
21. Anesthesia Administered By - Not available for 13 percent and incomplete for 12 percent. This item can be better phrased to improve the response by eliminating the issue of supervision of CRNAs and providing for "not applicable" in cases where no anesthesia was administered.
22. ASA Classification - This was not available for 46 percent of the cases and incomplete for 6 percent. Unless an anesthesiologist was consulted, the ASA classification would seldom be provided.
23. Post-Operative Anesthesia Assessment - "Good" was checked on 57.9 percent of the abstracts and "not stated" on 41.1 percent.
24. Diagnoses - Coded principal diagnoses were provided for 93 percent of the cases. In about 90 percent of the cases both narratives and ICD-9-CM codes were provided for principal and other diagnoses.
25. Procedures - Procedures were coded in ICD-9-CM in about 79 percent of the cases, in CPT-4 (HCPCS) in 64 percent, with about 25 percent having both codes. Narrative descriptions were always available, although some narratives were insufficient to be coded. Hospitals almost always had ICD-9-CM codes while CPT-4 codes were the predominant mode for procedures in FSASC records.
26. Assistants in Surgery - Information on this item was provided in only about a fourth of the abstracts.
27. Other Services Provided - This item yielded poor response from freestanding ASC records, although there were fewer but still many incomplete responses from the hospital ambulatory surgery cases.
28. Outcome - This item is not available in 53 percent of the abstracts, although the reported absence varied from about 30 percent of freestanding ASC cases to 60 percent of hospital cases.

From the field test we conclude that certain items should be deleted from the data set, while others need to be redefined or combined. We recommend collapsing "race" to white, black, and other. Ethnicity should be deleted, as should marital status. We recommend changing the status/disposition item to include discharge to "observation status", discharge to "recovery center", and "surgery terminated/cancelled". Item 15, surgery cancelled or terminated, can then be deleted. The patient or visit type is recommended for deletion. Pre-op time is too unreliable for collection. Recovery room and discharge time should be combined and relabeled as "recovery" time. Total charges should be deleted from the data set as long as the principal source is to be the medical record. Type of anesthesia, who administered the anesthesia, and ASA Classification should be combined into a single item, using a branching logic. Post-operative anesthesia assessment should be deleted. We recommend collecting the surgical procedures data before the diagnoses, requesting both ICD-9-CM and CPT-4 codes, if available, and providing a narrative for each procedure for which neither code is abstracted. We recommend deleting the assistants in surgery and outcome followup items.

4. Data Collection Methodology

The tested methodology closely resembled that used for the NHDS. We gave facilities the option of using in-house staff to do the sampling of surgical cases or permitting us to send in an outside person. The NHDS uses the Bureau of the Census to provide personnel to induct hospitals, provide training to hospital staff if the hospital elects to draw the sample and complete the abstracts, and uses Census staff to do the abstracting if

the hospital is unwilling to provide the staff. We simulated this process by hiring personnel who had worked on the 1990 census through Bureau of the Census contacts, then trained them and sent them in to collect the ambulatory surgery data in those facilities unwilling to do so with in-house staff. We prepared manuals for our "Census" staff and for hospital use.

We achieved a 70 percent participation rate among freestanding ASCs and 71 percent among hospitals contacted. Identification and sampling of ambulatory surgery cases was very complex in only about 5 of the 51 participating hospitals. However, these hospitals represent a disproportionate share of the ambulatory surgery volume, particularly for certain selected procedures which may not be performed on an outpatient basis in most other hospitals.

We conclude that a retrospective records review methodology for collection of ambulatory surgery data is feasible. Comparisons with alternative methodologies, such as the prospective data collection method used with NAMCS, indicated that each alternative has serious cost or data utility limitations. An advantage of the NAMCS methodology, however, is the ability to include data elements which currently are not reliably recorded in the medical record. Moreover, using the NHDS methodology will permit future integration of the two data collection efforts.

5. Estimated Costs for A National Survey

Although the one-time costs of starting up a new survey are large, we estimate that the annual costs for a National Survey of Ambulatory Surgery, using a methodology similar to that used with the NHDS, will be similar to those for the NHDS, assuming an equal number of facilities and about a 50 percent reduction in number of records. Maintenance of the facilities sampling frame and participating facilities is more costly. Sampling within large complex medical centers is more complex, but this is offset by the ease in sampling small freestanding ASC lists of surgical patients. Abstracting will include several more complex data elements and training of data collectors will be more difficult. However, the simplicity of the medical records found in freestanding ASCs will offset the addition of the several more difficult to abstract items.

Table 1

PROVISIONAL DATA SET FOR FIELD TEST SURVEY OF AMBULATORY SURGERY

A. CASE IDENTIFICATION
1. Facility ID Number
2. Satellite or Separate Unit Number
3. Medical Record Number
4. Date of Surgery
5. Social Security Number
6. Residence ZIP code

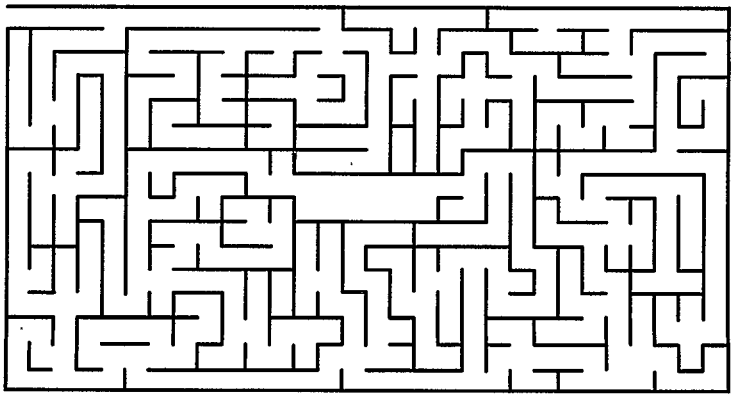
B. PATIENT CHARACTERISTICS
7. Date of Birth
8. Age (if Date of Birth not available)
9. Sex
10. Race (Include all Census Categories: white, black, American Indian/Eskimo/Aleut, Asian/Pacific Islander, Other)
11. Ethnicity (Hispanic Origin, Non-Hispanic)
12. Marital Status
13. Expected Source(s) of Payment
14. Status/Disposition of Patient (Routine to Home, Transfer/Admission to Hospital for Inpatient Stay, Not Stated, Other)

C. SURGICAL VISIT DATA
15. Was Surgical Procedure Cancelled or Terminated? (If so, during pt prep, but before entering the OR; as anesth admin before surg; during surg, surg incomplete)
16. Place of service
    - OR dedicated for ambulatory surgery
    - special procedure room in OR suite
    - OR used for inpt and outpatient surgery
    - service/dept special procedure room outside of OR
    - satellite facility
17. Patient and visit types
    - scheduled outpatient surgery
    - non-scheduled outpatient surgery
    - patient scheduled as inpatient but converted to outpatient
    - patient scheduled as outpatient, but converted to inpatient
18. Time (Pre-op, Operating Room, Recovery Room, and Discharge Time)
19. Total charges (If Available, Indicate What Charge Elements Included)

D. MEDICAL DATA
20. Type of Anesthesia
21. Anesthesia Administered by (anesthesiologist, CRNA, surgeon, other)
22. ASA Classification of Patient
23. Post-Operative Anesthesia Assessment
24. Diagnoses (list principal diagnosis and all "other diagnoses", provide a narrative and ICD-9-CM code for each)
25. Surgical Procedures (list principal, secondary and all other procedures, provide a narrative and both ICD-9-CM, and HCPCS/CPT-4 codes for each)
26. How Many Physicians Were on the Case in Addition to the Primary Surgeon (were there assistants at surgery)?
27. Other Services Provided
28. Was There Outcome Followup (if so, when was it conducted)

Session D

Improving Vital Statistics



A BIRTH CERTIFICATE AUDIT PROGRAM IN PENNSYLVANIA

Marina P. O'Reilly, RRA, Pennsylvania Department of Health

Beginning in October 1989, the Pennsylvania Department of Health introduced an onsite birth certificate audit program in all hospitals in the Commonwealth providing maternity services. All hospitals in the Commonwealth received an inservice on the proper completion of birth certificates prior to the implementation of the birth certificate audit program. The Commonwealth currently has 158 hospitals offering maternity services and this presentation will report on the results of the first 58 of these hospitals to have received their first audit.

PURPOSE

The intent of the birth certificate audit program is to monitor and improve the reporting accuracy of all birth certificates submitted to the Department of Health and to assure that all births occurring in Pennsylvania Hospitals are registered with the Division of Vital Records in accordance with state law, which states that a certificate must be filed with the state or local registrar within 10 days of the birth of the child.

PROCEDURE

Initial Request

Two hospital sources, listings of newborns with ICD-9-CM discharge codes of V30-V39 for a specified time period and medical records of the newborn and mother, are utilized during the audit. As most people probably know, ICD-9-CM is the International Classification of Diseases, 9th Edition, Clinical Modification, and is used in hospitals to assign a number code to diagnoses to allow for ease of indexing, etc. V30-V39 are the codes which correspond to the newborn diagnosis.

Approximately eight (8) weeks prior to the date of an audit, the hospital is sent a letter describing the purposes of the audit, date of the audit, and requesting a listing of all newborns with discharge codes of V30-V39 within a specified quarter of the year along with their birth date and mother's name.

Preaudit Review

All births identified from the hospital listing are then compared to the Division of Vital Record's data base to assure completeness of registration.

A sample of 25 records or 2%, whichever is greater, is selected from the hospital listing and sent approximately 4 weeks in advance of the audit date. This allows ample time for the hospital to have the records pulled for the date of audit. Copies of the actual birth certificates for the audit records are retrieved from the Division of Vital Records and brought to the audit along with the list of certificates not located in the Division's data base, if any.

Actual Audit

The hospital is given a copy of the list of certificates not located in the Division's data base on the day of the audit so that these records may be pulled and reviewed manually by the auditor. In some instances, there has been a name change that the auditors were unaware of which made location of the file impossible, the certificates may have been filed late, or, in some circumstances, the certificate may not have been filed at all. In one instance, the hospital had two certificates that were not filed at the time of audit. The original certificates had not been pulled for mailing and were found filed with the medical record.

The sample certificates are then compared item by item to the documentation in the newborn's and mother's records. If the data on the certificate is not the same information reported in the medical record, or if the information cannot be located in the medical record, the item is considered incorrect and is marked as such on the birth certificate audit form with a notation in the comment section on the difference between the certificate and the medical record.

For example, if the newborn's name was Anne, and the certificate was spelled Ann, the "no" box would be checked, and, in the comment section, it would state "Anne not Ann". (Figure 1)

At the conclusion of the audit, an exit interview is held with the hospital staff who are responsible for the completion of the birth certificate (it is not always the medical records department). A provisional accuracy rate is provided along with a discussion of individual items which are considered "Problem Areas" (items with an accuracy rate of below 90%). Initial recommendations for improvement are discussed so that resolution of problems may begin immediately, and a possible reaudit schedule is discussed.

Audit Reports

Within four (4) weeks of the date of audit, a written report is forwarded to the hospital. The report gives a summary of all findings: the quarter reviewed;

the number of records from the audited quarter not filed in the Division's data base; the number of records requested for audit; the number of records actually reviewed (due to readmissions, etc., some records may not be available for the audit); the number of reviewed certificates filed late (those filed with the state or local registrar more than 10 days after the date of birth); and the overall accuracy rate.

Next, accuracy rates for each item on the certificate are presented, and a list of "Problem Areas" is developed (those items with an accuracy rate below 90%). For each problem area, the exact errors that were made are spelled out. For example, under Complications of Labor and Delivery, we list which complications were not reported and how many certificates did not report the complications. Recommendations for improvement of the problem areas are provided. These recommendations list where in the medical record the items were located, gives synonyms for some of the more difficult items, lists what should be reported in the "Other" categories in the medical check box questions; and lists what need not be reported at all. Finally, a summary is given which reviews the overall accuracy rate again and discusses when the next audit will be scheduled.

Reaudit Schedule

Reaudits are scheduled in one of five ways depending on the initial audit results. If the facility has a total accuracy rate of below 95%, a complete reaudit will be scheduled within 12 months from the date of the audit report. If the total accuracy rate is above 95%, but individual items have an accuracy rate of below 70%, a focused reaudit will be scheduled within 12 months of the date of the audit report to review just the items that fell below 70%.

Most facilities have the mother complete some type of birth certificate worksheet to obtain the legal information (parents' names, dates of birth, race, education, etc.). In some instances, the facility does not keep this worksheet or does so for only a short time after the delivery. If this happens, there is no way to review the legal information for accuracy as there is nothing to compare. The first recommendation made in this instance is that they make the worksheet a permanent part of the medical record or plan to keep the worksheet for a longer period of time. This will protect the hospital in the event that questions arise regarding this information and will allow for complete audits. A reaudit in this case will be scheduled within 18 months from the date of the audit report to allow ample time to implement this procedure.

If the hospital has an accuracy rate above 95%, some individual items below 70%, and had no worksheets, a focused reaudit will be scheduled within 12 months from the date of the audit report on the items that fell below 70% and those that were not reviewed due to worksheets being unavailable.

If the facility has none of the above mentioned problems, they will be reaudited in 24-36 months from the date of the audit report.

PROBLEMS WITH IMPLEMENTATION

Sample Size

As with any new program, some difficulties arose in the first few audits that were completed. The first hurdle was an appropriate sample size. Initially, the program began by reviewing 10% of the records in a quarter. This number proved to be too ungainly a number to work with. We finally settled on a sample size of 25 records or 2%, whichever was greater. This was felt to be a good balance between statistical accuracy while not inundating the hospitals with record requests.

Medical Reporting

The next major hurdle came with the review of the medical check box questions, items 38a-43, Medical Risk Factors for this Pregnancy; Other Risk Factors for this Pregnancy; Obstetric Procedures; Complications of Labor and Delivery; Method of Delivery; Abnormal Conditions of the Newborn; and Congenital Anomalies. Initially, it was difficult to decide when a condition should or should not be reported. It was felt that the field staff was not qualified to decide when hypertension was or was not a medical risk factor or when a nuchal cord became a complication of labor and delivery or when jaundice became an abnormal condition of the newborn.

To answer these questions, we first contacted the National Center for Health Statistics (NCHS) to find out how to decide when something should be reported. According to NCHS, these items must be reported on an occurrence basis, not an outcome basis. For example, if a woman has hypertension during her pregnancy, it does not matter if this condition affected her pregnancy in a negative manner or if the case was managed without problems. If she had the condition, it should be reported as a medical risk factor. Similarly, if there was a nuchal cord (umbilical cord wrapped around the baby's neck), it does not matter if there was a good outcome (healthy baby) or not. If it occurred, it should be reported as a complication of labor and delivery.

Next, Ronald David, MD, Deputy Secretary for Public Health Programs of

the Pennsylvania Department of Health, was contacted for assistance in the reporting of Abnormal Conditions of the Newborn and Congenital Anomalies. Dr. David, a physician neonatologist, provided lists of conditions that should be reported in these categories, conditions that should not be reported, and conditions that may be reported depending on the circumstances.

Finally, the recommended standard medical definitions were utilized for clarification of disease categories. These definitions also play an integral part in the recommendations used in the audit report. These definitions are used to list synonyms for diseases; to explain which conditions should be reported in the "Other" categories, and to explain which conditions need not be reported.

INITIAL RESULTS

State Average

These initial results deal with the first 58 hospitals offering maternity services to have received their first birth certificate audit. 75,339 items were reviewed in these hospitals with 72,531 items being reported correctly (the information on the certificate and in the medical records corresponded). The overall accuracy rate for the 58 hospitals is 96.3% with 31 hospitals having an accuracy rate above this average and 27 having an accuracy rate below this average.

Lowest Accuracy Rates

When the audits were started, there were few surprises regarding the items with the lowest accuracy rates, the prenatal information and medical check box questions. Of course, some items were reported more accurately than others with some achieving an accuracy rate of 100%. Examples include date of birth, sex of the newborn, and facility name. The name of the newborn was not without error with 3 of the 1509 names reviewed being reported incorrectly on the birth certificate (figure 2).

Complications of Labor and Delivery had (and has) the lowest accuracy rate with only 66.4% of the items being reported correctly. This is followed closely by Obstetric Procedures at 72,7%, Other Risk Factors at 83.8%; Date of Last Normal Menses at 85.5%; Month of Pregnancy Prenatal Care Began at 87.3%; and Abnormal Conditions of the Newborn at 89.4%(figure 3).

In our experience, the accuracy rates are, many times, affected by who is responsible for the completion of these items. In general, when the medical records or maternity staff is responsible for completion of the items, there tends to be better and more accurate reporting than if the physician is responsible, especially with the prenatal information. For example, in one facility, a physician decided that every woman gains 20, 30, or 40 pounds during the pregnancy and arbitrarily assigned one of these three weight gains to his patients. When compared to the information in the prenatal record, some of his estimates were very close, most were not.

Incorrect reporting on some items, Obstetric Procedures and Complications of Labor and Delivery, appears to be due to a general lack of understanding on what should be reported. Some data providers do not realize they are to report procedures occurring throughout the pregnancy, not just during the delivery. Another problem with the reporting of obstetric procedures is the failure of some data providers to realize than an artificial rupture of membranes (ARM or AROM) is considered an obstetric procedure. Whether it is an induction of labor or a stimulation of labor depends on whether or not labor has begun when the rupture takes place.

Conditions frequently not reported in Complications of Labor and Delivery included nuchal cords, lacerations, and fetal distress. Two reasons for non-reporting seem to be prevalent here. First, the data provider did not realize that the condition was considered a complication and therefore did not report it, as with nuchal cords and lacerations. Second, the data provider was unaware of synonyms for reportable conditions. For instance, synonyms for fetal distress include multiple variable decelerations, late decelerations, and prolonged decelerations. Unless the record specifically stated fetal distress, these conditions were not reported.

FUTURE

Although the audit program was implemented almost two years ago, no reaudits have yet to be completed, even though several hospitals have fallen into the 12 month reaudit category. We initially delayed the sending of the audit reports until numerous audits had been completed so that we could gauge which information would be most appropriate and beneficial to the health care facility. The first reaudit is tentatively scheduled for November 1991.

Once the reaudits have begun, we will be completing interval reports on improvements seen and further steps planned to improve the accuracy.

We also anticipate changing the lowest acceptable accuracy rate. Currently, it is at 95%, but we plan to modify this to the state wide accuracy rate. In the future, hospitals falling below the state wide average will be

reaudited in 12 months rather than those falling below 95%. We would hope that the state wide accuracy rate will continue to improve with continuing audits and education of data providers.

We also plan on changing the percentage at which a hospital will receive a focused reaudit. Again, we will change this to the state average for the item. For example, if the state average for Abnormal Conditions of the Newborn is 89.4%, a hospital will have a focused reaudit when their average falls below this number rather than when it falls below 70%.

A study is also planned to demonstrate the differences in accuracy rates in hospitals where the physician has responsibility for the completion of portions of the certificate and the hospitals where just the hospital staff is responsible for completion of the certificate.

Please contact me if anyone is interested in receiving any of the forms utilized during the audit or if anyone would like the results of the studies that are planned.

FIGURE 1

Birth Certificate Audit Form

Hospital name: XYZ
Date of audit: 3-3-91
Auditor: O'REILLY
Record & File Number: 999999 999999

Item	YES	NO	COMMENTS
Name correct?		✓	ANNE not ANN
Date of birth correct?			
Time of birth correct?			
Sex correct?			
City of birth correct?			
County of birth correct?			
Place of birth correct?			
Facility name correct?			
Certifier title correct?			
Mother's name correct?			
Maiden name correct?			
Date of birth correct?			
Age correct?			
Birthplace correct?			
Mailing address correct?			
Actually live correct?			
Mother Social security correct?			
Father social security correct?			
Father's name correct?			
Date of birth correct?			
Age correct?			

FIGURE 2

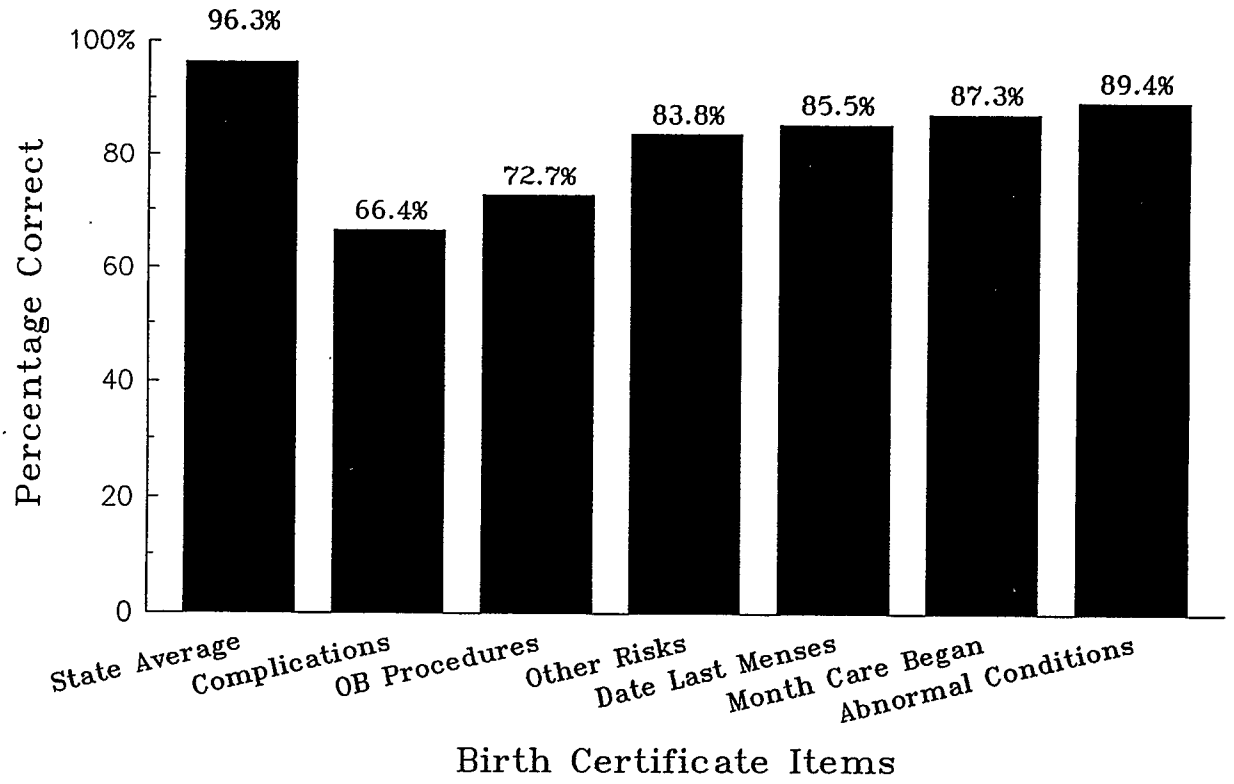
A BIRTH CERTIFICATE AUDIT PROGRAM IN PENNSYLVANIA
AUDIT RESULTS

DATA ITEM	NUMBER AUDITED	NUMBER CORRECT	%
Name	1509	1506	99.8%
Date of Birth	1609	1609	100.0%
Time of Birth	1609	1591	98.9%
Sex	1609	1609	100.0%
City of Birth	1609	1609	100.0%
County of Birth	1609	1609	100.0%
Place of Birth	1609	1609	100.0%
Facility Name	1609	1609	100.0%
Certifier Title	1609	1608	99.9%
Mother's Name	1484	1480	99.7%
Maiden Name	1609	1608	99.9%
Date of Birth	1609	1601	99.5%
Age	1609	1608	99.9%
Birthplace	1291	1290	99.9%
Mailing Address	1609	1601	99.5%
Actually Live	1484	1478	99.6%
Father's Name	1266	1258	99.4%
Date of Birth	1216	1209	99.4%
Age	1241	1235	99.5%
Birthplace	1216	1212	99.7%
Informant	1360	1351	99.3%
Hispanic Origin Mother	1090	1078	98.9%
Hispanic Origin Father	1090	1076	98.7%
Race Mother	1427	1413	99.0%
Race Father	1265	1240	98.0%
Education Mother	1241	1224	98.6%
Education Father	1241	1215	97.9%
Live Births Living	1609	1550	96.3%
Live Births Dead	1609	1605	99.8%
Other Terminations	1609	1502	93.3%
Mother's Marital Status	1609	1606	99.8%
Date Last Menses	1609	1375	85.5%
Prenatal Care Began	1609	1405	87.3%
Prenatal Visits	1609	1456	90.5%
Birth Weight	1609	1568	97.5%
Gestation	1584	1475	93.1%
Plurality	1609	1609	100.0%
1 Minute APGAR	1609	1557	96.8%
5 Minute APGAR	1609	1574	97.8%
Mother transferred	1609	1607	99.9%
Newborn transferred	1609	1604	99.7%
Medical Risk Factors	1516	1415	93.3%
Other Risk Factors	1609	1349	83.8%
Obstetric Procedures	1609	1170	72.7%
Complications	1516	1007	66.4%
Method of Delivery	1609	1497	93.0%
Abnormal Conditions	1516	1356	89.4%
Congenital Anomalies	1516	1495	98.6%
Death Under 1 Year	1609	1604	99.7%
Adoption	1609	1609	100.0%
TOTALS	75,339	72,531	96.3%

FIGURE 3

Birth Certificate Audit Program in Pennsylvania

Items With Lowest Accuracy Rates



WASHINGTON STATE BIRTH CERTIFICATE DATA QUALITY STUDY AND FIELD PROGRAM DESIGN

Sandra Kindsvater and Patricia Starzyk, Washington State Center for Health Statistics

Birth certificate data can provide a wealth of information about risk factors associated with adverse pregnancy outcomes. The data are used to make decisions about areas of need for family planning and prenatal care services and programs to deal with high-risk pregnancies. For example, birth certificate data on prenatal care and birth outcome were used by one of the larger counties in the state to make decisions about the importance of access to basic maternity services and the financial and health impact of inadequate access to care. Whether these are good or bad decisions depends at least in part on the quality of the birth certificate data. Thus, quality assurance is an important aspect of birth certificate data collection.

Earlier data quality studies conducted at the national level (1,2) and in New York State (3) indicate that individual items on the certificate are reported with varying degrees of completeness and accuracy. Washington State recently completed a birth certificate data quality study, to update these earlier studies and assess additional items currently on the Washington State birth certificate. The results of this study were used to design a field program aimed at improving birth certificate data quality. This report describes both the data quality study and the subsequent field program design.

METHODS

The method used for the data quality study was a comparison between birth certificates and hospital medical records, to determine how accurately and completely the information was transferred from the medical record to the birth certificate form. The comparison involved a sample of 1987 Washington State birth certificates from a sample of hospitals.

A. Hospital Sampling Procedure: The aim of the hospital sampling process was to have as wide a geographic representation of hospitals as possible. Accordingly, we selected at least one hospital from all but eight of Washington's 39 counties. The remaining eight counties were not represented in the study either because they had no hospitals or because the only hospital in the county had ten or fewer deliveries annually (except for one county which was omitted by an oversight). We chose several hospitals from each of the larger counties, to represent a variety of hospital sizes and locations within the county where possible.

We then sent a letter to the selected hospitals describing the study and requesting their participation. Only two hospitals refused, one of which stated that they no longer had any deliveries. The study thus consisted of 50 hospitals, which delivered 72 percent of the 69,346 live births occurring in Washington State in 1987.

B. Certificate Sampling Procedure: We selected a random sample of about 15 certificates for each hospital in the study (range 11-20). We expected that 15 comparisons could reasonably be completed in one day, which would minimize the cost of the study and the inconvenience to the hospitals. A total of 765 certificates were included in the study, covering about one percent of Washington State occurrence births. For each certificate, we compared 50 items to hospital records. The only certificate items not compared were six items used for local documentation. These items are not part of our data base and hospitals play no role in providing the data for most of them.

Because a constant number of certificates was sampled for each hospital, the error rates given in the Results section weight each hospital equally, whereas a state total error rate would give more weight to the larger hospitals with more deliveries. Thus, these error rates represent overall state error rates only in cases where small and large hospitals have the same error rates (see Table 4 and discussion). *

C. Data Collection: All data were collected in visits to participating hospitals by an Accredited Record Technician (ART). About two weeks before a visit, we sent the hospital a copy of the identifying information from each certificate, so that patient records would be available at the time of the visit. We requested two records for each certificate: the mother's and the newborn charts. During the hospital visit, a copy of the actual birth certificate was used as a worksheet and any discrepancies between the certificate and either chart were noted in red on the certificate. Different worksheet designs were tested early in the study and we found that this birth certificate copy was the easiest to use. At the end of each visit, an exit interview was conducted with the Birth Registration Clerk and the Director of Medical Records (if available) to describe errors found and ways to correct the problem.

We also surveyed each hospital to determine what procedures were used to complete the birth certificate. Data on hospital size (number of beds) were obtained from hospital licensing information. These procedure and size data were used to test whether different hospital characteristics have an effect on data quality.

D. Data Analysis: We classified the errors found in the comparison study into one of five types:

1. Unknown: The item was reported as 'unknown' ('not given', etc) on the certificate when data were available in the hospital record;

2. Blank: The item was left blank on the certificate when data were available in the hospital record;

3. Completion: There was a problem in completing the certificate, i.e., the completion instructions given in handbooks provided to the hospitals were not followed;

4. Difference: There was a difference between data on the certificate and in the hospital record. This category includes check box items for certain conditions or complications where the hospital checked 'none' on the certificate and a condition or complication was noted in the record;

5. Partial: The item was only partially completed when full information was available. This error type is found only for items with several parts, such as the date of last normal menses or previous pregnancy history.

Five variables were included on each record to describe hospital characteristics:

1. Who completes the certificate (e.g., medical records personnel or doctors);

2. Whether they interview the mother or just give her a worksheet to complete;

3. Whether the worksheet information is supplemented by medical records data;

4. Whether the worksheet is a copy of the birth certificate or a hospital-specific design;

5. The size of the hospital (number of beds).

All data were keyed into a microcomputer using the dBASE package. Keying was verified by having a different person re-key the data. The two files were compared and corrections made. The resultant file was then loaded into a Univac mainframe and SPSS used to analyze the data.

The analysis of hospital characteristics involved studying the effect of each of the five variables defined above on error rates. This effect was studied by holding all other variables constant, comparing error rates for hospitals where the only difference in characteristics was the variable under study. For example, the effect of hospital size was studied by comparing only hospitals where medical records staff completed the certificate without interviewing the mother, using a hospital-designed worksheet and supplementing the worksheet with medical records data. In this case, the only difference between the hospitals was the number of beds. Error rates given in *Table 4 for the two hospital size categories thus refer only to those hospitals.

RESULTS

A. Overall Error Rates and Types of Error: We examined a total of 38,250 items in this study (50 items on 765 certificates). For these items, 1,478 errors were found, giving an overall error rate of 3.9 percent or an average of two items per certificate.

Table 1 gives data on types of error.

As Table 1 shows, the major source of error was a difference between the birth certificate data and the hospital record, accounting for 61.5 percent of the errors. These data differences are not always due to incorrect transfer of data from the medical record to the birth certificate. Sometimes there are data differences between the two hospital charts or between the chart and the worksheet. Because it is not always possible to decide which record is in error, the hospital chooses one or the other record, according to its policy.

B. Error Rates and Types of Error by Section of the Certificate: The Washington State birth certificate (Figure 1) contains 56 items of data, 50 of which were examined in this study. For purposes of analysis, we separated the certificate into three sections, as follows:

1. Legal (items 1-25): Information used to identify the record;

2. Middle (items 32-51): Background information on the parents and some outcome information (e.g., birth weight);

3. Bottom (items 52-56): Medical information on the current pregnancy.

Table 2 gives error rates by section of the certificate.

TABLE 1. ERROR RATES BY TYPE OF ERROR
Washington State Birth Certificate Data Quality Study, 1987

TYPE OF ERROR*	NUMBER OF ERRORS	ERROR** RATE(%)	PERCENT OF ERRORS
Unknown Reported	151	0.4	10.3
Item Left Blank	247	0.6	15.4
Completion Problem	99	0.3	7.7
Data Difference	898	2.4	61.5
Partial Reporting	82	0.2	5.1
TOTAL	1477	3.9	100.0

* Error types defined in Methods Section
**Error rate based on 38,250 possible errors, see text

TABLE 2. ERROR RATES BY SECTION OF CERTIFICATE
Washington State Birth Certificate Data Quality Study, 1987

SECTION OF CERTIFICATE	ITEM NUMBERS*	ERROR RATE(%)	RANGE OF ERROR RATES(%)
Legal	1-25	0.6	0.0- 6.3
Middle	32-51	5.2	0.1-21.7
Bottom	52-56	14.9	11.5-20.0

*Item numbers defined on Figure 1; items 26-31 were not examined in this study

Obviously, the legal part of the certificate is the most straightforward to complete, with an overall error rate of 0.6 percent, and the bottom part is the most difficult, with an overall error rate of 14.9 percent. However, as the range of rates shows, there is overlap between the sections in error rates for individual items.

Table 3 presents data on types of error for the two items in each section with the highest error rates. Types of error and error rates for all items studied are given in the Appendix. *

Different problems are seen for the various items. The birth attendant is the only item studied having substantial completion problems. Hospitals did not follow the instructions to complete this item only if the person attending the birth was different from the one who certified the birth. This error was confined to five of the study hospitals. The menses date was the only item where partial reporting was the greatest source of error. Hospitals supplied the month and year but not the day. For most other items, a data difference was the most frequent source of error. The second most frequent source generally varied between 'unknown' and blank items on the certificate.

C. Error Rates by Hospital Characteristics: The most common procedure used by hospitals in the study to complete the birth certificate is to have the mother fill out a worksheet herself, using a hospital-designed worksheet. From this worksheet, supplemented by medical records data, the birth registration clerk completes the legal and medical sections and the physician completes the bottom part. However, this procedure is only used by 13 (26%) of the hospitals in the study. We found 21 different procedure combinations for the study hospitals. For this reason, we found it important to study whether particular hospital characteristics were associated with higher or lower error rates, using the five hospital variables defined in the Methods Section.

Another interesting finding is that OB staff had fewer errors than medical records in completing the legal/middle section when they used the same procedures. Crude rates showed the opposite pattern, with OB staff having error rates (9.2%) nearly twice as high as medical records personnel (4.7%). This difference probably arises because OB staff tends to use only the worksheet considerably more often (80% of the certificates), compared to medical records staff (12%). When both groups used the worksheet only, the OB staff had fewer errors. In any case, it appears that supplementing the worksheet with medical records data produces the most accurate data, regardless of who completes the certificate.

TABLE 3. TYPE OF ERROR FOR TWO WORST ITEMS IN EACH SECTION
Washington State Birth Certificate Data Quality Study, 1987

SECTION AND ITEM	ERROR RATE(%)	PERCENT OF ERRORS DUE TO*				
		Unknown	Blank	Completion	Difference	Partial
LEGAL						
Attendant	6.3	0.0	2.1	91.7	6.3	0.0
Hour of Birth	0.0	0.0	0.0	0.0	100.0	0.0
MIDDLE						
Menses Date	21.7	12.0	5.4	0.0	38.0	44.6
# of Prenatal Visits	13.9	25.5	7.5	0.0	67.0	0.0
BOTTOM						
Conditions of Newborn	20.0	0.0	24.2	4.6	70.6	0.7
Method of Delivery	15.0	0.0	23.5	7.8	68.7	0.0

* Error types defined in Methods Section

Two additional variables affected error rates on the bottom part. Better results were obtained with a worksheet based on the birth certificate, rather than a hospital-designed worksheet, possibly because all of the categories for these items are delineated on the birth certificate form. Thus, it is easier to see what conditions to include for each item. Smaller hospitals had lower error rates for the bottom part, but no significant difference by hospital size was found for the legal/middle part.

Interviewing the mother (vs having her complete the worksheet on her own) had no effect on measured error rates. However, this study was primarily designed to test how accurately the data were transferred from the hospital record to the birth certificate form. It is still possible that interviewing the mother could provide more accurate data on the worksheet itself, as the interviewer can probe for more information or clarify any items which the mother may find confusing. There was no way for the current study to test this possibility.

DISCUSSION: THE FIELD PROGRAM

The results of this study suggested some avenues for followup which were used to develop a field program for improving the quality of birth certificate data. This program has four aspects: training, feedback to hospitals, followup surveys, and in-house data audits.

A. Training: We will use these results to modify hospital handbook which give instructions on how to complete the birth certificate. We will also use the results in field training sessions for hospital and county health department personnel.

B. Feedback to Hospitals: We are sending a copy of this report to all Washington State hospitals which deliver babies and to all birthing centers in the state, so that they will be aware of major sources of error in completing the birth certificate. In addition, we sent participating hospitals a copy of hospital- specific results, in comparison to state totals. A sample results table is given in Table 5 (next page). This table was accompanied by one of three cover letters:

TABLE 5. SAMPLE TABLE OF RESULTS SENT TO PARTICIPATING HOSPITALS
1987 BIRTH CERTIFICATE DATA QUALITY STUDY
RESULTSFORHOSPITAL X

TYPE OF ERROR*	ERROR RATE (%) All Hospitals	Hospital X
Unknown Reported	0.4	0.0
Item Left Blank	0.6	0.5
Completion Problem	0.3	0.2
Data Difference	2.4	4.1
Partial Reporting	0.2	0.3
TOTAL ERROR RATE	3.9	5.1

*DEFINITION OF TYPES OF ERROR

1. Unknown Reported: Item reported as 'unknown', 'not given', etc on certificate but data available in hospital record

2. Item left blank: Item not completed at all on certificate but data available in hospital record

3. Completion problem: Completion instructions not followed or not used.

4. Data difference: Difference between data recorded on birth certificate and data in hospital record

5. Partial reporting: Only part of item completed, e.g., menses month and year reported but day missing even though data available in hospital record

1. For hospitals with error rates above the state average for one or more error types, the letter recommended that they institute quality assurance programs and offered assistance in designing such programs.

2. For hospitals at or below the state average for all error types, the letter commended them for low error rates but recommended continued monitoring of data quality.

3. For the four hospitals with overall error rates of less than one percent, an extra congratulatory message was added to letter #2. These hospitals and their Birth Certificate Clerks were also given special certificates of appreciation signed by the governor as an incentive to maintain high quality.

As a result of this mailing, 12 of the 50 participating hospitals have requested more detailed study results for their hospital, so that they could plan quality assurance programs. Six of these requests came from hospitals with the ten highest error rates. Each hospital requesting more information was sent a list of certificates in error, giving the item number(s) and type(s) of error for each certificate. Several hospitals expressed surprise that their error rates were so high and thus this study was a valuable educational tool for them.

C. Followup Surveys: Because of the good response to this feedback program, we decided to extend the data quality study to the remaining hospitals in the state with more than ten deliveries annually. Of the 32 remaining hospitals, two had refused to participate in the original study and one merged with another hospital in 1988, leaving 29 hospitals to be studied. We will also study the two birthing centers in the state with more than ten deliveries annually. We will use essentially the same procedure for this new study, except that 1988 birth certificates will be used. As there were only minor changes to the birth certificate form between 1987 and 1988, the results of these two quality studies should be comparable.

We will also conduct a followup data quality study among the hospitals in the current study with the ten highest error rates, to see if improvements have been made. This second study will use 1990 birth certificates. We are not using 1989 birth certificates because the certificate form underwent a major revision in 1989. The first year of a new certificate form has data quality problems caused simply by lack of familiarity with the form. Therefore, we did not feel that 1989 would be a good representative year for this study.

In addition, we reevaluated the five hospitals with high rates for completion errors (error type 3) to see if they were still having completion problems. Two of the hospitals had improved, but three still had problems. We are working with these hospitals to correct the problem.

D. In-House Audits: We examined the results of this study (which used a sample of certificates) to see if any data audits could help detect errors in the total birth file. We decided that the only error types for which audits were feasible are blank and partially reported items. Accordingly, we are initiating a computer edit to identify any item left blank or partially completed. A monthly edit listing will then be sent to the hospital requesting the missing information. Based on the distribution of errors by type (Table 1), this query program should effect a 21 percent reduction in overall error rates. It will be particularly useful for the menses date, maternal smoking, and malformations, where blank or partial reporting accounted for more than 40 percent of the errors.

By keeping the hospitals informed about problems and working with them, we hope to improve the quality of data reported on the Washington State birth certificate. At least, we can make birth certificate data as complete and accurate as data in the hospital records. In this way, we can help to improve the quality of both decisions made with the birth certificate data and various research/analysis projects predicated on the data.

*Due to space limitations, Table 4 and the Appendix has been omitted.

Study conducted by:

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USING NEONATAL MORTALITY RISK TO IMPROVE INFANT DEATH REPORTING AND SURVEILLANCE

John W. Senner, Arkansas Department of Health

The Association for Vital Records and Health Statistics reported in its October, 1990 newsletter on a survey of registration areas regarding procedures assuring complete and accurate reporting of infant deaths. Two-thirds of the respondents to this survey use a sentinel factor to select a set of birth records for staff review. These sentinel factors vary considerably among the states, ranging from the selection of only those births weighing less than 750 grams not matched to a death certificate, to a review of all births weighing less than 1500 grams or with a five minute Apgar score less than 4.

This study will demonstrate a method for comparing various strategies of record selection, and show how to combine several variables into an efficient single statistic which will improve the selection of records for review. It will show how this statistic is implemented in Arkansas and discuss the registration problems discovered from the birth certificate query program.

The examples that follow are based on a relatively clean set of data - the cohort of births occurring in Arkansas during the years 1985 to 1989 and linked to all known neonatal deaths of that birth cohort, regardless of when or where these deaths were filed. A handful of cases with missing sex or race of mother and a few months of 1985 data which did not get coded for congenital anomalies are excluded. Arkansas keeps open data files, so the data have been cleaned by a bootstrap process: changes discovered in one round of trial computation and query are incorporated into the source for the next round. The final file contains 160775 births and 934 neonatal deaths - giving a neonatal death rate of 5.8 per thousand.

The process of selection of a set of records to review, is equivalent to the application of a screening test to the data, analogous to the use of a laboratory screening test to detect a disease. Figure 1 shows the results of selecting Arkansas births weighing less than 1000 grams. In the terminology of epidemiology, the selected births test "positive". One measure of the quality of a test is the percent of the truly positive (neonatal deaths) that also tested positive (weigh less that 1000 grams). This percentage is called the sensitivity of a test. In this example, 407 of the 934 neonatal deaths weighed less than 1000 grams, giving a sensitivity of 44 percent.

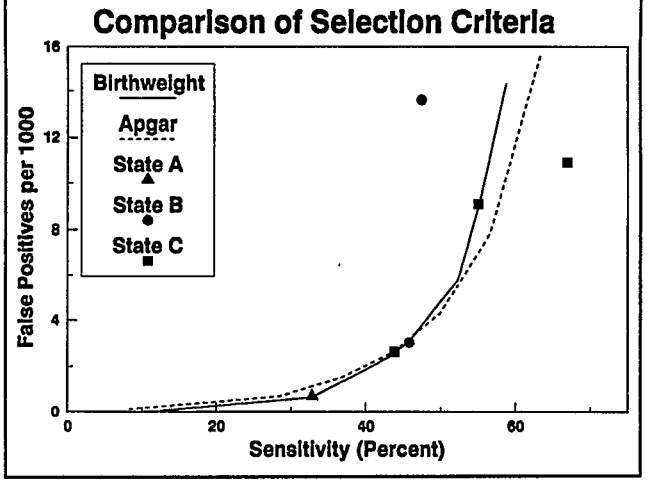
Figure 1
Selection of Infants Weighing Less than 1000 gr
Arkansas Births, 1985 - 1989

	Died	Survived
Selected	407	395
Not Selected	527	159,446

The infants selected by the test who survive are also important, because they represent the cost of running a query system. The epidemiologist calls these cases "false positive". In this example, 395 of the 159841 surviving infants weighed less than 1000 grams, giving a false positive rate of 2.5 per 1000 births.

When the selection criteria are varied both the sensitivity and the false positive rate change. Figure 2 shows the relationship between these quantities. One of the lines shows how sensitivity and the false positive rate increase as increasingly higher levels of birthweight are used as a selection criterium. The other line shows an essentially identical relationship between these quantities at increasing levels of five-minute Apgar score.

Figure 2



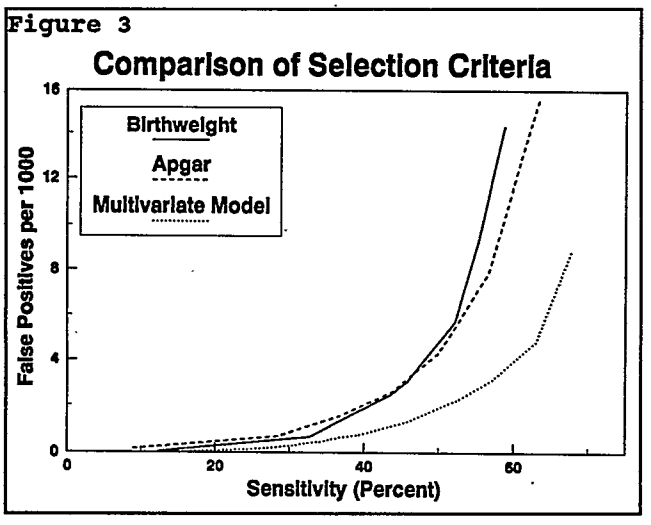
The points illustrate the results of applying several sample selection criteria to Arkansas data. State A queries only births weighing less than 750 grams. State B queries births under 1000 grams or born out of hospital. Two points are shown, with and without the out-of-hospital criterium. State C queries births weighing less than 1500 grams or with five-minute Apgar score less than 4. Three points are shown, the birthweight and Apgar score criteria singly and in combination.

State B illustrates the fact that sensitivity and false positive rates are affected by context. This state queries all out-of-hospital births because nearly all of these births are unplanned, emergency deliveries. Arkansas, on the other hand, has a moderately active lay-midwife community, and most out-of-hospital births are planned. In this context, adding the criterium of out-of-hospital delivery to the 1000 gram limit adds only a little sensitivity but much to the cost.

State C illustrates the fact that criteria can be combined in a useful way. In this case selecting infants by either of two criteria, birthweight or Apgar score, added substantially to sensitivity without adding greatly to the cost.

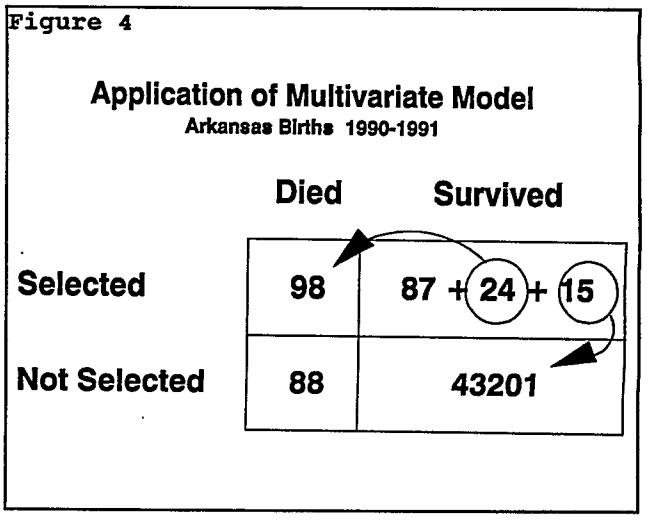
This process of combining criteria can be extended to any number of variables by using multivariate logistic regression to compute a probability of neonatal death. Figure 3 shows the relationship of sensitivity and the false positive rate when selection of records is based on the probability of neonatal death computed as a function of birthweight, five-minute Apgar score, sex of the infant, the presence of either anencephalus or renal agenesis, and race of the mother. A later model added a four level variable for the type of birth facility, and expanded the number of congenital anomalies scored. At all levels of query, a given level of sensitivity is achieved at less cost (false positive rate) than single variable criteria.

Figure 3



A supplement with the details of computing the probability of neonatal death is available from the author at 4815 W Markham - Slot 19; Little Rock, AR 72205-3867. There are two phases to the computations, generation of the probability equations from clean data, and routine application to dirty data. Quarterly, deaths are matched to births and all apparent survivors with probability of death greater than 20 percent are queried by letter to the hospital of birth or transfer. This letter lists the name of both infant and mother and the data used to generate the probability. The letter asks that the data be checked for correctness and the outcome of the birth be reported.

Figure 4



The results of application of the probability equations to five quarters of data are shown in Figure 4. During this time, 126 records were selected for query. Of these, 15 infants erroneously appeared to be high risk because of wrong data. Most of the errors were made in Apgar score - a "10" that was typed as a "1", a "0" that was used to mean that the score was not taken. There were a few birthweight errors and one notation of a severe congenital anomaly was withdrawn. Twenty-four of the infants were correctly identified as high risk but appeared as false positive records because they had, in fact, died.

Records of these infants were traced until the responsibility for failure to file a death certificate was identified. There are two persistent problems.

First, there is miscommunication between funeral homes and hospitals on the outcome of the birth. A hospital files a live birth certificate or a fetal death certificate - but not the death certificate. And a funeral home files the death certificate, unless it thinks that the birth was a miscarriage. Correct procedures are not followed unless both the hospital and the funeral home agree on the birth outcome. The registrar has responded to this problem by asking that every funeral home check on the live birth/fetal death status of the infant, and every hospital communicate the outcome status of a birth to the funeral home. These efforts have helped, but the problem has certainly not disappeared.

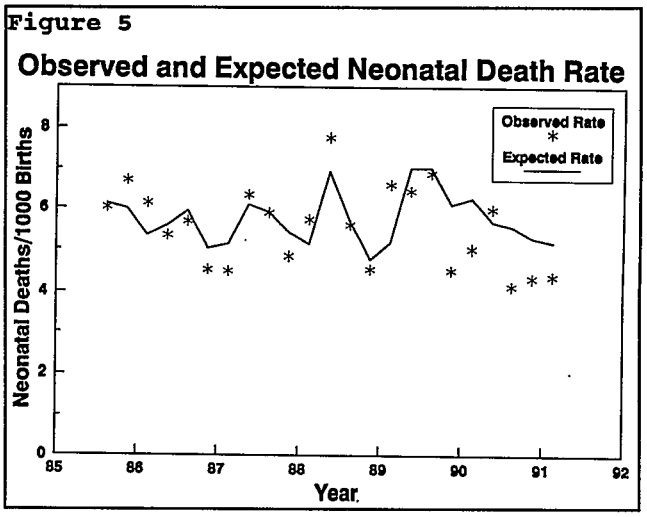
Second, hospital pathology departments are reluctant to do their paper work. One pathologist admitted that he found the task distasteful, and put it off as long as possible. Medical records departments can help to assure that the records are filed promptly but one hospital discovered that their computer system was not as reliable in reporting the status of the infant as thought. Thus, the medical records personnel did not have a accurate double check that all records had been filed.

Approximately 20 percent of the query returns indicated that the infant was transferred alive to another hospital. While some of these transfers occurred after the birth certificate had been filed, many should have been recorded on the transfer field of the certificate.

The Association for Vital Records and Health Statistics report on registration practices commented that existing wide variations in registration procedures among the states prevent fair comparisons of state infant mortality rates. A regular and systematic query of surviving high risk infants is needed to assure that all death certificates are filed and counted. The procedure will also detect and correct data errors and enhance the reporting of transfers to other hospitals. Because of variations in birthing practices, specific birthweight or Apgar score criteria are not desirable. Rather, the intensity of query should be standardized at some agreeable level of sensitivity. States will then find that a multivariate criterium can achieve the agreed level of sensitivity at less cost than a single variable criterium.

One efficient multivariate criterium is based on the probability of neonatal death. This statistic is a transformation of birth characteristics (birthweight, Apgar score, sex, etc.) into an

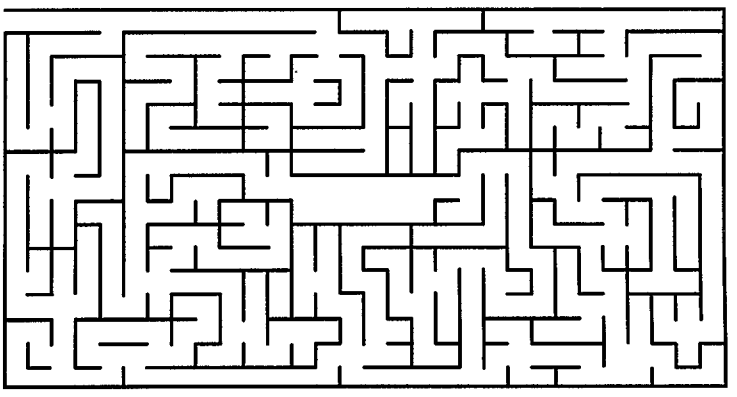
Figure 5



expected number of neonatal deaths. These can be summed over periods of time, areas of residence, hospitals of delivery, or type of attendant and compared to the actual number of deaths. Figure 5 shows, as an example, the history of the last six years of neonatal mortality in Arkansas. The solid line gives the expected neonatal death rate, as computed from the birth characteristics, and the stars show the actual rate. Note that the "quality" of the births has not changed, but that recently the neonatal death rate has been persistently below expectation, coinciding with the implementation of ECMO (extra corporeal membrane oxygenation) therapy. Similar computations can be used to identify areas of the state with poor access to perinatal care. A formal statistical test can be performed by computing the traditional chi-squared test whenever the expected number of deaths exceed five.

Session E

Year 2000 Surveillance and Data Systems– Comparable Methodologies



COMPARABLE METHODOLOGIES: A NATIONAL PERSPECTIVE

Mary Anne Freedman, National Center for Health Statistics

Successful achievement of the Year 2000 Health Objectives will depend in part upon our ability to monitor and compare progress toward the objectives at all levels of government. This presentation provides a brief overview of some of the issues related to tracking the Year 2000 objectives at the national level and some suggestions for developing comparable data collection methods for use at the national, state, and local levels.

NATIONAL TRACKING EFFORT:

Healthy People 2000[1] contains 300 objectives. There are also 220 sub-objectives targeting minority groups and other special populations. In addition, many objectives have multiple components. Thus, the tracking system will need to follow about 700 data elements. These data will come from over 75 unique data systems.

There are several problems with the objectives themselves that may impact on our ability to monitor progress toward all of the objectives. First, there is a group of objectives that are relatively easy to monitor but that had no data source at the time they were formulated. NCHS and other agencies are modifying existing surveys and developing data for these objectives.

Second, there are a few objectives which raise analytic or measurement issues (e.g., years of healthy life). We are working on solutions to these issues.

Then there are some objectives which not clearly defined (e.g., ...people who have discussed issues related to nutrition...with family members...). While we are attempting to develop survey instruments to address these objectives, their inherently vague nature makes them difficult to measure.

Finally, there are a few objectives which relate to populations that cannot be identified or monitored through general purpose surveys (e.g., IV drug users not under treatment...; mental disorders among children...). These are the most problematic objectives. Realistically, they cannot be followed through national surveys, but will need to be tracked through small, intensive, catchment area studies. Thus, it may be difficult to construct national estimates for these objectives.

Despite these problems, we estimate that, at present, national data sources exist to monitor over 90 percent of the objectives. The concerns at the state and local levels are considerably greater. Much of the data to monitor national progress toward the objectives will come from national surveys. Similar surveys are often not feasible at the state and local levels. In 1989, the Public Health Foundation surveyed states to determine their ability to measure progress toward the (at that time, draft) objectives and sub-objectives. Responding states indicated that, on average, data was available to track 39 percent of the objectives and sub-objectives in the draft set. Individual state responses ranged from 27 percent to 58 percent.[2]

OBJECTIVE 22.3:

This brings us to Objective 22.3: *to develop procedures for collecting comparable data for each of the Year 2000 objectives and to disseminate these among Federal, State, and local agencies.*

At the preceding session, we heard presentations about the work of Committee 22.1 and the development of the health status indicators. That process was successful because it incorporated input from a wide spectrum of interested parties. As we define a process for addressing Objective 22.3 we can learn from the 22.1 experience. First, we must insure that interested parties have a means to provide input. Second, we must recognize that many of the issues in 22.3 are technical. Thus, in addition to the policy groups that participated in the development of the health status indicators, we need the involvement of organizations like the Association for Vital Records and Health Statistics, the Council of State and Territorial Epidemiologists, and the National

Committee on Vital and Health Statistics. We also need to consult with technical experts within state and federal government and in the schools of public health.

The process to develop comparable data collection methods should address the following areas:

- **technical definitions.** There are specific terms within the objectives, the health status indicators, and related areas (e.g., the base population for age-adjusting) that need to be defined.

- **standard data collection methods.** National data collection methods should be examined to determine which are/are not appropriate for state and local use.

- **alternate methods and calibration.** There will be times when the standard methodologies are too expensive or too cumbersome for use at the state and local levels. Alternate techniques must be developed and calibrated with the methods used at the national level.

This is a major undertaking which will take time to complete. Therefore we must get started soon. We must also segment the process so that results can be released as they are developed. It is important that states and localities have this information as early as possible for use in assessing progress toward the objectives.

In summary, the development of comparable data collection methods will require broad input the public health community. We look forward to working with all of you on this important project.

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ESTABLISHING HEALTH DATA SYSTEMS AS A PRIORITY - PAST AND PRESENT

Garland Land, Missouri Department of Health

The public health system is launching into the 90's with some new significant directions not the least of which is the year 2000 objectives and more specifically the objective 22 on surveillance and data systems. Those of us who make a career of developing and using data systems and attempting to impact public policy through data find it assuring, if not hard to believe, to see data given such a high priority in establishing the nation's health agenda. Making data systems one of the twenty-two objectives follows the Institute of Medicine's report which pointed out that assessment is one of the cornerstones of public health.

I am reminded that this is not the first time that an emphasis has been given to the creation of health data systems at the local, state and national level. When I was hired 20 years ago, one of the first documents given to me was what we called the flag book, A State Center for Health Statistics, which was published in 1969. This was the first resource developed to promote the creation of state centers for health statistics. Legislation was passed in 1970 to establish what became known as the Cooperative Health Statistics System. State Centers for Health Statistics were developed in almost all states over the last couple of decades. As a formal program, the CHSS lasted until 1981 but many of the principles have carried on past the time when funding ceased.

Now we have a new emphasis on data. I would like to review briefly some of the data principles, concepts and programs which were promoted in the 70's and how those relate to the current emphasis on data and surveillance. There are some striking similarities and dissimilarities in the approach to strengthen health data systems which was made in the 70's and the one we are launching in the 90's.

First, I would like to reflect on some principles and activities of the CHSS. As the name implies, we were trying to build a national health statistics system on a cooperative basis between the federal, state and local governments. The program was developed in the heyday of health planning. Naturally, the program was geared towards meeting the statistical needs of health planning. Health planning was a federal concept which in many states was received with little enthusiasm. Although on paper health planning had a broad mission, most of the emphasis was placed on health facility and manpower resources. It was only natural from the federal perspective to strengthen the data systems in these areas. So the CHSS initially focused on vital statistics, hospitals, nursing homes, heath manpower and hospital discharge data.

It should be noted that the emphasis was on specific data systems. Vital statistics was a natural ally to public health agencies because the data system was in place although in a rudimentary fashion in some states. However, the other data systems of the CHSS were typically not in place. Considerable developmental efforts were required. Most state agencies at the time did not have a wealth of experience in planning and managing large data systems. This problem was complicated by the necessity of developing new collaborative arrangements with provider associations and licensing boards which controlled the data in one fashion or another.

For the most part the primary users of the facility and manpower data systems were the planning agencies. However, their data needs were rather vague and nondescript. State Centers for Health Statistics were mainly in state public health agencies whose primary mission related to the prevention and control of diseases. However, state centers were developing data systems that were only marginally related to the primary mission of the state health department.

The emphasis of the CHSS was on developing data tapes which met the federal technical specifications. Possibly because of a lack of resources or maybe because of a lack of knowledge of how to use the data, analysis of the type which could frame policy decisions occurred infrequently in many states. The panel to evaluate the CHSS noted this problem and recommended " the first priority in the CHSP be to strengthen the ability of States to identify health data needs, to develop appropriate collection mechanisms, and to build capacity to analyze and use health data ..." Ten years after that recommendation was made we have a new direction for health data systems. I would like to compare the present plan with our past experience.

First, the present plan is part of the National Health Promotion and Disease Prevention Objectives, Healthy People 2000 publication. This is clearly a different planning framework than the earlier health resources planning focus. Currently data for health planning is seen in a much broader context.

The CHSS data systems were mainly focused on inputs of the health delivery system--

manpower and facilities. The year 2000 objectives are strongly weighted towards outcomes. While few of us would argue with this change in emphasis, I believe we all would admit that it is much easier to count hospital beds and physicians in a county than it is to measure and collect data on health status. This was borne out by the divergency of opinion voiced at the meeting to recommend the health status indicators called for in Objective 22.1.

Obviously the big difference between the present approach and the CHSS is that we are not developing large multi-variable data systems. Instead the emphasis is on collecting data to measure specific objectives. Sometimes that will require a new data system. I believe this addresses the major criticism of the CHSS that we were spending a great deal of effort collecting data when we did not know if or how the data would be used.

The CHSS emphasized data collection and data tapes. Objective 22.5 focuses on analysis and publication of data needed to measure progress toward objectives. Objective 22.6 focuses on data transfer but not just sending tapes to the NCHS. The narrative states "Such a system could provide standardized tabulations and allow users the flexibility to rapidly analyze, graph, and map information to meet specific needs." Objective 22.7 focuses on the need for timely release of national surveillance and survey data to measure progress toward the national health objectives.

Whereas the CHSS focused on a relatively small number of data systems, the year 2000 objectives require probing into literally hundreds of data systems. As with the CHSS, not all the data systems are housed in public health agencies. Cooperation will be required to obtain data from such non public health sources as law enforcement, welfare agencies, schools, private employers etc.

In 1968 the NCHS established the Applied Statistics Training Institute (ASTI). This was in recognition that states and local governments had statistical training needs which were not being met. Later the NCHS developed the Statistical Notes for Health Planners to convey standard statistical techniques to those working with health data. Both of these programs were disbanded when the CHSS lost its funding and health planning was de-emphasized at the federal level. It is good to see that the concept of resurrection is understood in Washington, for the old ASTI program and the statistical notes series have been brought back to life. It will be important that these two programs maintain their relevance by focusing on statistical techniques of analysis that complement the year 2000 objectives.

One of the major accomplishments of the CHSS is that through federal funding almost all states developed in some fashion a state center for health statistics. Most states have dropped or limited the collection of data which were given such a high priority 20 years ago. However, the state centers live on. Different data systems have emerged, more focus is placed on public health programs, needs assessment and evaluation. Unfortunately most state centers are still rather small with few resources. I hope the lessons learned from the CHSS are not forgotten. Federal financial resources do pay off. States will respond. However, without financial resources the national objectives of data comparability at the federal, state and local level will never be met. I believe one of the most important lessons which we should have learned from the CHSS is that the federal funding should not be limited to data collection but instead funds should be dedicated for analysis.

A final challenge which we have is how to make the local health units a part of this process. The CHSS struggled with this concept and in fact, in the early days, the name included local in the title. The title was changed and for the most part the locals were left out. Now again we are confronted with the reality that public health services are provided at the local level and data for planning, assessing, allocating and evaluating are needed at the level of service delivery. I believe this is the most paramount reason for developing strong state centers for health statistics. Most local health units are relatively small. They do not have the time, expertise and often the interest in developing data systems for analysis and to assist policy making. Other than in a few large metropolitan health departments, I do not think we should expect most local health departments to become proficient in the data requirements of the year 2000 objectives. This should be the responsibility of the state with the support of the federal government.

In conclusion, the CHSS which was started 20 years ago paved the way for the health statistical approach of today. Obviously times and priorities have changed. Some of the concepts have been dropped but others have withstood the test of time and are reappearing. I find it exciting to see this reemergence on health data as a public health priority. However, I think we need to be asking ourselves what it will take to institutionalize health data as a priority and not see it wane after ten years as did the CHSS. I believe the answer to that question rests in our ability to make data relevant to policy formulation. Not just more tables, fancier colored maps and pie charts but down to earth analysis of the data

pertaining to the phrased or unphrased questions of the program managers and policy makers. We need to understand their world and then bring our world to them so that the major health goals of the nation can be accomplished.

DATA FOR THE HEALTHY PEOPLE 2000 OBJECTIVES: THE PUBLIC HEALTH FOUNDATION'S NEW CORE DATA BASE

Sue Madden, Public Health Foundation

I'm pleased to be here today to talk with you about the Public Health Foundation's new core data base, answer the most frequently asked questions, and share some sample outputs.

In 1986, the Public Health Foundation convened a Role Review Panel to:

- Evaluate the purpose and role of the ASTHO Reporting System;
- Critique some of the fundamental assumptions underlying the ASTHO Reporting System; and
- Recommend ways that the Reporting System and its outputs might be more useful to state health agencies.

Among other things, the Panel recommended that we revise the core data base.

In 1989, PHF convened a Steering Committee of health data experts to develop the parameters for the new core data base. The committee recommended that the new core data base:

- Focus on high-priority public health problems and what health departments are doing to alleviate the problems;
- Be outcome-oriented and firmly tied to the *Healthy People 2000* objectives; and
- Focus initially on a limited number of public health goals where interventions have a proven relationship to outcomes.

Through an interactive group process, the Steering Committee selected nine areas for the core data base. The nine are:

- Infant mortality
- Adolescent pregnancy
- Cancer
- Cardiovascular disease
- AIDS & HIV infection
- Sexually transmitted diseases
- Vaccine-preventable diseases
- Injury prevention
- Environmental health

The new core data base addresses at least one objective in 17 of the 22 priority areas in the Healthy People 2000 Objectives.

Most Frequently Asked Questions About the New Core Data base

Question 1 - Why Revise the Current Data Base?

As a community, we have done an abysmal job of telling the story of what public health is and what health departments do. As you know, public health is not an easy sell.

We've tried to devise a more compelling way of telling policymakers and fellow citizens about the impact health departments are having on national health problems.

Question 2 - Why Those Nine Goals?

We wanted the system to be successful so we limited it to the nine goals selected by the Steering Committee. We will add other areas as there is more documentation of the relationship between interventions to outcome and as resources become available.

Question 3 - Who Designed the New Core Data Base?

Not just Public Health Foundation staff. The data base was designed by 64 public health officials representing:

- 26 state health agencies
- 6 local health departments
- 5 federal agencies

The federal, state, and local representatives included:

- 11 state and local health officers
- 28 program experts
- 6 statisticians
- 16 health planners/administrators
- 3 fiscal/budget directors

The Steering Committee directed PHF to convene a national core data workshop with participants divided into four work groups—maternal and child health, infectious disease, chronic disease, and environmental health/injury control—to determine the data elements for the nine areas. Composition of each work group included:

- Four program experts;
- Two state health agency administrators;
- Two local health officers;
- One statistician; and
- Two federal representatives.

Question 4 - How Was It Designed?

In 1990, PHF convened the national core data workshop and charged the participants with developing a core data base capable of telling a more compelling story about the impact health departments are having on national health priorities. PHF gave the participants a seven-step process to use in defining the data base that:

- Focused on designing outputs rather than forms;
- Forced the work group to consider data availability;
- Considered the impact of health department activities on desired health outcomes; and
- Limited the new data base to a reasonable size.

The seven-step process is as follows:

Step 1 Review the Model End Product

Step 2 Identify the most important health department interventions that influence desired health outcome

Step 3 Identify measures for each intervention

Step 4 Design graphic outputs for each measure identified in step 3

Step 5 Evaluate availability and strength of each measure according to ranking criteria

Step 6 Modify graphic outputs as necessary

Step 7 Select outputs for core data base after considering the assigned rankings and determining which ones tell the most compelling story

Our overall advice to work group members was—When In Doubt—Think Impact

As a part of the process, the work groups created more than 400 graphic outputs that display significant indicators of health status or surrogate measures for health status. The work groups recommended for inclusion in the data base those graphics that best depict the impact health departments are having on national health priorities, and for which data are readily available or for which data could be obtained with no more than a modest investment of time and resources. A number of the graphics reflect health outcome measures that can be obtained from existing data sources such as the National Center for Health Statistics. The remaining data elements will be collected directly from state health agencies.

Question 5 - What About Fiscal & Staffing Data?

The National Core Data Workshop addressed the output side; but we also wanted data on the input side. PHF convened two additional work groups in 1990 that identified resources (both financial & personnel) associated with the nine goals of new core data base.

Question 6 - Who Has Reviewed It?

Information on new core data base has now been shared with hundreds of public health professionals in federal, state, and local health agencies. We have received much helpful feedback on the graphics and survey instruments.

Question 7 - How Will It Be More Useful to States?

Briefly, in the old data base, fiscal data and information on state organization are the most useful. The new core data base, by focusing on impact and selected public health problems, will make services data more useful; and should have equal utility at the federal, state, local levels.

Question 8 - When Will New Data be Available?

Survey Instruments will be fielded in late summer 1991. Preliminary data will be available beginning at the end of 1991.

Question 9 - What Happens Next?

Current PHF activities in three areas:

- Designing new survey instruments--7 survey instruments have been developed, pretested, and reviewed by state and local health agencies, work group members, and others. We are currently finetuning the survey instruments based on comments received.

- Researching existing data sources--Staff have been identifying and gathering data from existing data sources, where available.

- Designing a new data base--PHF is redesigning its computer system to accommodate the new core data base, and plans to put the data base on the Public Health Network to maximize its utility.

The following slides are a sampler of graphics displaying information that will be available through the new core data base. Nearly all the slides depict "mock" data.

1. Gonorrhea incidence rate compared to year 2000 objective

   Source: PHF

   Description: Good way to compare state progress toward a specific objective.

2. Total number of partners of STD cases identified and treated, by disease

   Source: PHF

   Description: Effectiveness of casefinding & penetration of treatment services.

3. States providing publicly-funded AZT treatment or covering AZT treatment through Medicaid

   Source: PHF

   Description: Shows which states are ensuring access to AZT therapy for HIV positive/AIDS patients.

4. Number of outbreaks investigated and number controlled within three generations

   Source: PHF

   Description: Measures the effectiveness of epidemiological efforts when primary prevention has failed.

5. Percentage of designated target population immunized against measles

   Source: PHF & CDC

   Description: Measures adequacy of resources and effectiveness of outreach and enforcement.

6. U.S. Infant mortality rates, by race, 1970-1987

   Source: NCHS

   Description: General outcome measure that shows how existing data sources will be tapped in our quest to tell a

compelling story.

7. States conducting state, regional, or local infant death reviews

   Source: PHF

   Description: Increasingly popular intervention that can reveal underlying causes of infant deaths and suggest interventions that might further reduce infant mortality.

8. Percentage of adolescents in need receiving family planning services

   Source: PHF

   Description: Measure of access to family planning and primary care services.

9. Number of children screened for lead poisoning, number found positive, and number receiving appropriate follow-up

   Source: PHF

   Description: Indicator of state efforts at casefinding, treatment, remediation of this serious environmental problem.

10. Number of states with selected motor vehicle safety legislation

    Source: PHF

    Description: Indicator of state activity in injury control.

11. Percentage of population using seat belts and number of highway fatalities, by state

    Source: BRFSS, DOT

    Description: Scattergram that indicates correlation between seat belt use and occupant safety.

12. Seat belt usage and motor vehicle crash mortality in states with mandatory seat belt laws, 1987-1990

    Source: BRFSS, FARS

    Description: Plots rate of seat belt usage against rate of motor vehicle crash mortality and should show how an increase in the former would result in a reduction of the latter.

13. States mandating coverage of screening mammography

    Source: PHF

    Description: Shows which states have moved to improve access to this intervention proven to assist early detection and control of cancer.

14. Percentage of women aged 40 and over screened for breast cancer by race and by type of screening

    Source: BRFSS

    Description: Uses BRFSS data as an indicator of service penetration in any at-risk population.

15. Percentage of persons aged 18 and over with high blood pressure not under care, 1970-1990

    Source: NHANES (NCHS)

    Description: Shows percentage of population at-risk for stroke and heart disease not being treated. Focuses on unmet need.

YEAR 2000 OBJECTIVES ON SURVEILLANCE AND DATA SYSTEMS COMPARABLE METHODOLOGIES

Steven M. Teutsch, Centers for Disease Control

Public health surveillance is the ongoing, systematic collection, analysis, interpretation, and dissemination of information for public health action. It relies on the timely availability of information that can be placed in a public health perspective. The Year 2000 Objectives address several basic issues to assure the availability of comparable and timely information. These include the development of health-status indicators that will assure that a minimum amount of information about the overall health status of state and local communities will be available in comparable formats. Common data elements will be developed to assist in data collection at all levels so that when data are collected, there will be guidance as to recommended procedures and facilitate comparison with other jurisdictions collecting similar information.

Much of the data that CDC uses for surveillance comes from state health departments, which in turn rely on a variety of organizational units and mechanisms to collect, analyze, and disseminate the data. The complexity has been compounded by the fact that individual CDC programs, largely independently, develop paper and electronic systems for surveillance of individual conditions. State epidemiologists and laboratory directors, in particular, have requested standardization of the electronic systems to facilitate more uniformity in operating procedures within state health departments and to enhance the quality, comparability, and availability of the data.

In response to those needs, CDC's Surveillance Coordination Group developed the following recommendations for electronic systems:

Recommendation 1:
Standard Core Variables

For CDC surveillance systems, "core variables" such as race, ethnicity, date of onset of health event, and geographic location should be characterized the same way whenever possible using standard definitions, categories, and coding schemes.

Recommendation 2:
Telecommunications

A single gateway to allow CDC and outside sources to exchange information should be provided by CDC.

Recommendation 3:
Software Development

Software applications designed by CDC for entering, analyzing, and transmitting surveillance data should strive to have consistent interfaces and should incorporate specifications for organizing data files so that data can be sent to CDC through the telecommunications gateway.

Recommendation 4:
Data Exchange Between Health Agencies in States

Surveillance data originating in state or local health departments should be sent electronically to the state office responsible for disease control before or at the same time the data are sent to CDC.

Recommendation 5:
Training and Support

CDC should provide the necessary ongoing technical support to epidemiologic, laboratory, and other staff in state health departments that use electronic public health surveillance systems designed by CDC.

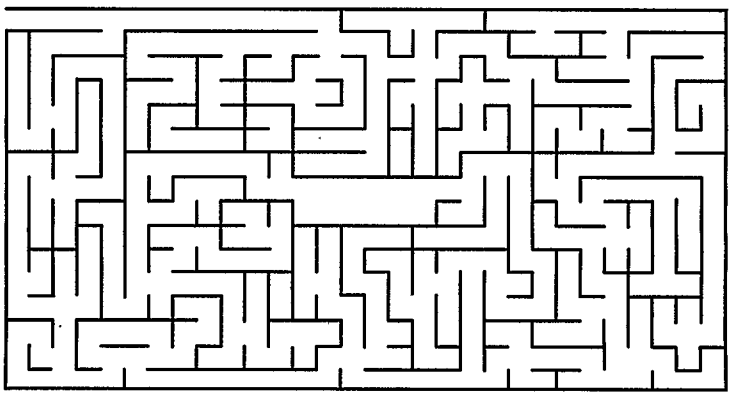
Recommendation 6:
Availability of National Surveillance Data

Summaries of national surveillance data transmitted electronically should be available to public health officials in an electronic format on a timely basis.

These recommendations are currently being implemented and should greatly enhance the availability of timely information available to public health professionals. We hope that they will also simplify the use of CDC-designed software and surveillance systems.

Session F

Identifying Health Care Access Barriers



IS PRIMARY CARE ACCESSIBLE TO THE MEDICALLY NEEDY?

Sonya R. Albury, The Health Council of South Florida, Inc.

Adequate access to health care for all has become one of the most compelling and difficult topics in America today. The literature is replete with articles on various issues pertaining to access such as health care rationing, spiraling health care costs, and ethical medical practices for the young, the old and the poor. The difficulty in responding to this health care challenge lies in the complex nature of the health care system itself. It is further compounded by special interest groups, the fragmentation of funding streams and a variety of other programs competing for scarce resource dollars.

This paper serves as a window into one key aspect of this diverse health care system: Primary Care. This fundamental service component is believed by many to be a basic right. Yet, many indigent and medically indigent people must forego needed treatment. In fact, the United States spends more money per capita on health care than any other country; yet one of every six Americans has no insurance (public or private) to cover health care costs. What factors preclude them from access to needed care? Are there barriers to health care delivery that need to be removed? Who needs primary care? And where do people receive care when they can't access a primary care center?

These questions as well as many others have been addressed through the 1991 Indigent Health Care Report the results of which are highlighted in this paper. The study represents the second in a series of reports designed to assess the impact of Florida's primary care initiatives and provides a baseline of information which documents existing needs, resources and the continuing pattern of inappropriate hospital emergency room utilization in Dade and Monroe Counties. It offers insights into the reasons why people seek treatment for non-urgent conditions in the emergency room. It also discusses barriers which exist when access is sought in community based primary care settings. Finally, conclusions are presented which point to the need for additional resources for primary care centers and potential site locations for new centers.

I. BACKGROUND

Health Council

The Health Council is a planning and policy making organization which serves as a resource to the community in the areas of health planning, administration, research and education. The Council's service area encompasses Dade and Monroe Counties or what is more widely known as the greater Miami area and the Florida Keys. The Health Council is also one of nine sister agencies located throughout the State of Florida which all share common purposes and goals. This network of Councils is headed by a Statewide Health Council located in Tallahassee, Florida.

Legislation/Statewide Effort

Since its inception over 20 years ago, The Health Council has had a long standing concern regarding Indigent Health Care. Then in 1984, the Health Care Access Act was passed in Florida and a formalized statewide approach was undertaken. The Act declares that access to adequate health care is a right which should be available to all Floridians regardless of socioeconomic status.

Since that time, several studies have been performed to assess the health care delivery system for the indigent population. Most recently, the study has focused on primary care as a key means for containing costs and providing timely treatment. In fact, one of the original intents of the Florida legislation was to reduce inappropriate utilization of costly ER care through the creation of primary care service programs throughout Florida. Primary care initiatives were established with State funds in combination with federal and local dollars in an effort to provide a "medical home" for those in need.

II. OVERVIEW OF DISTRICT

Population

For comparative purposes, one of the initial steps of the study process was to develop a demographic profile of the service area.

According to the 1990 Census data, the population of Dade County or the Greater Miami area, is comprised of over 1.9M people, up 17.7% since 1980.

Monroe County (i.e., the Florida Keys) has 76,056 residents, and experienced a 20.4% increase over the past decade. Florida, on the other hand, grew by 31% overall. While the study area has a slower growth rate than the State as a whole, South Florida continues to represent a significant portion of Florida's 12.8M people, at 16%.

The study area is also culturally diverse. Over the past decade there has been fundamental changes in the population. Hispanics are the fastest growing group, although they are quite varied in and of themselves representing a variety of countries. Key trends include: Latin immigration, a large influx of Cuban and Haitian refugees, and a "white flight" to other parts of Florida and northern climates.

Dade County is particularly diverse, whereas Monroe County is much more homogeneous. (See Table 1).

TABLE 1

County	Hispanics	% Change	Non-hispanic White	% Change	Blacks	+/- % Change
Dade	49.2%	64.4	30.2%	-24.4	20.5%	46.8
Monroe	12.3%	33.2	82.3%	22.5	5.4%	18.7

Economic Status

Over the past decade, South Florida has served as a haven for people from other countries seeking sanctuary and political freedom. As a result, the growing number of immigrants have had a dramatic impact on the health care delivery system. The health status of refugees has tended to be poor and many have had difficulty in obtaining employment. Many Haitian women of child-bearing age have reached our shores and this has led to extensive use of publicly supported health services.

In terms of the overall problem of health access, 2.2M Floridians are uninsured or approximately 18% in contrast to 13% for the U.S. Moreover, the uninsured are disproportionately Hispanic and nonWhite indicating that the magnitude of the problem is even more pronounced in the Greater Miami/South Florida area.

And, while immigration has slowed in recent years, it is continuing from the Caribbean as well as from Central and South America into South Florida. Out-migration by existing residents portends of a shift in the composition of the population and an increasing number of health needs and reliance on limited resources.

III. STUDY RATIONALE

Overview of Primary Care Initiative

Given these emerging trends, coupled with Legislative interest and recent initiatives related to universal access, a study of local hospital emergency departments was performed. The study was designed to track the state's effectiveness in reducing inappropriate utilization of costly emergency care through its Primary Care Initiative implemented in 1984.

Funding for the program is provided through the Public Medical Assistance Trust Fund (PMATF). This is supported through a 1.5% assessment levied against the net operating revenues of all hospitals in the state. The current allocation is at 30M (implemented in FY 1984-85; Dade's share has been 1.8M since 1988).

The Primary Care Initiatives are mandated to be comprehensive in service scope with a mix of preventive and illness care services wherein they become "medical homes" for low income individuals. They are designed to be family oriented, accessible and targeted to the Medicaid eligible population. Offerings include nutrition counseling, WIC, home health, dental services, early detection, prenatal care and overall continuity of care.

While these programs are supported by the State in conjunction with Federal and local dollars, the most optimistic estimates are that the primary care programs are reaching only 25-30% of the needy. The majority of the medically needy/indigent remain without access to primary care services. Faced with a multiplicity of economic and geographic barriers to care, many non-emergent patients seek treatment in hospital emergency rooms.

In fact, the AHA estimates that between 60-70% of ER patients are nonemergent. Some national studies further indicate it can be as high as 85% in medically underserved areas.

IV. EMERGENCY DEPARTMENT STUDY

The principal focus of the study conducted was to examine hospital emergency department utilization patterns. Its purpose was to determine:

a) to what extent patients seek care in the emergency room for nonemergent conditions, and

b) why patients continue to use the ER instead of primary care projects

It was also designed to examine the utilization patterns by demographic indicators, to assess whether specific groups (e.g., Medicaid and nonpaying patients) are more likely to use the ER for nonurgent care and for what conditions and reasons.

Methodology

The methodology employed incorporated a study of 14 hospitals throughout Dade and Monroe Counties, representing a diversity of sizes, ownership statuses and geographic locations. Hospitals in Dade were selected from each of the health planning areas. In Monroe all three hospitals in the county participated, representing the Upper, Middle and Lower Keys areas. Jackson Memorial Hospital, the area's large, public tertiary hospital also was included in the study.

The study gathered data on each patient coming into the ER, or a sample thereof, for the first full week in November 1990. Patients were studied on a round-the-clock /24 hour a day basis to determine any

fluctuations by time of day. Approximately 3,000 patients were studied in relation to a patient total of about 6700. Excluding the major tertiary hospital, a 90% response rate was achieved from the participating hospitals.

During the site visits, interviews were also conducted with the emergency department personnel concerning their perceptions regarding both appropriate and inappropriate utilization of hospital emergency rooms.

Patient demographic data was collected as well as economic, service, and medical information. Data were then computerized, tabulated and weighted. Cross-tabulations were performed by demographic, arrival, economic and visit type data. A key indicator was visit type which encompassed levels of severity: emergent, urgent, and non-urgent status.

Results/Findings

Demographics

Of the patients treated in the Dade hospitals' emergency rooms, approximately 18% were over the age of 60. In Monroe, the percent was slightly lower at 15.5%. The gender breakdown was fairly even in Dade whereas there were 20.6% more males than females treated in Monroe County Emergency Rooms. The distribution by ethnicity in Dade also differed from Monroe. In the Keys, 78.7% of the patients were White Non-Hispanic, in contrast to only 38.9% in Dade. Conversely, Monroe County hospitals saw only a small portion of Hispanics (8.1%) and Blacks (7.2%) compared to 24.0% Hispanics and 28.5% Blacks in Dade institutions.

Type of Visit

Patients presenting at the emergency department were categorized by visit type or level of severity. (See Table 2). In District XI, the largest portion surveyed were categorized as having urgent conditions (34.6%). These minor emergencies were followed by non-urgent patients at 28.6%. Only 17.3% were considered truly emergent, requiring prompt treatment.

In Monroe County specifically, however, a markedly different pattern emerged. Nearly half of the patients seen in the ER were non-urgent (48.1%). In contrast, 27.3% were reported as non-urgent in Dade.

Date and Time of Arrival

Arrival data were generated to provide an overview of whether there are any particular peak periods of hospital emergency department utilization.

The data by date of arrival indicate that the peak day of the week in the ER for Dade County is Wednesday, followed by Monday, Sunday and Tuesday.

In Monroe County, the largest number of people went to the ER on Sunday, closely followed by Monday, Tuesday and Wednesday. Despite the fluctuations between the counties during the early part of the week, both tend to taper off in usage during the latter part of the week.

In terms of time of arrival, about 67% of the patients for whom data was recorded arrived at the emergency department between the hours of 9:00 a.m. and 9:00 p.m. The peak period was during the mid to late morning hours from 9:01 a.m. - 12:00 noon. The activity lessens through the lunch period and then rebounds in the late afternoon. Patients activity then begins to diminish throughout the evening hours. The least amount of activity seems to occur from midnight to 6:00 a.m. in the morning. This overall utilization pattern was consistent in both Dade and Monroe Counties.

Disposition

The majority of patients seen by the emergency room staff were treated and discharged home (58.9% Districtwide). Less than 13% were ill enough to require admission to the hospital. Only a small proportion were referred to public clinics or urgent care centers in either county.

Reasons for Non-Urgent Use

A final question on the survey inquired about the reasons for non-urgent utilization of the emergency department. It was designed to probe into the underlying reasons for non-urgent patients going to the emergency room instead of visiting their private physician or seeking treatment at a primary care center. One caveat to these findings, however, was that there was a very low response rate to this optional question (15%).

The findings illustrate that, based on the

TABLE 2

VISIT TYPE BY COUNTY

COUNTY	*EMERGENT*	*URGENT*	*NON-URGENT*
DADE	17.5	34.7	27.3
MONROE	13.2	33.6	48.1
DISTRICT XI	17.3	34.6	28.6

perceptions of hospital staff who completed the questionnaire, many people utilize the emergency department out of convenience or expediency. Another common reason is proximity/location followed by being sent by a physician/school/employer. The latter may be, at least in part, reflective of the lack of school based clinics and physician liability concerns leading to the practice of defensive medicine.

When crosstabulated with payor sources categories, the principle reason for non-urgent use was convenience. For Self/No Pay patients, the next largest number went to the emergency room because they had no money, followed by the lack of insurance and the need for immediate attention. Interestingly, the reason for non-urgent use among Medicaid patients was similar to that for the total.

Non-Emergent Diagnoses/Conditions

Several diagnoses may be considered emergent, urgent or non-urgent, based on severity. However, clear distinctions emerge on selected conditions. Diagnoses most likely to be non-emergent in nature include: surface wounds/wound checks, strains/sprains/pain; otitis media; upper respiratory infection/cold; nausea, et al; and viral infections.

Visit Type by Age, Gender, Race/Ethnicity

The seriousness of the patient's condition was cross-tabulated with the patient's age, sex and race.

Persons 15-30 years of age represented the largest share of non-urgent users. Persons ages 46-60 years (32.5%) and children under age 15 (30.4%) on the other hand, represented the groups most likely to present with non-urgent conditions.

Gender breakdown by type of visit indicates that while women are somewhat more likely to have a scheduled visit to the ER, males are somewhat more likely to present with emergent and non-urgent conditions.

A disproportionate share of Hispanics were identified as frequent users of the ER for non-urgent conditions, representing 39% of their total (See Table 3). Next were Blacks at 27.4% and Whites were at 23.9%. A large share of Hispanics also tend to be Medicaid, Self Pay or No Pay Patients (40.7%) as do Blacks (61.7%).

Visit Type by Payor Source

There was a positive correlation between Medicaid patients and non-urgent conditions; about 35% of the Medicaid patients presented with non-urgent conditions in contrast to 29% for all payor classes within District. (See Table 4).

TABLE 3

VISIT TYPE BY RACE/ETHNICITY DISTRICT XI

VISIT TYPE	*WHITE*	*BLACK*	*HISPANIC*
EMERGENT	17.8	25.1	10.2
URGENT	31.2	33.4	42.9
NON-URGENT	23.9	27.4	38.6

TABLE 4

VISIT TYPE BY PAYOR SOURCE DISTRICT XI

	TOTAL	*MEDI-CAID*	*ALL PRIVATE*	*SELF/ NO PAY*	*WORKER'S COMP*
EMERGENT	17.3	18.0	7.8	20.4	8.5
URGENT	34.6	32.6	28.2	39.7	35.0
NON-URGENT	28.6	34.7	29.6	27.1	44.6

Visit Type by Hospital

Finally, a particularly compelling set of information is the data compiled by individual institutions. (See Table 5). A striking 60% of the patients who present in the ER at Fisherman's Hospital in the Middle Keys had non-urgent conditions. This was the highest percentage for any of the fourteen hospitals studied. Florida Keys Memorial Hospital was also high at 53%. Conversely, Mariner's Hospital, the third Monroe County Hospital, was below the average for the District at 24% (the overall average for both counties was 29%).

In Dade, over 53% of the ER patients at AMI Kendall Regional Medical Center presented with non-urgent conditions as well, the highest for the county and located in rapidly growing West Dade.

Ambulatory Care Sensitive and Low Income Area

For comparative purposes, an analysis of hospitalization patterns by "ambulatory care sensitive" (ACS) conditions was performed for Dade County. ACS rates were constructed from conditions which were considered to be responsive to timely and effective outpatient care. These diagnoses included diabetes, asthma, cellulitis, among others. Thus, an area with a low ACS admission rate would be an indication that the outpatient delivery system was performing adequately and that needed ambulatory care was relatively accessible. Conversely, a high ACS rate could be an indication of serious access barriers or problems with the delivery of outpatient care. When plotted with low income areas, well over half of the ambulatory care sensitive areas are co-located in low income areas.

Conclusions/Discussion

Is Primary Care Accessible to the Medically Needy?

The ER study data, coupled with comparative zip code analysis areas and the locations of primary care service centers suggest that the primary care centers are located in many of the appropriate areas, particularly in Dade County. However, based on interviews with hospital ED staff and an informal telephone survey of the primary care centers - access is severely limited due to overwhelmed programs. Many ER personnel do not even attempt to refer patients out; waiting periods can be as long as several weeks to several months.

In Monroe County access to primary care services is even more pronounced than in Dade. While some patients must wait several months for an appointment in one of Dade's 9 centers; in Monroe there is only one primary care center (located in Key West) serving the entire county. As previously mentioned, over half of the emergency room patients at two of the hospitals are presenting with non-urgent conditions. The lack of primary care in the Middle Keys a critical hardship since the Key West program is limited and the next closest program is in Homestead, approximately a two hour drive.

In terms of why patients present in the ER for non-urgent conditions the rationale is simple -- it is easier to wait 2-3 hours in the ER than to wait several weeks or months for a primary care appointment. This is especially true for a mother with a young infant, or a person who may fear that he/she could develop a life-threatening condition should the diagnosis and treatment be delayed.

TABLE 5

VISIT TYPE BY SELECTED HOSPITALS

	TOTAL	*JACKSON/ ED*	*JACKSON/ UCC*	*AMI/ KENDALL HOSP.*	*JAMES A. SMITH HOSP.*	*FISHER-MAN'S HOSP.*	*FL KEYS MEM. HOSP.*	*MARINERS HOSP.*
EMERGENT	17.3	41.6	1.7	5.3	15.4	7.6	5.5	40.6
URGENT	34.6	28.9	54.6	28.8	69.6	27.3	34.5	35.2
NON-URGENT	28.6	19.9	37.0	53.4	5.8	60.0	53.1	24.2

In summary, ER care is being inappropriately utilized by a large share of patients and the situation is most pronounced in the Western portions of Dade County and the Middle and Lower portions of Monroe County. The problem is further compounded by the fact that ER is more costly and not always the best care and treatment for the patient. By the time a person learns how to negotiate the system, or if medical care is delayed, an acute condition can develop and even cost a person his/her life.

V. RECOMMENDATIONS

Specific recommendations include to:

- Enhance the funding of community based primary care services through implementation of the recommendations of the Task Force on Government Financed Health Care.

- Promote a public education campaign utilizing the media to demystify the roles of primary centers and hospital emergency rooms.

- Encourage on-site education of emergency department staff regarding the resources available in the community (when they are adequately funded).

- Support the location of a new primary care center in the Middle Keys and West Dade. New centers should be also located in close proximity to hospital emergency departments.

- Encourage the development of school based clinics with certified school nurses.

- Promote the development of health clinics within local churches and synagogues.

Resources must be enhanced, both for primary care personnel, administration and training to provide an effective and adequate level of care -- care which encourages patients to receive timely treatment in the most appropriate and least costly setting available.

SEQUELAE OF TRAVELING SUBSTANTIAL DISTANCES FOR PRENATAL CARE AND BIRTHING: THE USE OF BIRTH AND LINKED BIRTH/INFANT DEATH RECORDS TO ASSESS RACIAL DIFFERENTIALS IN HEALTH CARE[1]

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William H. McBroom Sam H. Sperry

Introduction:

Montana is the fourth largest state with an area of approximately 145,000 square miles and an estimated 1986 population of 819,000. The population concentrations vary widely within this area ranging from more than 120,000 in the most populous county to well under 1,000 in the least populous. Four of the State's 56 counties are individually larger than such states as Rhode Island, Connecticut, and Delaware. As might be expected, the population density in the State is low -- for Montana overall there are less than 6 persons per square mile and six counties have population densities under one person per square mile. With such a widely dispersed population, there are difficulties in access to medical services for all citizens. For example, nine of the 56 counties have no hospital at all and another eight have hospitals lacking specifically designated obstetrical facilities.[2] Inevitably, some women must travel from their home counties to have access to medical care while giving birth.

Montana has only one sizable minority population. There were estimated to be 38,820 Native American Indian residents in 1986, 4.74% of the total population. The Indians, too, are dispersed throughout the State, but are concentrated in areas near the seven reservations.

The purpose of this paper is to describe the distributions of population and of obstetrical services in the State of Montana and to identify the consequences of relative isolation for prenatal medical care and birth outcomes.

Data:

The analysis that follows uses two data sets. The records for all births in the State for all White and Indian residents for the years 1980-1985 constitute one set of data. The Registrar of the State of Montana systematically links the death record of each infant with that same infant's birth record. This results in a linked birth/infant death file that allows not only examining the birth circumstances of those infants who die within the first year of life, but also calculating infant mortality rates for any sub-population of births. The linked birth/infant death file was also limited to the same six year cohort of births and to Indians and Whites who were resident at the time of their children's birth.

The analysis that follows is limited to the 80,506 births to Indian (8,008) and White (72,498) State residents for the years 1980 through 1985. Some tables that follow show less than this figure due to missing values on some variables. These births represent 95% of all births in Montana during the period.

Analysis:

The main focus of the analysis consists of linear regression to predict which women leave their counties of residence to give birth, when prenatal care started, the number of prenatal visits, adverse outcomes of birthing such as complication for labor and delivery, operations for delivery, and low birth weight. Since all births in the population are included, tests of statistical significance are not used. The distributions of the variables do not deviate from the assumptions for regression analysis sufficiently to require other forms of analysis. Operationalizations are shown in the Appendix.

Findings:

The population, the health care resources, the minority ethnic population and the birth occurrences in the State are distributed unevenly. Table 1 shows the State's 56 counties divided into quartiles by population. Nearly three fourths of the population lives in the most populous 14 counties. About the same proportion of the Indian population lives in the second most populous quartile. The effect of Indians living in the less populous counties is seen in the third row. Only 8% of the non-federal physicians practice in the counties

where 70% of the Indians live. This, however, understates the medical and obstetrical services available to Indians in these counties, because all of the State's Indian reservations (three of which have IHS birthing facilities) have IHS supplied medical facilities. Those inhabitants living in the most populous counties seldom travel to give birth, while residents of the less populous counties often deliver out of their counties of residence.

Table 1. Selected State Characteristics for County Quartiles (Population)

Selected Character-istics	County Quartiles (least to most populous) 1 (Least)	2	3	4 (Most)	Total (cases)
% State pop.	3%	8	17	71	819,000
% Indian pop.	3%	10	70	17	38,821
% non-fed M.D.s	1%	3	8	87	1,111
% births to non-mig.	1%	5	13	80	66,260
% births to migrating residents--all:	11%	23	44	22	14,246
(Indians)	(1%)	(1)	(74)	(14)	2,411
(Whites)	(12%)	(25)	(38)	(24)	11,835

Figure 1 shows the distribution of the State's health care facilities for the four groups of 14 counties. Eight counties have no hospitals at all. Clearly, the less populous counties have few obstetrical beds.

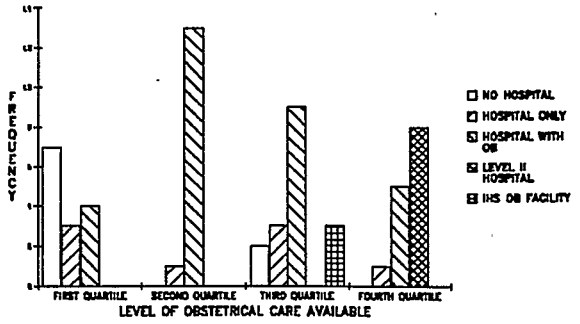

Figure 1 - Distribution of Obstetrical Services in Montana Counties by Population

The destinations of those who cross county lines to give birth vary substantially by ethnicity. Whites (80.4%) who travel for birthing go to counties with more sophisticated facilities than are available in their home counties. In contrast, only 58.4 % of the Indians achieve a similar gain in quality of facilities by migrating.

Table 2 shows the results of linear regression analyses which predict travel across county lines to give birth using background measures, measures related directly the individual pregnancy, the level of health care available in the county of residence and the change in the level of hospital care that was achieved by leaving the county of residence. The explained variance for Whites is R^2 = 0.63 while that for Indians is R^2 = 0.38. For both Whites and Indians, the two dominant factors predicting travel for birthing reflect the level of medical care in the mother's county of residence.

Table 2. Predicting Migration for Birthing for Indians and Whites; Montana, 1980-1985

Predictor Variables	Whites β	Indians β
Background Factors		
Age	.003	.001
Education	-.002	.034
Marital status	-.014	.001
Natality Factors		
Previous terminations'	.004	-.005
Living CEB	-.005	-.009
Month care started	-.003	-.042
Number prenatal visits	-.028	-.068
Length of pregnancy	-.001	.020
Health Care Factors		
O.B. svc. in county	-.150	-.100
Net change level O.B. svc.	.700	.576
R^2	.630	.384
N	72,477	8,007

'Terminations under 20 months gestation.

Table 3 introduces the distinction of travelling to give birth for both White and Indians. The prediction of both the timing of the initiation of prenatal care and the number of prenatal visits are shown in Table 3. Indians begin prenatal care about one month later, on average, than do Whites and receive about two fewer prenatal visits. Prediction of the number of prenatal visits is about twice as good for Indians than for Whites (R^2 = 0.17 and 0.16 vs. R^2 = 0.09 and 0.09). Much of that increment in predictive power is accounted for by marital status and number of living CEB.

Table 3. Predicting Prenatal Care for Indians and Whites by Migration Status; Montana, 1980-1985

Criterion and Predictor Variables	Whites		Indians	
	Nonmigr. β	Migrate β	Nonmigr. β	Migrate β
MONTH CARE BEGAN (mean):	2.7	2.8	3.8	3.6
Background Factors				
Age	-.086	-.069	-.020	-.071
Education	-.095	-.115	-.066	-.055
Marital status	.212	.229	.244	.229
Natality Factors				
Previous termins.*	-.017	-.015	-.041	-.059
Living CEB	.142	.139	.176	.168
Length of pregnancy	-.054	-.036	-.105	-.069
Health Care Factors				
O.B. svc. in county	-.042	-.009	-.020	.049
Net level change O.B. svc.	---	-.016	---	-.031
R^2	.097	.100	.112	.095
N	60,644	11,833	5,596	2,411
NUMBER OF PRENATAL VISITS (mean)	10.8	10.2	8.2	8.2
Background Factors				
Age	.058	.015	.084	.088
Education	.071	.114	.100	.094
Marital status	-.137	-.138	-.266	-.211
Natality Factors				
Previous termins.*	.055	.043	.042	.045
Living CEB	-.137	-.120	-.214	-.218
Length of pregnancy	.160	.186	.169	.181
Health Care Factors				
O.B. svc. in county	.081	.059	.067	-.049
Net level change O.B. service	---	.070	---	.112
R^2	.086	.094	.173	.156
N	60,644	11,833	5,596	2,411

*Terminations under 20 months gestation.

Table 4 shows that complications of labor and delivery are far higher for those Indians who migrate than for those who do not. The standardized regression coefficients show that this difference is accounted for almost entirely by the increment in service that Indian who travel for birth gain by leaving their counties of residence. The State IHS, reports[3] that it is their policy to refer all questionable cases to the next higher level facility. Perhaps the large coefficient associated with the increment in service reflects this policy. Finally, Table 4 shows that those who migrate have babies of lower birthweight than do those who do not migrate. This difference is greater for Indians than for Whites. Length of pregnancy accounts substantially for this difference. The close monitoring of Indians' pregnancies on reservations is consistent with this finding.

Table 4. Predicting Pregnancy Outcomes for Indians and Whites by Migration Status; Montana, 1980-1985

Criterion and Predictor Variables	Whites		Indians	
	Nonmigr. β	Migrate β	Nonmigr. β	Migrate β
COMPLICATIONS OF LABOR AND DELIVERY (proportion):	.27	.32	.23	.40
Background Factors				
Age	.070	.068	.067	.051
Education	-.022	-.002	-.030	-.029
Marital status	.006	-.008	-.014	.019
Natality Factors				
Previous termins.*	.020	.016	.008	.019
Living CEB	-.078	-.068	-.054	.022
Length of pregnancy	-.083	-.124	-.072	-.091
Health Care Factors				
O.B. svc. in county	-.072	.083	.087	.198
Net level change O.B. svc.	---	.124	---	.343
R^2	.019	.036	.018	.113
N	60,644	11,833	5,596	2,411
BIRTH WEIGHT (GRAMS) mean:	3,373	3,341	3,431	3,378
Background Factors				
Age	-.015	-.020	-.048	.002
Education	.089	.079	.072	.077
Marital status	-.041	-.026	-.027	.033
Natality Factors				
Previous termins.*	.165	-.035	-.023	-.042
Living CEB	.109	.098	.087	.030
Length of pregnancy	.178	.250	.116	.306
Health Care Factors				
O.B. svc. in county	-.049	-.046	-.118	-.034
Net level change O.B. service	---	-.073	---	-.116
R^2	.084	.131	.063	.171
N	60,644	11,833	5,596	2,411

*Terminations under 20 months gestation.

Infant mortality is the ultimate adverse outcome that might accompany migration. The effects of migration for birthing on infant mortality differ by ethnicity. Whites who migrate for birthing experience higher infant mortality rates than do those who do not migrate (10.1 vs. 8.5). Table 5 shows that this general finding does not hold for Indians. Strikingly, the highest infant mortality rate for Indians (15.8) is for those who reside in the eight counties having Level II OB services (the highest level of service offered in the State) and who give birth there. It may be that cultural and social supports that are available in the reservation setting more than compensate for deficiencies in medical care that may exist.

Table 5. Infant Mortality Rates (per thousand) for Indians and Whites by Level of Facilities and Migration to give Birth; Montana, 1980-1985

Level of Services in County of Residence 1986	Whites		Indians	
	Nonmigr.	Migrate	Nonmigr.	Migrate
No Hospital				
Nonviable	[ ]	2.1	[ ]	[ ]
Neonatal	[ ]	3.6	[ ]	[ ]
Post-neonatal	[ ]	3.1	[ ]	[ ]
Total	[ ]	8.9	[ ]	[ ]
Number	(35)	(1,925)	(0)	(21)
Hospital w/o OB Care				
Nonviable	2.6	2.5	[0.0]	[19.6]
Neonatal	4.3	3.7	[12.2]	[0.0]
Post-neonatal	3.6	5.6	[12.2]	[4.9]
Total	10.6	11.7	[24.4]	[24.5]
Number	(3,051)	(1,620)	(82)	(204)
Hospital w/OB Care				
Nonviable	2.8	4.7	1.8	2.4
Neonatal	2.0	2.5	2.3	4.3
Post-neonatal	3.6	2.5	8.8	6.1
Total	8.4	9.7	12.8	12.8
Number	(14,403)	(7,597)	(3,981)	(2,105)
Level II Hospital				
Nonviable	2.5	3.8	5.1	[0.0]
Neonatal	2.3	5.0	2.5	[0.0]
Post-neonatal	3.6	5.0	8.2	[0.0]
Total	8.4	13.8	15.8	[0.0]
Number	(43,540)	(795)	(1,577)	(108)
GRAND TOTAL	8.5	10.1	13.7	13.1

NOTE: Rates shown in brackets are based on 250 or fewer births; no rates are shown for 50 or fewer cases.

Conclusions:

These findings have a clear implication: there is a cost associated with living in an area of a large state where there is low population density and few or no medical facilities. Women who leave their counties of residence to give birth incur higher rates of adverse outcomes both for themselves and for their babies. Data limitations do not allow us to address questions of substantial importance to this query. For example, neither the birth record nor the death record indicate whether the migration for birth was recommended for medical reasons.

1.The results reported herein are based on data provided by the Montana Department of Health and Environmental Sciences, but do not constitute an official report of the State of Montana.

2.The comparisons we provide here and in subsequent sections refer to the period 1980 to 1985. The population, geographic and other descriptions of the State were drawn from the U.S. Bureau of the Census, *County and City Data Book*, Washington, D.C.; U.S. Government Printing Office, 1988.

3.Personal communication with Dean Effler, M.D., Director of Medical Services, Billings Area Office, I.H.S.

APPENDIX

Operationalizations:

Age: actual years
Education: actual years
Marital status:
1 = married
2 = single
Previous terminations:
actual number reported
Living CEB: actual number reported
Month prenatal care started:
actual number reported
Number prenatal visits:
actual number reported
Length of pregnancy:
number of weeks since last normal menses minus 2
O.B. Service in County:
1 = no hospital in county
2 = hospital with no O.B. service
3 = hospital with O.B. service
4 = hospital with Level II O.B. care
Net change in level O.B. service:
1 = lower
0 = stayed the same
1 = increased level of service
Birthweight in Grams:
actual weight reported
Complications of labor and delivery:
0 = none
1 = some

BARRIERS TO CARE FOR WOMEN & CHILDREN WITH HIV DISEASE

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National Perinatal Information Center (NPIC)

As of May 1991 nearly 15,000 cases of HIV had been reported to the CDC among women of childbearing age. For children, the figure stands at over 3,000. These numbers represent a nearly 500% increase in cases among women and a greater than 400% increase for children since 1987. AIDS has become the leading cause of death for women 25 - 34 and the 9th leading cause of death for children 1 - 4. In certain locales, eg. large northeastern central cities, the statistics are much worse.

Despite the persistent spread of HIV disease among women and children, only recently have researchers begun to focus on these populations. The discussion below summarizes findings from the second year of a three year study of pediatric and maternal HIV disease in seven sentinel cities across the country. This study is being conducted by the National Perinatal Information Center (NPIC) with funding from the Agency for Health Care Policy and Research (ACHPR). The National Perinatal Information Center is a private non-profit agency devoted to health services research in maternal and child health, perinatal care health policy analysis, and hospital information services.

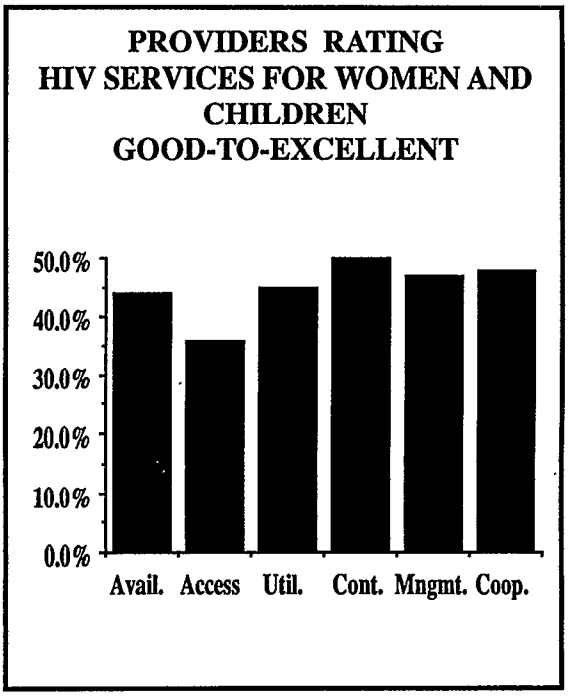
Study goals include: describing service delivery models for women and children with HIV, document their inpatient utilization and costs, & determining local responses to the crisis. The study involves both quantitative inpatient data analysis and qualitative case studies. The findings presented here are from case study interview data gathered from providers (physicians, nurses, social workers, administrators) representing 86 programs in Baltimore, Boston, the Bronx, Chicago, Los Angeles, Miami and Newark.

The programs are equally divided between hospital-based and community based agencies. Approximately half serve children only, about one third have both women and children among their clients, and just under 20% serve women only. Most programs are exclusively for HIV affected individuals but some are broader in scope.

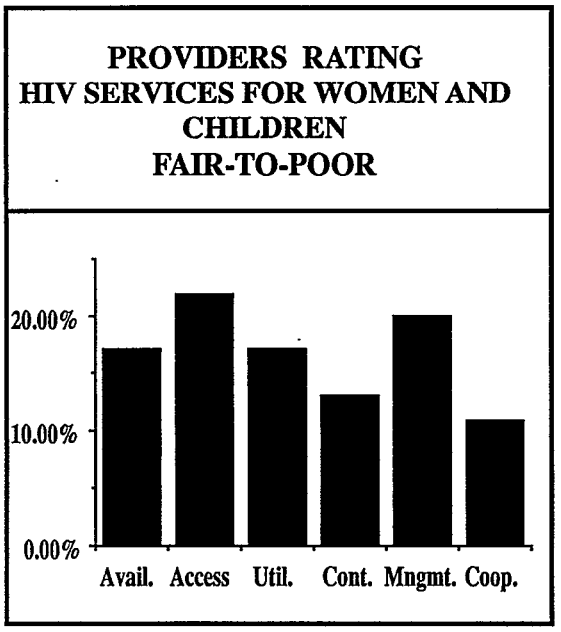
On-site interviews covered issues of availability/accessibility/utilization of services, continuity of care, case management, and interagency cooperation. Providers were asked to rate each of these aspects of HIV services on a scale of one (excellent) to five (poor). Mean ratings are displayed below.

AVERAGE PROVIDER RATINGS: HIV SERVICES FOR WOMEN & CHILDREN	
Availability	2.6
Access	2.8
Utilization	2.5
Continuity	2.5
Case Management	2.5
Agency Cooperation	2.5

Not surprisingly, differences in means for our fairly generic questions were not great. However, the area rated weakest by HIV providers was accessibility of services. This is reinforced when we look at the proportions rating local HV services for women and children as *"good-to-excellent"*. Access is least often named: 37% vs 44%-50% for other items.



In contrast, more providers rated accessibility of HIV services as *"fair-to-poor"* than any other aspect of care (22%). Interagency cooperation was perceived as least problematic (11%).



BARRIERS TO CARE FOR WOMEN & CHILDREN WITH HIV

A. Most Frequently Identified

- SYSTEMIC / ORGANIZATIONAL
  - Bureaucracy / Complexity
  - Waiting Times
  - No Child Care
  - Immigration / Custody Policies
- TRANSPORTATION

B. Often Identified

- CULTURAL BARRIERS
  - Language
  - General Insensitivity
  - Racial / Ethnic
- DRUG ABUSE / DYSFUNCTIONAL FAMILIES
- LACK OF KNOWLEDGE
  - Disease
  - Treatment
  - Services

C. Sometimes Identified

- PROGRAM LIMITS
  - Funding
  - Staffing
- POVERTY/MONEY
- PSYCHOLOGICAL
  - Denial / Guilt / Fear
- STIGMA
- LACK OF IDENTIFICATION
- CONFIDENTILAITY POLICIES

These barriers will be more fully discussed in future reports. Work is currently underway comparing differences in service limitations and identified problems for women vs children with HIV as well as cross-site comparisons of findings.

USING LONGITUDINAL DATA TO MEASURE ACCESS BARRIERS TO HEART TRANSPLANTATION

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Bernard Friedman

1) INTRODUCTION

Every year, as many as 75,000 people suffer from end-stage heart diseases.[1] These people have only one real hope for survival--a heart transplant. Unfortunately, transplantable hearts can be found for only about 1.8% of those with end-stage heart diseases.[2] Access to life-saving transplants is inevitably limited by the scarcity of donor organs. Thus, organ transplant providers must decide who should receive a transplant and who should not.

There are many ways to select candidates for life-saving transplant procedures. According to Annas,[3] organs could be allocated randomly, or they could go to:

- the most severely ill,
- patients with better chances for recovery,
- anyone on a first-come first-served basis,
- those who contribute the most to society,
- people with the most dependents, or
- patients who can guarantee payment.

This paper focuses primarily on whether ability to pay influences access to heart transplants.

Most of the evidence regarding the influence of ability to pay is anecdotal and comes from only a few transplant patients or providers. However, two studies are broader in scope. The first was undertaken by the General Accounting Office (GAO).[4] That study covered 18 heart transplant centers eligible to receive Medicare reimbursement and those that participated in the National Heart Transplant Study. Some evidence of financial barriers to access was reported. Fourteen of the 18 centers required large cash deposits from patients without insurance. Yet among the 547 patients rejected for transplantation, only 7% were rejected for financial reasons.

The second national study on this issue was by Ozminkowski, Friedman, and Taylor.[5] That study applied a multiple regression framework to discharge data from 15 heart transplant centers and over 500 other hospitals where patients with end-stage heart diseases were treated. A proxy measure of ability to pay was generated from information about the availability of insurance (i.e., expected primary payor) and the median income of the patients' ZIP code of residence. Results indicated that this proxy measure of ability to pay influenced access to heart transplantation in the late 1980s.[6] Additionally, evidence of queue-jumping on the basis of ability to pay for heart transplants was found. Discharges expected to have the highest medical risk and the most ability to pay were significantly more likely to receive a heart transplant than those expected to have lower medical risk and less ability to pay.

The present study offers a refinement of this earlier work by Ozminkowski, Friedman, and Taylor. We analyze discharges and patients at a subset of 77 hospitals where patients with multiple discharges could be followed over time. Previously multiple discharges could not be linked over time. Therefore, it was not known whether the same patient was represented both as a potential candidate with heart disease and as an actual transplant recipient. A large number of such patients could have resulted in an underestimate of the effects of ability to pay. Also, some patients may have been represented as candidates more than once with different states of illness. This could complicate the regression error structure and make it more difficult to determine whether ability to pay had a statistically significant influence on access to treatment.

The remainder of this paper is organized as follows. Section 2 provides a brief description of our hypotheses. Section 3 describes data sources and methods. Section 4 presents the results from logistic regression analyses of the effects of expected ability to pay on access to heart transplantation. Section 5 offers tentative conclusions, discussion, and suggestions for future research.

2) HYPOTHESES

Does queue-jumping on the basis of ability to pay for heart transplants really occur? Our conceptual model suggests that providers act in the best interests of society, subject to their own financial constraints and the limited availability of organs. This view is consistent with the one held by the Task Force on Organ Transplantation. The Task Force stated that donor organs are a scarce public good that should be "used for the good of the community," regardless of ability to pay.[2] Subsequent to the Task Force, Medicare payment regulations were implemented with a concentration on achieving high survival rates.

Accordingly, our major null hypotheses are as follows. Patients with the highest expected health benefit, or least medical risk from the procedure, will be more likely to receive new hearts.[7] Moreover, if potential health benefit is the primary determinant of access to care, we do not expect to see any queue-jumping on the basis of ability to pay. Riskier patients who are expected to have the most ability to pay should not be more likely to receive a transplant than those at lower medical risk.

Another hypothesis is that women will be less likely to receive heart transplants. There are two reasons for this hypothesis. First, Kjellstrand's discussion of access to kidney transplantation[8] notes that women may be at higher risk because they are more likely than men to have cytotoxic antibodies that pre-sensitize them to potential kidney donors. If this discussion is relevant for heart transplantation as well, one would expect fewer heart transplants among women. Second, Steingart, *et al.*[9] found that women with coronary artery disease were less likely than men to undergo some invasive cardiac procedures (not including transplantation), "despite greater cardiac disability in women."

Next, we expect non-whites to be less likely to obtain transplants. Kjellstrand also noted racial differences in blood and tissue types. The risk of organ rejection is higher when organs from similarly matched donors and recipients cannot be found, and most organ donors are white.

Additionally, we expect older patients to be less likely to receive new organs. This is due to age-related differences in post-operative complication rates.[8]

Finally, we expect patients who live farther from organ transplant centers to be less likely to obtain heart transplants. This is because organs must be stored until patients can travel to the transplant center. Longer storage time increases the risk of organ spoilage, thus reducing the likelihood of a successful clinical outcome.

3) DATA AND METHODS

Discharge abstract data from the Hospital Cost and Utilization Project (HCUP) were used to test these hypotheses. HCUP data include a census of nearly 30 million discharge abstracts from a sample of over 500 hospitals across the country, from 1980-87. More information about these data can be found in Coffey and Farley.[10] Since the widespread diffusion of organ transplantation is a phenomenon of the mid-to-late 1980s, we confined our analyses to 1986 and 1987.

Selecting Transplant Recipients and Candidates

As in Ozminkowski, Friedman, and Taylor,[5] two groups of discharges from this period were selected from the HCUP data. The first group included discharges from all 518 HCUP hospitals with ICD-9-CM procedure code 37.5, which indicated that a heart transplant was performed. There were 272 heart transplant discharges, representing about 9.6% of the total number of heart transplants performed in the United States during 1986-87.[11]

The second group of discharges included potential candidates for heart transplantation. Briefly, these included discharges with ICD-9-CM diagnosis codes indicating the presence of an end-stage heart disease without evidence that a transplant was received. Several discharges were eliminated from this group. These included discharges over age 70, those with absolute contraindications to transplantation and those transferred to other facilities. We also restricted the candidate group to discharges from the 77 HCUP hospitals where patients with end-stage heart diseases could be followed over time. There were 1086 discharges in our candidate group. The detailed criteria for selecting these discharges are provided elsewhere.[5]

Variable Definitions

Logistic regression analyses were used to estimate the effects of ability to pay on access to heart transplantation. The dependent variables for these analyses were coded as one if a transplant was performed, and as zero otherwise. As suggested in Section 2, independent variables included measures of expected ability to pay, medical risk, interactions between medical risk and expected ability to pay, age, sex, race, and distance between the patient's residence and the nearest heart transplant center.

Most of the independent variables are straightforward. However, two of the concepts we measured were considered to be multidimensional. These concepts are medical risk and expected ability to pay. As in Ozminkowski, Friedman, and Taylor, both concepts had three levels.

The three levels of medical risk depended upon severity of illness and the existence of relative contraindications to transplantation. Severity of illness was measured by Disease Staging.[12] Relative contraindications (i.e., medical problems that would complicate post-operative treatment), included but were not limited to mild diabetes, hypertension, or obesity. A more complete list of these medical problems is provided elsewhere.[5]

Discharges at lowest medical risk had principal diagnoses with Disease Stage levels less than 3.0, and had no relative contraindications to transplantation.[13] Discharges at highest medical risk had principal diagnoses with Disease Stage levels greater than or equal to 3.0, and at least one relative contraindication to the transplant. All remaining discharges were classified as medium medical risk. Those at medium medical risk were used as a comparison group in the logistic regression analyses.

The three categories of expected ability to pay depended upon the expected availability of insurance and a proxy measure of expected income. Information about insurance coverage was available on the discharge abstract, in the form of "expected primary payor." Discharge abstracts did not contain measures of income. We obtained estimates of median income by ZIP code from a private vendor. The median income of the ZIP code area of the patient's residence was used as a proxy measure of income.

Information on expected primary payor and median income were combined to form our measures of expected ability to pay. Discharges were assumed to have the most ability to pay if they lived in high-income areas (with median 1987 incomes greater than $26,000) and their expected primary payor was private insurance. Discharges were assumed to have the least ability to pay if they lived in low-income areas and were self-paying or received care free of charge. All remaining discharges were assumed to have medium ability to pay. Those with medium ability to pay served as the comparison group in the logistic regression analyses.

For patient-level analyses, medical risk and ability to pay were defined in exactly the same way for each discharge. Then, for patients with multiple discharges, one discharge was randomly selected to provide the patient's characteristics.

Hypothesis Testing

Three logistic regression equations were estimated to see how sensitive results may be to the characteristics of the sample. All three equations included the same 272 discharges for those who received a transplant. However, the equations differed in the samples of candidate discharges that were included. Chi-square tests of independence were therefore used to compare the

characteristics of the samples used in the three equations.

The first equation was estimated at the discharge level, using all 1358 discharges in the heart disease sample. Chi-square tests of independence were used to compare the characteristics of these discharges to those from the 518 hospitals used in our earlier work.

The 1358 discharges used in the first equation included 47 pre-transplant discharges from candidates who eventually received a transplant. For our second logistic regression equation, we excluded these 47 discharges, leaving 1311 in the analysis. This restricted the analysis to discharges from candidates who never received a transplant, along with the single transplant discharge for each heart recipient.

The 1311 discharges used in our second equation represented 1163 separate patients. For our third equation--estimated at the patient level--we used only one discharge for each patient. For the 114 candidates discharged more than once, the characteristics associated with one randomly selected discharge were used for this equation.[14] Thus, the third equation avoids cross-sectional correlation among the regression errors that would make it difficult to determine levels of statistical significance.

For each equation the effects of ability to pay on the odds of receiving a transplant were tested in three ways:

First, we applied a Chi-square test of the overall contribution of the four ability to pay variables.[15] This test indicated whether these variables, as a group, added significantly to the explanatory power of the logistic equations. If so, one would conclude that ability to pay influenced access to heart transplants.

Second, we tested for the effects of the individual ability to pay variables. This was done by using the logistic regression coefficients to estimate the relative odds of receiving a heart transplant. The odds of receiving a transplant for those with the most or least expected ability to pay were divided by the odds for those with medium expected ability to pay. We concluded that individual ability to pay variables influenced access to treatment when 95% confidence intervals for these odds ratios did not include 1.0.

Third, the logistic regression results were used to test for queue-jumping on the basis of ability to pay. This was done by considering the interactions between medical risk and ability to pay. For example, suppose the indicator for highest medical risk and most ability to pay had a positive sign, and a Chi-square test indicated that its effect was significant at the 5% level. This would mean access to transplantation was more likely for those expected to have the most ability to pay, even though they were also expected to be high risk patients. A negative or non-significant coefficient would show no evidence of queue jumping on the basis of ability to pay.

The effects of other potential determinants of access to transplantation were also estimated from odds ratios based on the logistic regression coefficients. Ninety-five percent confidence intervals for these odds ratios were estimated to see if discharges or patients in three age categories, females, and non-whites were systematically more or less likely to receive a transplant than those aged 40-59, men, and whites, respectively.

4) RESULTS

No significant differences were found in the characteristics of the samples used in the three discharge- and patient-level analyses reported here. However, some differences were found between the discharges analyzed here and discharges from the 518 hospitals represented in our earlier study. A significantly larger proportion of discharges from the 77 hospitals used here were expected to have the most ability to pay (37% vs. 28%). Discharges from the 77 hospitals were also more likely to be at medium medical risk (60% vs. 55%). These discharges were significantly less likely to be elderly (65% vs 70%), female (30% vs. 35%), or non-white (17% vs. 23%). The potential effects of these differences on the regression results are discussed in Section 5.

The results from the logistic regression analyses indicated a significant influence of ability to pay on access to heart transplantation. The ability to pay variables added explanatory power to all three regression equations ($\chi^2 > 13.3$, $p < 0.01$).

Table 1 shows the relative odds of receiving a heart transplant for discharges and patients at various levels of expected ability to pay, medical risk, age, sex, race, and distance from a heart transplant center. The odds ratios in Table 1 were calculated from the logistic regression coefficients and should be interpreted relative to the appropriate comparison group. For example, consider the odds ratio in the first row and column of numbers in the table. This odds ratio, 0.24, suggests discharges with the least expected ability to pay were about one-fourth as likely to receive a heart transplant as discharges with medium expected ability to pay. However, this variable was not significant at the 5% level; its 95% confidence interval included 1.0.

Considering the analysis of all discharges for heart recipients and candidates (Table 1, column 1), we see two important differences from the results reported in our earlier study. First, in the current study of discharges from 77 hospitals, those expected to have the most ability to pay were not significantly more likely to get a heart transplant than those with less ability to pay. In our earlier work with discharges from 518 hospitals, a significant effect was found.

Second, we could not verify earlier evidence of queue-jumping on the basis of ability to pay. In this study, those expected to have the highest risk and the most ability to pay were estimated to be 3.15 times as likely to get a heart transplant as those expected to have medium risk and medium ability to pay, but this result was not statistically significant at the 5% level. Though not significant, this odds ratio was similar to that reported in our earlier work (3.29). That finding was based on a larger sample of discharges and was significant at the 5% level.[5]

The remaining entries in the first column of Table 1 show the odds of receiving a heart transplant for all discharges at various levels of medical risk, age, sex, race, and distance to a transplant center. As in our earlier work, the

Table 1. Relative Odds of Receiving a Heart Transplant for Discharge and Patient Level Analyses

Variable	(1) Discharges for Heart Transplant Recipients And All Candidates	(2) Discharges For Heart Transplant Recipients And Candidates Who Never Received a Transplant†	(3) Heart Transplant Recipients and One Randomly Selected Discharge Per Candidate
Least ability to pay	0.24	0.21*	0.20*
Most ability to pay	1.32	1.35	1.35
Lowest risk and most ability to pay	0.64	0.66	0.62
Highest risk and most ability to pay	3.15	3.67	3.40
Highest risk	0.24**	0.23**	0.24*
Lowest risk	0.21**	0.19**	0.20**
Age ≤ 19	2.81**	3.65**	3.45**
Age 20-39	1.53	1.65	1.67
Age 60-69	0.13**	0.12**	0.14**
Female	0.53**	0.47**	0.47**
Non-white race	0.32**	0.21**	0.33**
Distance	1.10	1.09	1.08
Heart Recipients	272	272	272
Candidates	1086	1039	891
Total Observations	1358	1311	1163
-2 Log likelihood	1009.3	957.7	923.6
Model p-value	< 0.01	< 0.01	< 0.01

Omitted categories: medium ability to pay, medium risk, age 40-59, male, white race
† 47 discharges for candidates who eventually received a transplant are omitted from this equation.
* $0.01 \leq p \leq 0.05$ ** $p < 0.01$

results indicated significantly lower odds of receiving a transplant for discharges at highest and lowest medical risk, compared to those at medium risk. In addition, significantly higher odds were found for younger discharges, men, and whites. Distance to a transplant center was not significant and its effect was small.

Table 1 also shows the results of logistic regression analyses that adjusted for the presence of candidates who eventually received a transplant (column 2) and for multiple discharges among some of the transplant candidates (column 3). For all but one variable, the odds ratios were similar in magnitude and statistical significance, compared to those generated for all discharges (column 1). As in our earlier work, having the least expected ability to pay did not affect access to care when all discharges were used in the analysis (column 1). However, this variable did have a significant influence in the other two analyses.

5) DISCUSSION

We used discharge abstract data and income information from a private vendor to estimate relationships between expected ability to pay and access to heart transplants in the late 1980s. Logistic regression analyses suggested that, controlling for some differences in medical risk, age, sex, race, and distance to a transplant center, ability to pay influenced access to transplant care. However, in contrast to the finding in Ozminkowski, Friedman, and Taylor, evidence of queue-jumping on the basis of ability to pay for heart transplants was not statistically significant.

To judge the robustness of the results and to adjust for potential methodological problems, we conducted analyses at the discharge level and at the patient level. For age, sex, and racial characteristics the results were similar to those reported in our earlier work.[5] For two of the ability to pay variables the results were similar in magnitude but not statistical significance.

The differences we noted between the analyses reported here and in our earlier paper could have occurred for two reasons. First, as described earlier, there were some differences in the characteristics of the analytical samples that may have influenced the results. Second, we replicated our earlier work by using data from a smaller set of hospitals where end-stage heart disease is treated. The smaller sample could have reduced the power to detect evidence of queue-jumping on the basis of ability to pay.

As illustrated here, longitudinal analyses are challenging because of the difficulties and costs of creating and maintaining a patient-specific database. For such databases to permit studies of access to relatively rare treatments such as organ transplantation, many hospitals must be included to yield a sufficient number of

recipients and potential candidates. Hospital discharge summaries are among the most standardized of health care records, yet it is very costly to pool discharge data from many hospitals to obtain a nationally representative sample of inpatient episodes.

Hospitals, other health care providers, and third-party payors have also been concerned about protecting patient confidentiality, even to the degree of denying access to patient identifiers in any computerized records. At this time, only 77 of the hospitals in the HCUP data base appear to have reported the information needed to construct person-specific identifiers. The mix of organ transplant candidates at these 77 facilities may not represent the entire pool of organ candidates as well as the discharges from the 518 hospitals used in our earlier analysis.

When longitudinal data are available from only a subset of hospitals in a nationally representative data base, one might wish to try adjustments to see if selection bias influences the statistical results. This would be desirable when patients are not randomly distributed between facilities reporting person-specific identifiers and the remaining hospitals. Differences in patient and physician characteristics may affect the probability of treatment in each type of facility. In our study, we did not attempt a selection bias adjustment, because of difficult identification problems. Information on patient or physician preferences that affect treatment location but not transplant status were not available. Thus, it is possible that selection effects may account, in part, for differences between the results reported here and in our earlier study.

Ideally, studies of access to transplantation would use longitudinal data based on each encounter with the medical care system, beginning with the first diagnosis of end-stage disease. All potential transplant candidates would be followed until their transplantation or death. Statistical techniques such as event-history analyses[16] could then be used which include information from multiple encounters with the medical care system.

Event-history analyses have two promising features. First, they may account directly for changes in the odds of receiving a transplant as time on transplant waiting lists continues. Federal regulations require those spending more time on a waiting list to be given priority when organs are allocated.[17] However, the longer the wait for an organ the more likely the illness will become so severe that transplantation is precluded. Thus, the relationship between the odds of receiving a transplant and time on a waiting list might resemble an inverted U. Event-history analyses can account for this by allowing for a time-dependent "hazard function" having this shape.

Second, some event-history estimation packages allow for changes over time in the values of the independent variables.[18] In our sample, more than 35% of the 114 heart candidates with more than one discharge had changes in health status from one admission to the next that influenced their values of medical risk. This did not affect the patient-level analyses conducted here; the odds ratios for the medical risk variables did not differ appreciably between the discharge- and patient-level analyses. However, it is unknown whether differences would have been observed in event-history analyses using all discharges from heart transplant recipients and candidates.

With increasing emphasis at the Federal level to create the data bases needed for intensive studies of access to care, the problems of creating longitudinal data bases may one day be overcome. Should this occur, researchers will take advantage of better data and powerful statistical techniques to arrive at more firm conclusions about the effects of ability to pay on access to life-saving medical care.

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6) We refer to this proxy measure as "expected ability to pay" in the remainder of the paper.

7) Less risky patients include the less seriously ill and those without contraindications to the transplant procedure. Contraindications are medical or psychiatric problems that reduce the likelihood of long term survival and sometimes preclude transplantation. These problems include but are not limited to malignant neoplasms, diabetes, and alcohol or drug addiction. The contraindications used to select discharges for this study are listed elsewhere.[5]

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10) Coffey R, Farley D. Hospital Studies Program Research Note 10: HCUP-2 Project Overview.

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11) HRSA. Report on the Scientific and Clinical Status of Organ Transplantation. Rockville, Maryland: U.S. Department of Health and Human Services, Public Health Service, 1989.

12) Gonnella JS, Hornbrook MC, Louis DZ. Staging of disease: a case-mix measurement. Journal of the American Medical Association 1984; 251: 637-645.

13) Generally, illnesses of Disease Stage 3.0 or above are characterized by serious involvement at multiple body sites. The prognosis for survival is poor for patients with these illnesses.[12]

14) The mean number of discharges for candidates discharged more than once is 2.30.

15) The four ability to pay variables include two indicators for the least and most expected ability to pay, and two interaction terms between these indicators and highest medical risk.

16) Event history analyses are sometimes referred to as survival, hazard, or failure-time analyses. The dependent variable for these analyses is based on the amount of time until an event of interest occurs. In our case, the event of interest is either the receipt of a transplant or death, whichever comes first.

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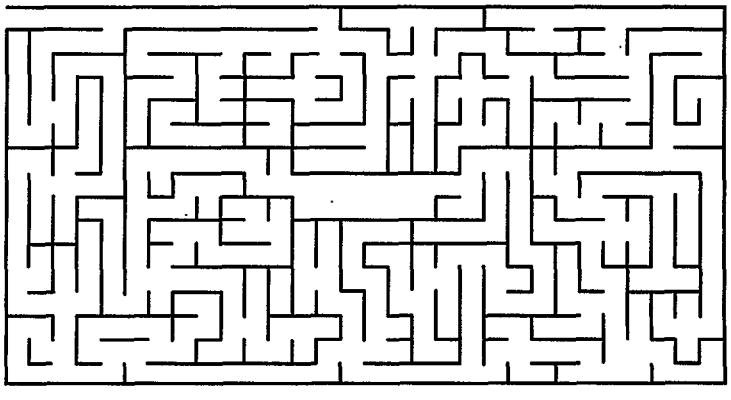
Session G

Economics of Health Care



TRENDS IN NATIONAL HEALTH EXPENDITURES

Suzanne W. Letsch
Health Care Financing Administration

The financing of health care in the United States is currently in crisis. Health costs continue to grow faster than the rest of the economy, while over 33 million people are without any type of health insurance. The two major financers of health care, business and government, have implemented many programs that attempt to control costs. However, none of these programs have met with any long-run success.

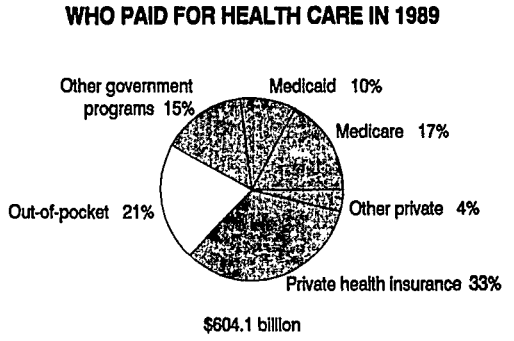
This paper provides an overview of the health care information available from the Office of National Health Statistics (ONHS) at Health Care Financing Administration. The National Health Accounts provide a framework for understanding the amount of money spent on health care in the United States (Lazenby and Letsch, 1990). ONHS has recently completed work assembling 11 years of data from the Current Population Survey (CPS). This data provides information on the insurance status of the U.S. population.

Over the past 30 years, growth in health spending has outpaced growth in the economy as a whole in all years but three. As a result, health care continues to consume a rising share of the Nation's output, as measured by the gross national product (GNP). In 1989, health spending accounted for 11.6 percent of GNP, more than double what it was in 1960 (Figure 1).

National health expenditures reached $604.1 billion in 1989, an increase of 11.1 percent from the previous year. This rate of increase marks the third consecutive year of accelerated growth.

Figure 2 shows who is paying for these rising costs. In 1989, third parties financed 79 percent of all health expenditures. Consumers paid the remaining 21 percent directly out of pocket. Out-of-pocket payments include amounts paid for co-payments, deductibles, and non-covered services.

Figure 2



In 1989, private health insurers financed one-third of all health expenditures, making this the most common type of third-party coverage. The government, through various programs, financed two-fifths of health spending. Medicare, which covers the elderly and is the largest single government program, financed 17 percent. Medicaid, which covers the poor, financed 10 percent making it the second largest program.

Before going into detail on each major source of financing, it is important to note the trends in sources of financing over the past 30 years. The most dramatic change occurred in late 1960s, when the

Figure 1

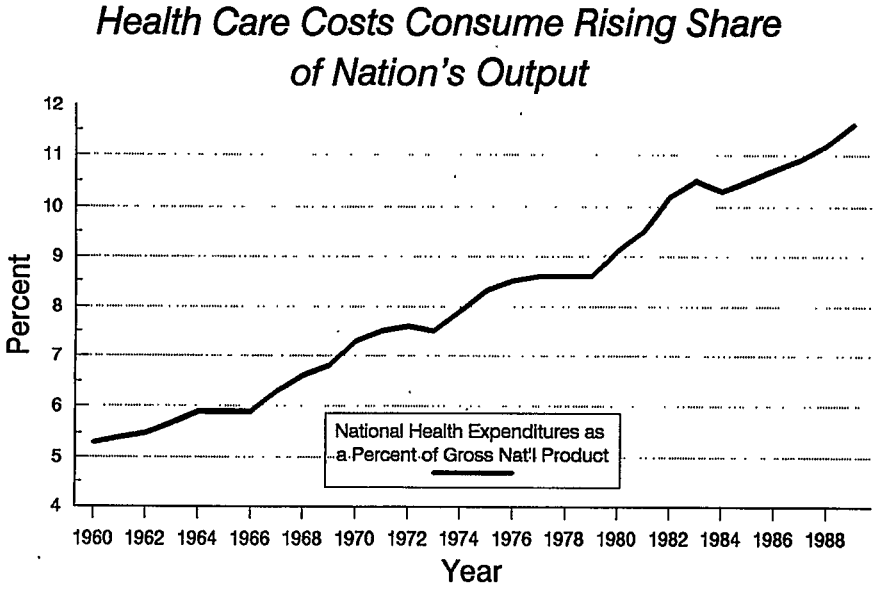
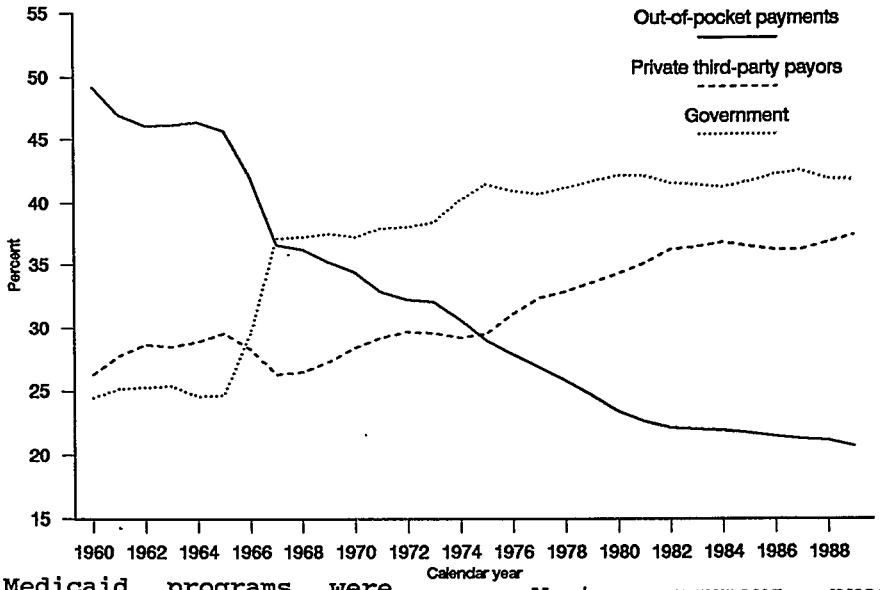


Figure 3

Distribution of national health expenditures, by source of financing: Calendar years 1960-89



Medicare and Medicaid programs were implemented. Government financing of all health expenditures increased from 25 percent to 37 percent during this period. This increase was primarily offset by a declining share paid by out-of-pocket sources (Figure 3). The share paid by private third-party payers, mainly private health insurance, also experienced a somewhat smaller decline during this time period.

Throughout the entire 30 year period, consumers demonstrated their desire to prepay for health care rather than incur the high cost of medical treatment when illness occurs. From 1960 to 1989, the share of health expenditures paid out of pocket by consumers declined from almost 50 percent in 1960 to 21 percent in 1989.

Most consumers prefer insurance coverage for the most costly types of health care. Hospital care and physician services have small shares financed out of pocket (5 percent and 19 percent respectively). However, out-of-pocket payments financed almost three-quarters of spending for drugs and vision products. In 1989, out-of-pocket spending for all health care expenditures amounted to $124.8 billion.

Over the past 30 years, out-of-pocket spending for health remained a fairly stable portion of consumers' disposable income. Since 1960, this share has been between 3 and 3.5 percent, which confirms American's desire to minimize the risk of large unexpected out-of-pocket health care costs (Figure 4).

Figure 4

National health expenditures and out-of-pocket expenditures as a percent of disposable income 1960-1989

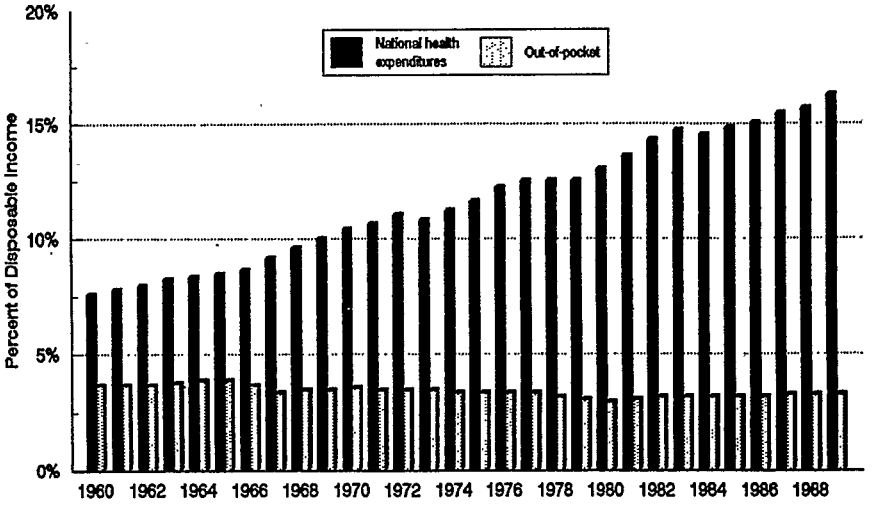
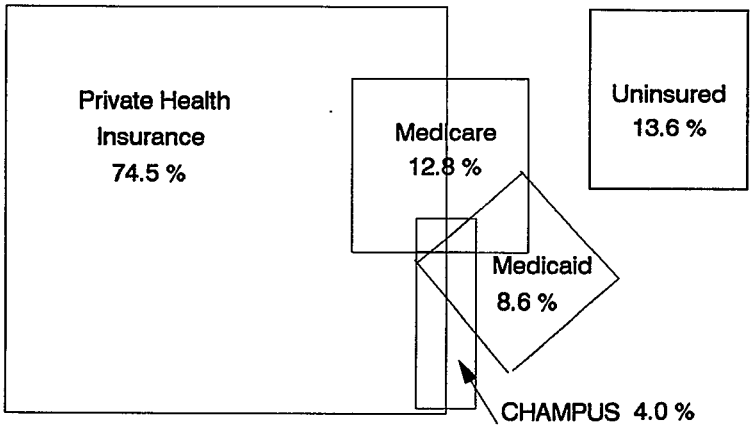


Figure 5

Insurance Status of Americans in 1990



Third parties provide the key to health care access. The insurance status of Americans is shown in Figure 5. Private health insurance is the most common source of coverage, covering three-fourths of the population. Private coverage is supplemented by Medicare for the elderly and disabled, Medicaid for the poor, and CHAMPUS for the military and their dependents. However, 13.6 percent of the population remains without any form the health insurance.

The percentage of the population that is uninsured varies by age group. Medicare covers most elderly. As a result only one percent of those 65 years of age and older are uninsured. Public coverage of the under 65 population is minimal. Instead, most people in this age group (71 percent) are covered by private health insurance, leaving 15 percent uninsured.

Insurance coverage varies by region. Figure 6 shows that there exists a great deal of variation among regions in the United States. Variations may exist for several reasons. One explanation may be that Medicaid eligibility rules differ a great deal from state to state. The types of prevalent industries may contribute to regional variation. Industries with high unionization and higher wage rates are most likely to offer employer-sponsored plans to their employees.

The most common source of third-party coverage is private health insurance, which financed one-third of all health care expenditures in 1989. Employer-sponsored plans account for 82 percent of all private insurance.

Government funds account for 4 out of every 10 dollars spent on health care, making it the largest single third party.

Figure 6

Percentage of Population Uninsured by Region: 1990

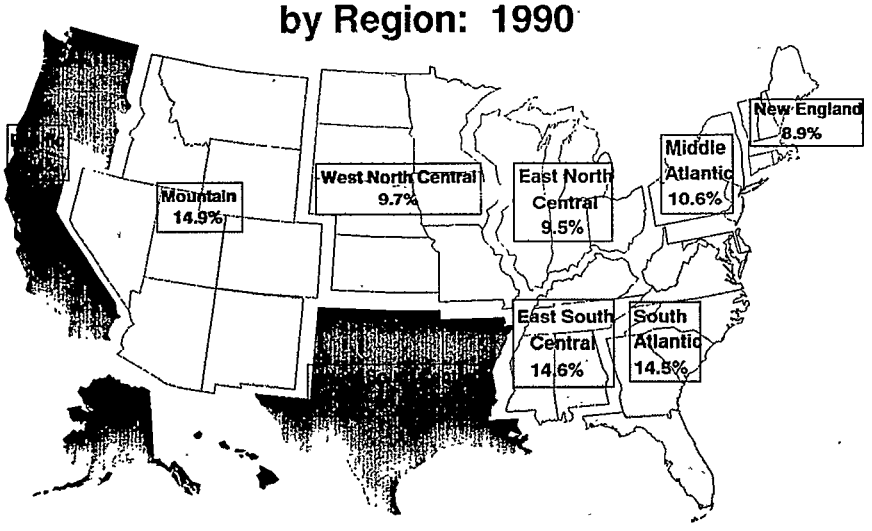
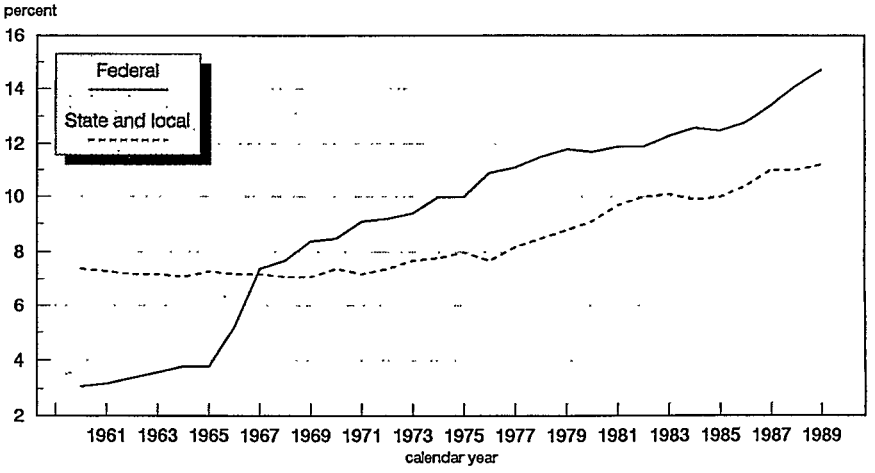


Figure 7

Government Health Expenditures as a proportion of Government Total Expenditures



With health costs growing faster than the rest of the economy, expenditures for health have grown as a proportion of total government expenditures (Figure 7). This increase puts an increasing strain on Federal and state-and-local governments.

Medicare, the largest public program, provided health care for 33.6 million elderly and disabled people in 1989. The Medicare program has two parts, each with a different financing structure. The hospital insurance program (Part A) is funded primarily by payroll taxes. The supplementary medical insurance program (Part B) is funded through premiums paid by the enrollee and general revenue (appropriations from general tax receipts). The general revenues which fund Part B have been causing a strain on the Federal government budget.

In 1989, Medicare program expenditures totalled $102.1 billion, an increase of 12.8 percent from the previous year. Medicare predominately funds acute care services--hospital care and physician services. Medicare financed 27 percent of all hospital care and 23 percent of all physician services.

Medicaid, the second largest public program, provided health care for certain types of poor people. Medicaid is funded by both Federal and State-and-local government funds. The Federal government sets minimum requirements for eligibility and services, allowing State governments considerable flexibility in designing the total scope of the program within the constraint of the State budgetary process.

Total Medicaid program expenditures amounted to $62.5 billion in 1989, an increase of 13.9 percent from 1988. Medicaid is the largest financer of nursing home care, financing 43 percent of all expenditures for this type of care.

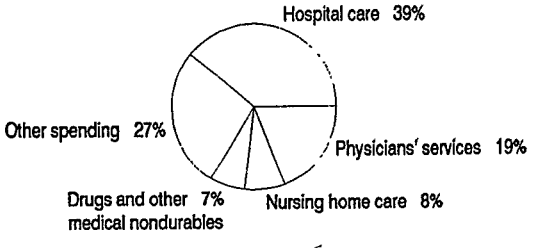
Besides Medicare and Medicaid, other government spending accounted for an additional 15 percent of total health expenditures. Included in this amount are programs for particular groups of people such as veterans, native Americans, pregnant women, and injured workers. Also included are expenditures for public health activity and publicly financed research and construction of medical facilities.

In addition to sources of health care financing, the National Health Accounts provide information on types of spending. The four largest types of spending are hospital care, physician services, nursing home care, and drugs and other medical nondurables. The share each of these components amounts to is shown in Figure 8.

In 1989, hospital revenues reached $233 billion, accounting for 39 percent of all health spending. This amount includes both inpatient and outpatient care.

Figure 8

WHAT EXPENDITURES FOR HEALTH CARE PURCHASED IN 1989



$604.1 billion
11.6 % of gross national product

During the late 1970s and early 1980s, hospitals experienced tremendous revenue growth. By about 1983, both private and public payers were struggling to pay these costs and had initiated plans to control costs. These plans met with some success, as costs remained low for several years. Yet this success was only short-term, as hospital costs began to accelerate once again beginning in 1987. Since 1987, accelerated growth continued, reaching 10.0 percent in 1989.

Expenditures for physician services reached $118 billion in 1989, accounting for 19 percent of health spending. On average, there were 5.4 physician contacts per person.

Spending for nursing home care accounted for 8 percent of all health spending in 1989. A total of $48 billion was spent on this type of care, an increase of 12.0 percent over the previous year. Facilities providing nursing home care operated an estimated 1.6 million beds and maintained a 90 percent occupancy.

Other types of health spending accounted for the remaining 27 percent. Included here is spending for dental care, other professional services, durable medical products, program administration, research, and construction of medical facilities.

Figure 9

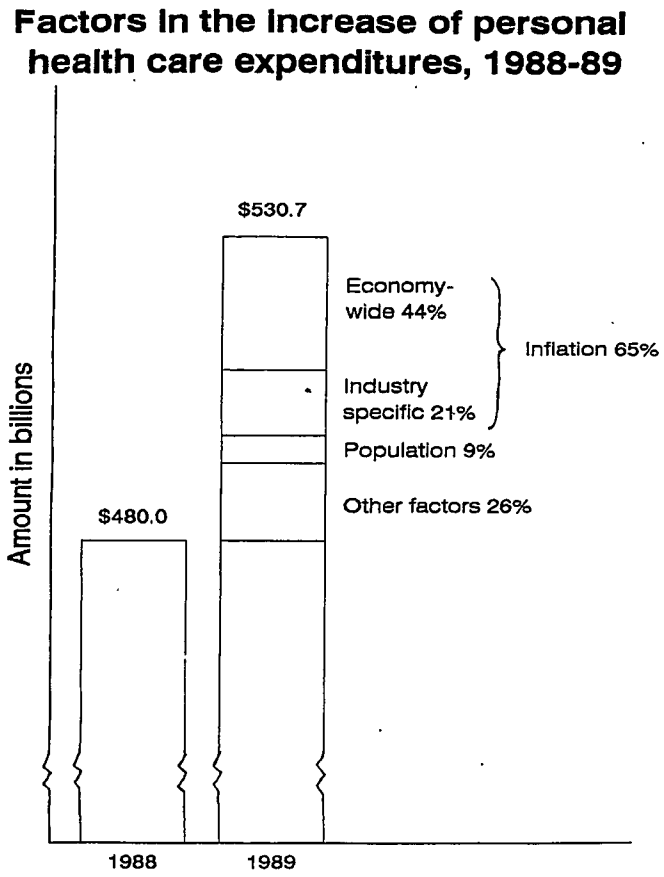
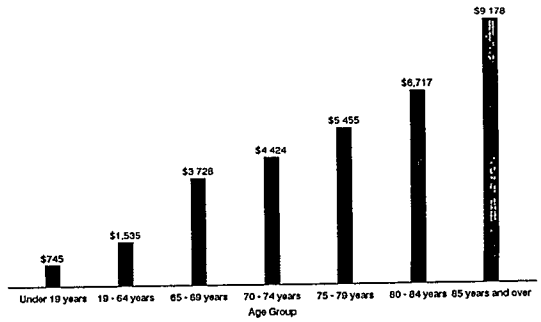


Figure 10



In order understand what causes medical care costs to grow at rates faster than the rest of the economy, it is helpful to separate some the factors which cause growth in health care expenditures. Using a simple accounting identity, it is possible to allocate growth in personal health care expenditures among the factors which cause growth.

Personal health care expenditures increased $50.7 billion from 1988 to 1989, a 10.0-percent growth rate. Inflation (increases in price) caused nearly two-thirds of this growth (Figure 9). Inflation can be further separated into economy-wide inflation (44 percent) and medical inflation that is in excess of economy-wide inflation (21 percent). Population growth caused 10 percent of the growth in health spending and the remaining 26 percent is caused by other factors. "Other factors" include any changes in use of health care services, new technology, the aging of the population, as well as any measurement error in the other factors.

While the aging of the population is not yet a big factor, it will be in about 20 years, when the over 65 age group is expected to grow dramatically. Figure 10 illustrates how health spending per capita increases by age group.

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The HCFA National Health Expenditure Projections Model
Projections to 2030

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Sally T. Sonnefeld
Daniel R. Waldo
David R. McKusick

Proposals for reforming the U.S. health care system come from two seemingly irreconcilable directions: demands for greater access for the those who lack health insurance or are underinsured, and demands for cost containment from those who pay the nation's health care bills. Plans designed to increase access would increase future health expenditures, while current payers are already struggling with today's costs.

The federal government projects that the Medicare Hospital Insurance trust fund will run out money shortly after 2000. Expenditures for Medicare Supplemental Insurance (Part B) and for the federal contribution to the Medicaid program, which are funded mostly out of general revenues, are increasing rapidly, straining the federal budget. State and Local governments are struggling to provide their contribution to Medicaid, and to finance care at public hospitals. Employers providing health insurance complain that increasing health benefit expenses are hurting corporate competitiveness. A new accounting standard will force private companies that provide retiree health benefits to increase their current reported liabilities, potentially causing a drop in corporate profits.

An understanding of future national health expenditures (NHE) is crucial to the debates about health care financing reform. The title of our paper "The HCFA National Health Expenditure Projections Model", and its sub-title, "Projections to 2030" go hand in hand: in order for 40 year projections to be meaningful, we must first know about the methods used to make them, and, most importantly, about the key assumptions used.

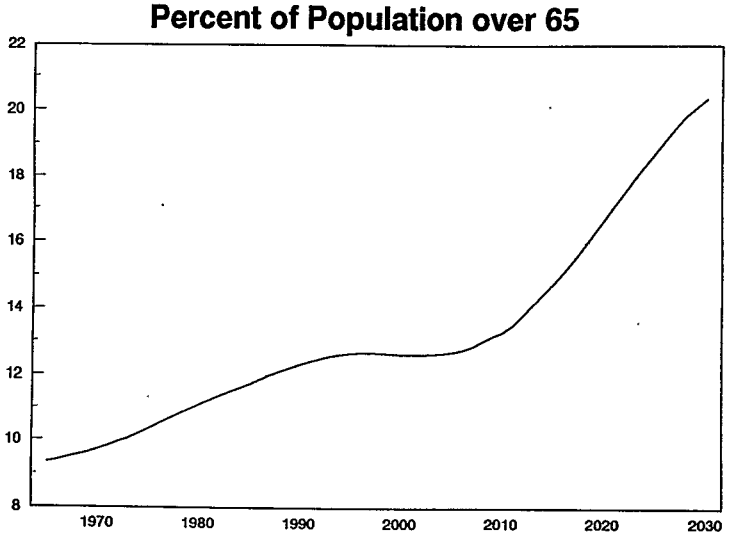
Of course, in the next 40 years the health economy will be affected by new treatments and procedures and by new financing mechanisms that we cannot anticipate now, so these projections are not meant to be predictions or forecasts. Rather, HCFA uses its projections to form baselines to help understand the possible impacts of future changes or reforms.

HCFA makes "current law" projections. We explicitly assume that the basic structure of the delivery and financing of health care service does not change much in the forecast period.

But our projections are not simple straight line extrapolations of current trends. In fact, since U.S. health spending has grown more rapidly than total economic output in almost all of the last 30 years, simple extrapolations of current trends would yield health spending approaching 100 percent of the gross national product (GNP) in the next 40 years, an absurd result.

We commonly use this ratio of national health expenditure to gross national product as a measure of the impact of health spending on the economy -- the percentage of our national resources that are consumed in health care services. The ratio can be a tricky one in analyzing individual years, since GNP may rise or fall from year to year with the business cycle.

Figure 1



Health spending, on the other hand, tends to be very stable -- the NHE to GNP ratio almost always rises rapidly in economic recessions, not necessarily because NHE growth has accelerated, but because GNP growth has fallen. But that is scant consolation to government officials and private employers who see health costs continuing to rise while business or tax revenues are not.

The HCFA Model

Our model is actuarial in nature. The model consists of a process of decomposition, analysis and reconciliation of trends. It takes into explicit account changes in the demographic (age and sex) distribution of the U.S. population, using factors that describe the effects of demographic change on the volume of health services per person, and on the "intensity" per unit of use.

We begin by analyzing trends in spending by major type of health service.

Types of Health Care Service

Hospital Care
  Community
    Inpatient
    Outpatient
  Non-Community
    Federal
    Other
Physician Services
Dental Services
Other Professional Services
Home Health Care
Drugs and Other Medical Non-Durable Goods
  Prescription
  Over the Counter
Nursing Home Care
Administrative Costs and Net Cost of Private Health Insurance
Public Health
Research
Construction

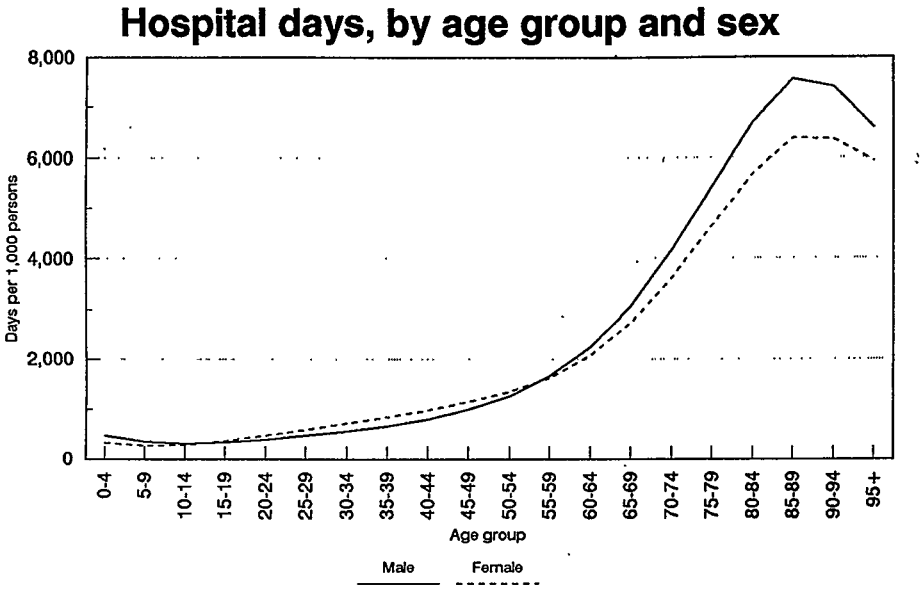
Spending in each type of service is decomposed into factors which account for its growth. This is called the Seven Factor Model.

Seven Factor Model

- Population
  Demographic Composition of Population (Age and Sex)
  - Use per Capita
  - Intensity of Service
- Use per Capita exclusive of Age/Sex
- Intensity exclusive of Age/Sex
- General Inflation (GNP Implicit Price Deflator)
- Medical Prices Relative to General Inflation

Population assumptions are consistent with the Medicare and Social Security Trust Fund reports (alternative II). The Social Security actuaries project that the U.S. population will grow slowly and age rapidly in the next 40

Figure 2



SOURCE: National Hospital Discharge Survey, 1981
Note: Hospital days exclude maternity and and newborn use.

years.

The proportion of population aged 65 and over has grown rapidly over the past 25 years from under 10 percent of the total population to over 12 percent. This aging of the population moderates in the next 25 years, reflecting low birth rates during the depression and World War II, but then explodes after 2015 as the post-war baby boomers begin to reach 65 (Figure 1).

The projected growth rate of the GNP implicit price deflator, our measure of economy-wide inflation, also comes directly from the Trustees' reports.

Demographic composition of the population effects both use of health services per capita and intensity of service (real cost per unit of use). Social Security population projections by sex and detailed age cohorts are applied to distributions of use and intensity by age and sex for most types of health service. (Figure 2 shows the use distribution used for inpatient hospital services, and Figure 3 shows the corresponding intensity distribution.)

We use data from various sources to measure change in medical prices for each type of health service. These sources include Consumer Price Indexes, regulatory price indexes, wage and salary escalation measures for government employees etc. The price indexes are then divided by the general inflation index to produce the factor for medical prices relative to general inflation.

Overall measures of use are derived from industry and government data sources. The demographic composition factor that applies to use (volume) per capita, is netted out, creating the factor for use per capita net of age and sex effects. Intensity net of demographic composition is a residual, and includes any measurement errors from the other six factors.

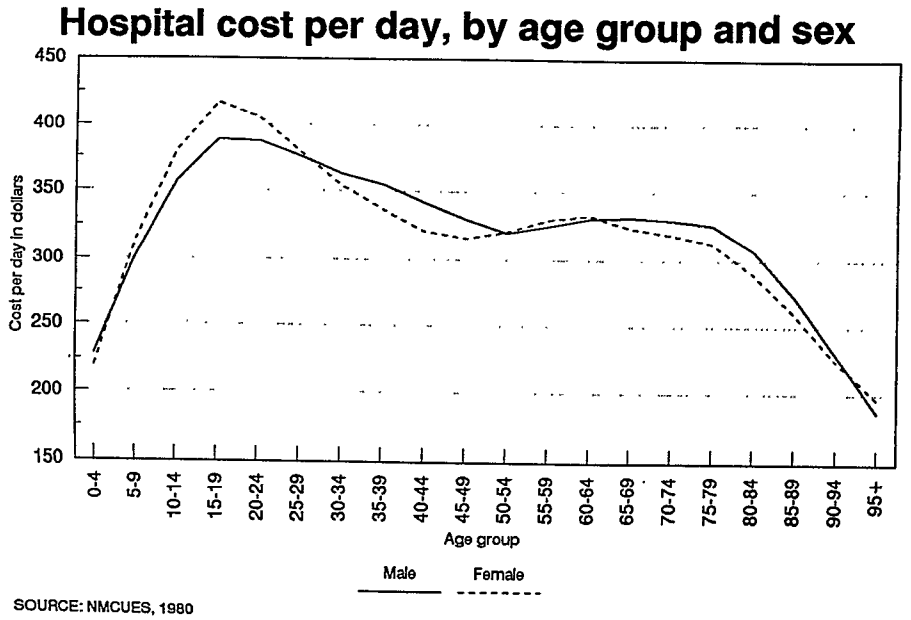
Projections of population and general inflation are exogenous; projections of demographic composition effects are calculated from use and intensity distributions and the exogenous composition of population projections; and projections of relative health prices and use and intensity net of demographic change are done internally by the modelers.

This combination of movement in the seven factors gives us a preliminary estimate of expenditure for each type of health service. Then we must reconcile these preliminary estimates with the trends in probable sources of funding for these services.

We balance our preliminary spending estimate against the official projections of Medicare benefits from HCFA, and against projections of Medicaid expenditures consistent with those prepared for the President's budget by HCFA. We also reconcile expenditure projections against trends in private health insurance, out of pocket spending and other government spending.

At current tax rates, Medicare expected to go bankrupt in about 2003. Clearly, in making these projections we assume that Medicare borrows or raises taxes to stay solvent. Similarly, we

Figure 3



SOURCE: NMCUES, 1980

assume that money to pay for private health insurance benefits and out of pocket costs comes out of future wages and incomes.

This reconciliation of probable demand for services versus sources of funds is then extended into reconciliations of expenditure for certain services which may be complements or substitutes for other services. Further, we check our results against estimates of the numbers of health practitioners, which are based on the ages and expected retirements of current practitioners and expected matriculation rates of future practitioners.

Special categories like research, public health and construction are projected differently: for example, construction forecasts are based on the number of beds needed to accommodate predicted use of hospital and nursing home services. Future bed requirements are combined with the current profile of facilities and their expected wear out dates to compute future construction spending flows.

Projection Scenarios

Figure 4 shows the last 25 years' history of the ratio between national health spending and the GNP, and three forecasts of that ratio to 2030.

The middle case represents our best judgement for the path of spending under the assumptions used. In this case health spending grows from about 12.2 percent of GNP in 1990 to over 13 percent in 1991 (mainly because the recession limits GNP growth), and continues to over 16 percent in 2000 and over 25 percent in 2030.

The high case uses the same general assumptions, but allows slightly higher long-term growth rates for some service types. In this case health spending reaches the uncomfortably high level of over 40 percent of GNP by 2030.

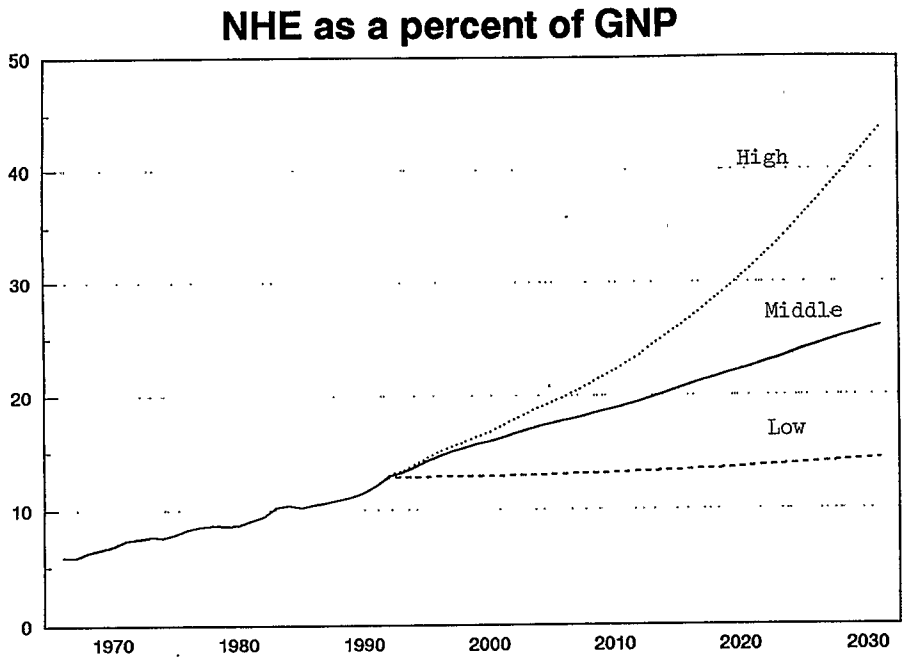
The low case represents an extreme scenario in which all health prices are immediately reduced to the general rate of inflation, and volume and intensity (except for the effects of demographic change) are not allowed to increase faster than real GNP per capita. Thus health expenditures grow no faster than the general economy except for the effects on use and intensity of the aging of the population. Health spending continues to grow in relation to GNP, but still does not exceed 15 percent of GNP in 2030.

Three notes about these scenarios:

1. The differences in the long-term growth rates used in the high and middle cases are not very large -- as health expenditure reaches an ever larger level, small increases in its growth rate cause large increases in spending.

2. Even in the high case, the long term growth rates are almost uniformly lower, relative to the economy, than in our experience of the last 10 years.

Figure 4



3. The low case demonstrates that the aging of the population, by itself, causes a relatively small increase in health spending relative to GNP.

Notice that we allow expected economic or demographic events, "external pressures," to impact health spending, but we do not allow the higher or lower health spending to go back and impact the economy. Further, we do not assume that increasing health spending has a noticeable effect on overall economic productivity, or that cost control would reduce health status enough to reduce productivity. Tracking the probable effects of health spending back on national economic activity and standard of living is one of our future goals.

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THE BURDEN OF CARING FOR ALZHEIMER'S DISEASE PATIENTS

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Patrick J. Fox, Walter W. Hauck, David W. Lindeman, Wendy Max, Tina Segura, Pamela Webber

Introduction

Alzheimer's disease (AD) places substantial financial burdens on the afflicted patient, his or her family, and the community. The onset and progression of the disease is characteristically gradual and follows a deteriorating course over time. People who originally managed to perform routine personal and household chores have difficulty with cognitive and functional tasks as the disease progresses and must rely on others for assistance in many of these activities. Thus, persons with Alzheimer's disease use both "formal" medical and social services and "informal" services usually provided by family members. Formal services refer to those rendered for a price in the traditional medical and social service marketplace. Informal services refer to those rendered outside those markets and for which providers are not reimbursed.

The United States is experiencing substantial growth in the elderly population, with the greatest increases occurring in the "oldest-old" segment. The number of persons 65 years and older is expected to more than double in the next 50 years rising from 31.6 to 68.1 million (Bureau of the Census, 1989). Those 85 years and older will almost quadruple during this period. The prevalence of AD in 1990 is estimated at 3.75 million, representing 10.3 percent of the population 65 years and older (Evans, 1990); by the year 2040, 9.0 million AD cases are projected. Almost half of all nursing home residents have severe dementia, including AD (NCHS, 1991). In light of these estimates the current and future burden on society of Alzheimer's disease are substantial.

It is important to translate this burden into economic terms to better understand the magnitude of this burden compared with that of other major chronic illnesses and to facilitate formulating policy about the use of resources. The most detailed estimate to date of the cost of formal and informal care for persons with AD and related dementias derived from primary data was a pilot study conducted by Hu et al. (1986). The researchers concluded that the total cost of senile dementia to society was $102.2 billion in 1983 and the marginal cost (the additional cost due to dementia only) was $77.6 billion. On a per capita basis, the 1983 costs of dementia were estimated at $22,458 per year for a nursing home resident, $14,815 for a severely demented person at home, and $6,515 for a mild to moderately demented person at home. This study did not consider non-elderly persons with dementia and it did not include any of the costs of health care services such as hospital visits, physician visits, and drugs.

Hay and Ernst (1987) examined the costs of caring for those with Alzheimer's disease using secondary data sources, including costs associated with medical care, lost productivity, and informal care. They estimated the costs to society for all persons first diagnosed with Alzheimer's disease in 1983 to be between $27.9 and $31.2 billion. Huang et al. (1988) calculated both the direct social and medical care costs and the indirect informal care costs of Alzheimer's disease. Their estimates were also based on secondary data and included costs associated with lost productivity and premature death resulting in direct medical and social service costs of $13.26 billion and indirect costs of community home care of $31.46 billion. Estimates of costs associated with premature death and productivity losses amounted to $43.17 billion. Combining direct and indirect costs results in a total of $87.89 billion in 1985.

While these studies highlight the high cost of informal care for people with Alzheimer's disease, none closely tracked the services of informal caregivers to determine what tasks they actually performed for people with AD, and to what extent these tasks went above and beyond what they would have done if the person had not had the disease. Neither did the studies track the provision of informal care and its associated costs once the demented person was admitted to an institution, in spite of the fact that caregivers continue to provide informal care up to, and including the period after placement (Zarit et al. 1986; George and Gwyther 1986).

The present study represents a step toward accounting for these shortcomings by tracking formal and informal care costs attributable to AD for individuals residing in community and institutional care settings.

Methods

Sample Selection and Data Collection Procedures

Data for this study were collected from 93 non-institutionalized AD patients and their primary caregivers and 94 institutionalized AD patients, their primary caregivers, and staff of the institutions in which the patients resided. The study sample for the non-institutionalized patients was drawn from patient

lists of specialized Alzheimer's disease diagnostic centers funded by the State of California Department of Health Services for the purpose of providing comprehensive diagnostic and treatment services, adult day health care programs that included among their clientele persons with AD, and membership lists from the Greater San Francisco Bay Area Chapter of the Alzheimer's Association. The institutionalized sample was drawn from sixteen skilled nursing facilities located in the San Francisco Bay Area, five of which had Alzheimer's disease "special care units."

If a potential participant did not have a formal diagnosis of AD, a content analysis of patient medical records was performed by a neurologist and neuropsychologist to determine whether a presumptive diagnosis of AD was warranted.

Primary caregivers were identified according to two criteria: 1) they assisted the patient most of the time with activities of daily living (ADLs), instrumental activities of daily living (IADLs), or both and; 2) they were unpaid. Where two or more individuals were contributing approximately equal time to the care of the patient, the person selected was the one legally responsible for the patient's welfare (e.g., the person with power of attorney, durable power of attorney, conservatorship or guardianship). In only one case, we were unable to determine the primary caregiver and in that case we interviewed two caregivers of one patient. Those patients for whom a private paid conservator or public guardian had been designated were eliminated from the sample because such caregiver-patient relationships blurred the distinction between informal unpaid care and formal paid care.

A total of 297 patient-caregiver pairs originally agreed to participate in the study. Of these, 70 dropped out following their initial consent to participate; 23 were eliminated because they did not meet diagnostic criteria; 5 were ineligible for other reasons (i.e., the caregiver was a paid conservator or guardian, the caregiver was subsequently institutionalized or moved out of the area); and 189 continued in the study. Two subjects were lost before one month of cost data could be collected for a final total sample of 187, comprising 93 noninstitutionalized and 94 institutionalized persons.

Primary caregivers were administered a baseline interview in their home which included questions pertaining to demographic, caregiving, and service utilization characteristics of both themselves and the patient. Primary caregivers were also asked to assess the patient's capacities in ADLs (Katz and Akpom 1976). A Mini-Mental Status Examination (MMSE) was administered to patients who resided in the community (Folstein et al. 1975). Patients in institutional settings were administered an MMSE during a separate visit and facility staff familiar with the abilities of the patient were asked to assess ADL functioning. Nursing home medical records were also reviewed for ADL information.

During the baseline interview, caregivers were provided a calendar designed by study staff that was based on similar instruments used in the 1977 National Medical Care Utilization and Expenditure Survey and the informal care portion of the Manitoba In-Home Care Survey (Paringer 1983). Caregivers were given instructions in the use of the calendar and were asked to record time spent on tasks related to caring for the patient, formal services used, formal costs associated with caring for the patient, and reimbursement received from Medicare, Medicaid, or private insurance. Caregivers were instructed to focus only on formal and informal care provided directly as a result of the patient having AD. These data were obtained from caregivers through monthly telephone interviews conducted by trained interviewers.

Measurement and Calculation of Costs

The study examines the economic costs associated with caring for a person with AD. To measure the incremental costs associated with caring for a demented person that could reasonably be attributed to the disease alone, a number of methods were employed to exclude costs associated with conditions other than AD. We relied on the primary caregiver's judgement regarding whether a formal service or an aspect of informal care was required due to the patient's demented condition. We also obtained billing records from primary caregivers and formal service providers; if billing or formal service data were not available from a provider or were incomplete, we relied on the primary caregiver's response. We excluded individuals with certain comorbid conditions that we thought would unduly influence costs.

The economic cost of AD represents the value of resources utilized or forgone as a result of the disease. Calculations of formal care costs include the value of all services provided in the marketplace by paid workers. Informal care costs are represented by the value of the time spent by unpaid caregivers, typically family members or friends, in caring for the person with AD.

Formal Care Costs. Formal care costs include expenditures for nursing home, physician, hospital, and social services, as well as for medications and other items or services utilized for the care of the person with Alzheimer's disease. For

most of these services, charges are used as a proxy for costs. For those who were hospitalized charges were reported by the caregivers when the hospital statement was obtained.

Charges for physician visits were reported by the caregivers and validated by obtaining bills. For medications prescribed to treat the symptoms of Alzheimer's disease, a neurologist developed a list of forty-four different drugs that would likely be prescribed specifically to treat symptoms of Alzheimer's disease, which we compared with patients medical records. Costs per unit of medication were obtained from a pharmacist consultant and reflect an average charge in the San Francisco Bay Area.

For care of AD patients in skilled nursing facilities, we used nursing home room and board charges. For patients living in the community included were additional food costs for special dietary items, or structural modifications to the patient's dwelling that were necessitated because of the disease. In most cases, these costs represent additional costs beyond those routinely incurred by the family for room and board.

Informal Care Costs. Informal care provided to the patient as a result of AD was valued using a replacement cost approach. The hours spent per week by all of the patient's caregivers were collected on a monthly basis based on fourteen possible types of services which were collapsed into four broad service categories: assistance with ADLs, and/or IADLs, behavioral management, social/recreational activities, and other activities. To assign dollar values to these activities, we assumed that if the patient had no system of informal caregivers, similar services would have to be performed by one of four types of paid employees: 1) nurse's aide for assistance with grooming, bathing, eating, mobility, transportation, social activities, medications, behavioral management, and other activities; 2) housekeeper for assistance with housekeeping, shopping, and cooking; 3) bookkeeper for assistance with financial/legal work; and 4) handyman for outdoor maintenance. The caregivers' hours were valued using the appropriate wage for the paid worker.

For informal care provided in skilled nursing facilities by volunteers or others who are paid by sources other than the patient or his/her family, we used wage rates for clergy, teachers, recreation workers, and welfare aides, depending on the services provided. Appropriate wage rates were multiplied by the number of hours the volunteer provided the activity and then divided by the number of persons in attendance to obtain an approximate cost per person. This portion of the cost was then assigned as an informal cost of caring for those sample participants who attended the activity.

Unit of analysis. The person-month was the unit of analysis used for our calculations. Monthly data obtained from caregivers and service providers were converted to a 30-day equivalent and the mean monthly charges for each participant was computed. Annual costs for formal and informal care were then calculated.

Findings

Characteristics of Sample Patients

Table 1 compares the demographic characteristics of AD sample patients by location of residence. Patients residing in the community are more likely to be younger than those living in institutions - 15 percent of the former were under age 65 compared with 9 percent of the latter groups. The oldest-old, those 85 years and over, comprised 12 percent of the community sample compared with 35 percent of the institutionalized sample.

Females were more predominant in both settings. However , more than three-fourths of the institutionalized sample was female compared with almost three-fifths of the community sample. With regard to race, a larger proportion of the institutionalized sample, 86 percent, compared with 76 percent of the community sample was white. It is possible that there is some acceptance bias of skilled nursing homes in the San Francisco Bay Area.

Institutionalized AD patients are more likely to be widowed than their counterparts in the community, 59 percent and 36 percent respectively. However, one-third of the institutionalized group are married compared with three-fifths of the community sample.

The institutional sample had lower incomes: 38 percent compared with 25 percent of the community sample had incomes below $10,000. At the other end of the income scale, 15 percent of the community sample versus 16 percent of the institutional group had incomes of $50,000 and over.

Not surpisingly, the institutional sample was more likely to be enrolled in the Medicaid program than their counterparts in the community (39 percent versus 12 percent, respectively) and less likely to have private health insurance (29 percent versus 61 percent respectively). Of those patients in the institutional sample, 38 percent had been in a nursing home less than one year, 22 percent between one and two years, 17 percent between two and three years, and 23 percent over three years. Of the institutional sample, 64 percent resided in a regular skilled nursing facility ward, 19 percent in a "special care"

unit of a nursing home, 15 percent in a distinct part skilled nursing facility attached to an acute hospital, and 2 percent in a "life care" skilled nursing facility.

Table 2 compares the cognitive and functional characteristics of AD patients by location of residence. Based on an informal survey of neurological psychologists from the AD Diagnostic and Treatment Centers in the State of California, we utilized a cutoff score of 12 or lower on the Mini-Mental Status Examination (MMSE) as an indicator of severe cognitive impairment. In spite of our efforts to recruit mildly impaired subjects, we were able to find only a small number of patients that fell into this category among the institutionalized patients. Only 6 percent of the institutionalized patients have MMSE scores of 13 or more. Substantially greater proportions of patients residing in nursing homes were cognitively impaired and dependent in ADLs, with almost all patients requiring assistance with dressing, grooming, bathing and toileting. Patients residing in institutions had substantially greater cognitive and functional impairments than those residing in the community, tending to support the notion of the nursing home as the caregiver of last resort for persons with Alzheimer's disease.

Characteristics of Caregivers

Primary caregivers of persons with Alzheimer's disease varied substantially along a number of dimensions when comparing those who cared for a person in the community versus an institution as shown in Table 3. The most notable differences are that caregivers of institutionalized patients were more likely to be male, a son or other relative, and had been caring for the patient for longer periods of time. Caregivers of AD patients in institutions were 45 percent males, 19 percent sons, 25 percent other relatives, and 37 percent had been caregivers for 6 or more years. Comparable proportions for the caregivers in the community are: 28 percent males, 9 percent sons, 11 percent other relatives, and only 9 percent were caregiver for 6 or more years. These findings are what would be expected based on the literature that indicates male caregivers are more likely to assume legal and financial responsibilities while females tend to take on personal care responsibilities. When males are primary caregivers, institutional care is more likely to occur (Chappell and Havens 1985; Zarit et al. 1986). The larger proportion of caregivers of institutionalized patients who had been caring for the patients over an extended period of time reflects the fact that most of the institutionalized patients are severely impaired and therefore assumed to be at a later stage of the disease.

Caregivers' Services

Caregivers of noninstitutionalized AD patients spent 8 times the number of hours that are given by caregivers of noninstitutionalized patients--286 hours compared with 36 hours per month, respectively. Thus, caregivers in the community spent on the average almost 10 hours per day (including weekends) in a variety of caregiving activities, compared with almost 10 hours per week for caregivers of institutionalized patients (Table 4).

Caregiving services vary significantly by the patient's location of residence. Almost one-third of the hours of caregivers of AD patients in the community were spent in behavioral management activities, while only 2 percent of the time was spent by caregivers of institutionalized patients in such activities. On the other hand, 44 percent of the hours spent by the latter group of caregivers were for social/recreational services compared with 13 percent of the caregiving hours of the former group. More than half of the hours provided by both groups of caregivers was for assistance in ADLs and IADLs.

Costs of Formal and Informal Care

The total costs of formal and informal care of AD patients in the San Francisco Bay area amounted to about $47,000 per AD patient in 1990. The total estimated costs per person were almost the same for both noninstitutionalized and institutionalized persons -- $47,083 and $47,591, respectively (Table 5). However, the distribution by type of care was significantly different by the location of residence of the AD patient. Informal care services comprised almost three-quarters of the costs for noninstitutionalized patients, while such services (including services of volunteers) were only 12 percent of costs of institutionalized patients. Social service costs were significantly higher than medical care costs ($9,580 compared with $2,985 per person) for AD patients in the community. For institutionalized patients, nursing home care was the most costly-- $38,980 per person.

About three-fifths of the formal costs in both settings were paid by the patient and/or his or her family (Table 6). Medicare paid 12 percent of the care for patients in the community compared with 3 percent for institutionalized patients. Medicaid paid 31 percent of the total formal costs of care for institutionalized persons and less than one-half of one percent of the costs for noninstitutionalized patients.

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Table 1

Demographic Characteristics of Alzheimer's Disease Sample Patients by Location of Residence

Demographic Characteristic	Location of Residence	
	Noninstitutionalized (N=93)	Institutionalized (N=94)
Age		
Under 65	14.9%	8.5%
65-74	32.3	13.8
75-84	40.9	42.6
85 and older	12.0	35.1
Gender		
Male	40.9	23.4
Female	59.1	76.6
Race/Ethnicity		
Black	12.9	7.4
Hispanic	3.2	4.3
Asian	2.2	1.1
White	76.3	86.2
Other	5.4	1.1
Marital Status		
Married	61.3	33.0
Widowed	35.5	58.5
Divorced/separated/never married	3.3	7.0
Declined to respond	0.0	1.1
Income		
Under $10,000	24.7	38.0
$10,000 - $19,999	20.5	17.4
$20,000 - $49,999	37.5	34.8
$50,000 and above	15.1	6.5
Declined to respond	2.2	3.3
Medical Coverage*		
Medicare Part A	85.9	80.9
Medicare Part B	65.3	64.9
HMO	25.6	12.8
Medicaid	12.1	39.4
Private insurance	60.9	29.0

* Types of coverage are not mutually exclusive

SOURCE: UCSF-UCD Alzheimer's Disease Cost of Care Study

Table 2

Cognitive and Functional Characteristics of Alzheimer's Disease Sample Patients by Location of Residence

Measure	Location of Residence	
	Noninstitutionalized (N=93)	Institutionalized (N=94)
Mini-Mental Status Exam Score		
12 or under*	54.8	94.1
13 or over**	45.2	5.9
ADL Dependencies***		
Eating	22.6	60.7
Transferring	12.9	71.8
Dressing	79.5	98.8
Bathing	78.4	100.0
Toileting	33.3	91.6

* A score of 12 or under indicates moderate to severe cognitive impairment.

** A score of 13 or more indicates mild to no impairment.

*** The patient is partially or totally dependent in this activity.

SOURCE: UCSF-UCD Alzheimer's Disease Cost of Care Study

Table 3

Demographic Characteristics of Alzheimer's Disease Patients Primary Caregivers by Location of Residence

Demographic Characteristic	Location of Residence	
	Noninstitutionalized (N=93)	Institutionalized (N=94)
Age		
Under 35	1.1%	7.4%
35-49	26.9	15.8
50-64	34.4	33.7
65-79	34.4	37.9
80 and older	3.2	5.3
Gender		
Male	28.0	45.3
Female	72.0	54.7
Race/Ethnicity		
Black	12.9	9.5
Hispanic	5.4	1.1
Asian	1.1	1.1
White	77.4	86.3
Other	3.2	2.2
Relationship to Patient		
Spouse	53.8	27.7
Daughter	26.9	28.7
Son	8.6	19.1
Other relative	10.7	24.5
Income		
Under $10,000	5.4	9.6
$10,000 - $19,999	10.8	16.0
$20,000 - $49,999	25.1	22.4
$50,000 and above	13.1	20.2
Income same as patient's	43.5	8.5
Declined to respond	2.2	23.4
Length of caregiving		
1 - 2 years	31.1	10.9
2 - 4 years	34.5	25.7
4 - 6 years	25.5	26.9
6 - 8 years	4.5	14.9
10 or more years	4.4	21.6

SOURCE: UCSF-UCD Alzheimer's Disease Cost of Care Study

Table 5

Total Cost of Care Per Person With Alzheimer's Disease by Type of Care and Location of Residence, 1990

Type of Care	Location of Residence			
	Noninstitutionalized		Institutionalized	
	Amount	Percent	Amount	Percent
Total	$47,083	100.0	$47,591	100.0
Formal Care	12,565	26.7	42,049	88.4
Hospital Care	1,646	3.5	496	1.0
Physician visits	460	1.0	632	1.3
Medicines	231	.5	371	.8
Nursing home care	62	.1	38,980	81.9
Social services	9,580	20.4	35	.1
Other	586	1.2	1,535	3.2
Informal Care	34,517	73.3	5,542	11.6
Caregivers	34,517	73.3	4,478	9.4
Volunteers	-		1,064	2.2

SOURCE: UCSF-UCD Alzheimer's Disease Cost of Care Study

Table 4

Monthly Hours of Informal Care Per Caregiver for Alzheimer's Disease Patients by Type of Care and Location of Residence

Type of Care	Location of Residence			
	Noninstitutionalized		Institutionalized	
	Number	Percent	Number	Percent
Total	285.8	100.0	35.6	100.0
ADL's*	66.8	23.4	8.7	24.4
Grooming	34.7	12.1	1.9	5.3
Bathing	8.7	3.1	.1	.3
Eating	12.6	4.4	6.2	17.4
Mobility	10.8	3.8	.5	1.4
IADL's*	86.8	30.4	10.0	28.1
Housekeeping	21.1	7.4	1.0	2.8
Cooking	26.6	9.3	.5	1.4
Transportation	14.6	5.1	2.0	5.6
Shopping	7.5	2.6	1.5	4.2
Financial/Legal	6.3	2.2	4.9	13.8
Outdoor work	4.9	1.7	.1	.3
Medicines	5.8	2.0	**	-
Social/Recreational	36.3	12.7	15.7	44.1
Behavioral Management	91.6	32.0	.8	2.2
Other	4.3	1.5	.5	1.4

Note: Numbers may not add to totals because of rounding
* The caregiver provides assistance in these activities
** Less than .05 of one hour
SOURCE: UCSF-UCD Alzheimer's Disease Cost Study

Table 6

Formal Cost of Care Per Person With Alzheimer's Disease by Type of Payer and Location of Residence, 1990

Type of Payer	Location of Residence			
	Noninstitutionalized		Institutionalized	
	Amount	Percent	Amount	Percent
Total	$12,565	100.0	$42,049	100.0
Medicare	1,525	12.1	1,305	3.1
Medicaid	47	.4	13,226	31.4
Private insurance	250	2.0	619	1.5
Health maintenance organizations	83	.7	636	1.5
Self-pay	7,745	61.6	25,338	60.3
Other*	2,915	23.2	925	2.2

* Includes charity organizations and Veterans Administration

HEALTH PLANNING AND REFORM IN NEW JERSEY: DATA CHALLENGES AND OPPORTUNITIES

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Introduction

The issue of access to health care has gained center stage in American policy debates. Thirty-seven million of our citizens remain uninsured while the costs of their care, and the care of everyone, become harder and harder to bear. The inability of these millions to get early preventive services may lead to billions in excess costs down the road. Meanwhile, state governments face rapidly increasing health care bills at the same time as state revenues shrink. The magnitude of these problems may differ from state to state, but the crisis is present across this nation.

On July 1, 1991, New Jersey Governor Jim Florio signed the Health Care Cost Reduction Act (HCCRA) into law. This signaled the culmination of almost two years of often rancorous debate over what to do about rising health care costs in one state. Specifically, the issues of the cost of medical indigency and the lack of access to health care for many of the state's residents had come to a head. For almost a decade, New Jersey had financed the inpatient care of its uninsured citizens via a specific add-on to hospital bills for hospital bad debt and charity care. Over the years, this evolved into the state's Uncompensated Care Trust Fund. The cost of this care quadrupled between 1983 and 1991, reaching over $900 million for this current year. This mechanism was repeatedly criticized for encouraging treatment of the uninsured in presumably high-cost hospital settings. The addition of this "tax" to hospital bills was seen as driving the cost of health insurance higher, leading to an increasing number of uninsured New Jerseyans, estimated variously at from 700,000 to 1,000,000[1]. This, in turn, drove the costs of uncompensated care higher. New Jersey's citizens were caught in a circular loop of decreasing insurance access and rising costs. A gubernatorial commission[2] on health care costs charged with seeking solutions to the twin problems of access and cost made 92 recommendations in October, 1990. Many of these dealt directly with the financing of bad debt and charity care and called for a "pay or play" approach to cover all New Jerseyans. While this did not find its way into the HCCRA, many other strategies did. Some of these sought to address the crisis of access through changes in the ways health care is delivered.

Major New Strategies

The HCCRA established a two-year 0.53% levy on the gross revenues of New Jersey's general hospitals. This was projected to raise up to $40 million annually. These monies were earmarked for a number of purposes (see Table 1) through a Health Care Cost Reduction Fund (HCCRF). One major assumption underlies the establishment of this mechanism - that medical care for the poor and uninsured could be delivered with higher quality and at lower cost in community-based primary care settings outside of hospitals.

TABLE 1
HCCRF Primary Care Initiatives

	Funds Allocated Yearly
Community Health Center Expansion	10.0 million
Community-based Primary Care Initiative	6.0 million
Physician and Dentist Loan Repayment	1.0 million
Medicaid Expansion to 185% of Poverty	8.4 million
Prenatal Care for Working Uninsured ("HealthStart Plus")	8.0 million
TOTAL	33.4 million

The anticipated expenditure of $33 million annually for primary care initiatives raises a number of serious concerns. Perhaps the foremost is deciding how to both target and evaluate these initiatives. In many instances, the indicators used in selecting the clinical settings and geographic regions to receive these funds would also be the indicators used to evaluate the results of these initiatives. Furthermore, the HCCRF is to expire after two years. Thus, if there is to be hope of continuing the primary care initiatives begun under the HCCRA in the past two years, the legislature will have to be convinced after approximately one year of operation. The indicators chosen to gauge the impact of the HCCRF will have to be understood by a broad audience and be germane to the concerns of the state's policymakers.

Ambulatory Care Sensitive Conditions

As the debate over health care reform swirled in New Jersey, a tool for measuring primary care access and need came to our attention. Ambulatory Care Sensitive (ACS) conditions were described by Billings and Hasselblad as diagnoses "where timely and effective outpatient management of the condition can help avoid the need for hospitalization".[3] Using the techniques of small area analysis, one could calculate the age- and sex-adjusted rates of admissions to general hospitals for these conditions in defined geographic areas of the state. The rates for deficient areas of the state could then be compared to each other as well as to the rate for the state as a whole. Hospital inpatient utilization in each geographic region could be expressed as the number of patient

days experienced by the area's residents for these ACS conditions. Additionally, the geographic variation in costs attributable to ACS conditions could be calculated.

The list of ACS conditions is shown in Table 2.

TABLE 2
ACS Conditions

1. Adult Otitis Media and URI
2. Pediatric Otitis Media and URI
3. Respiratory Infections and Inflammations
4. Chronic Obstructive Pulmonary Disease
5. Adult Pneumonia
6. Pediatric Pneumonia
7. Adult Bronchitis and Asthma
8. Pediatric Bronchitis and Asthma
9. Congestive Heart Failure and Shock
10. Hypertension
11. Angina Pectoris
12. Chest Pain
13. Cellulitis
14. Diabetes

Variations in the rates of admission for these conditions may be ascribed to one or more of many factors. Access barriers, be they financial, cultural, educational or otherwise, may be to blame. A lack of nearby services, inadequate outpatient follow up, physician practice patterns, lifestyle and population differences can also be responsible. While this merits further study, for our purposes we hope to use the ACS rates as another indicator of a community's well-being, much as one would use infant mortality or immunization rates. Localities with relatively high ACS condition rates would be given priority in terms of the primary care initiatives.

New Jersey ACS Rates

Table 3 shows ACS rates for selected New Jersey Hospital Market Areas (HMAs). The state contains 92 HMAs. On average, each HMA has approximately 85,000 residents. Table 3 displays the four HMAs with the highest rates, the four with the lowest, and the overall New Jersey rates.

Variations in admission rates of up to four-fold are seen among HMAs. Perth Amboy has a rate over twice the overall state rate. Communities with high ACS rates also tend to be those with low incomes and generally show other poor indicators of health status.

Utilization expressed as hospital patient days per 1,000 experienced by HMA residents for ACS conditions varies even more widely. The highest utilization (again in Perth Amboy) is 4.7 times that of the community with the lowest utilization for ACS conditions. Perth Amboy's rate is twice that of the state overall.

Finally, the economic consequences of ACS conditions also vary between areas of the state. In the Greenville HMA, over $136 is spent per capita on hospitalizations for ACS conditions. In Morristown, this figure is $37.79. Such a variation in costs per capita would mean that overall costs in one HMA for ACS conditions may be over $8 million higher

TABLE 3
Hospital Admissions for Ambulatory Care Sensitive Conditions
Selected New Jersey Hospital Market Areas
1988

Hospital Market Area	Admission Rate	Patient Day Rate	Costs per Capita
Perth Amboy	36.36	281.68	126.68
Greenville	35.11	278.72	136.35
Hammonton	33.12	274.38	117.89
Newark	32.14	267.25	124.74
State of NJ	18.14	136.68	70.12
Orange	11.26	78.99	43.79
Fairlawn	10.96	75.62	42.33
Westfield	9.22	65.43	39.45
Morristown	9.20	59.80	37.79

Note: Hospital admissions are the total admissions experienced by residents of the respective hospital market area for these conditions.
Patient days are the total days of hospital stay experienced by residents of the respective hospital market area for these conditions.
Costs include charges for admissions for these conditions of residents of the respective hospital market area.
Rates are age- and sex-adjusted and are computed per 1,000 residents of the respective hospital market area. Costs per capita are expressed per hospital market area resident.

Source: Codman Research Group

than those in another HMA. Dramatic differences in admission and utilization rates are thus directly translated into dollars spent.

Discussion

The variation in ACS condition indicators across New Jersey may point to major differences in the delivery of primary care in the state. Without teasing apart the many factors that may be causing these differences, it is safe to say that most are probably related to the access to health care. While other factors such as lifestyle may also be involved, such causes may still speak to the need for primary care interventions including health education. The rates of ACS condition admissions will help us to target the primary care initiatives envisioned in the HCCRA.

The study of ACS conditions may also help directly tie health status to health costs. It is very useful to be able to calculate the variation in hospital charges due to these admissions across the state. Such a number has great meaning to health policymakers including state legislators. Telling a community and its representatives that it is spending millions more than other communities because of a lack of primary care is a powerful statement. This may be one of the most potent uses of the ACS concept.

ACS is not, of course, the panacea for the health data problems surrounding the medically indigent. We still need to be able to determine who is using health services. This means better data on tracking individual inpatient use. In most states, it is impossible to determine whether 100 hospitalizations were due to 100 uninsured people each going to the hospital once, or 10 people each being admitted 10 times. There is a critical lack of outpatient data collection. We also need to know not only the demographic background of the uninsured in the state, but also the demographic background of those individuals whose care is being financed either through charity care or bad debt. The two groups of individuals may not be the same. Until we have answers to these questions, it will be hard to make intelligent choices about how to attack medical indigency. The ACS concept will help us find and understand those areas where it appears that people are not receiving the care they need.

Conclusions

The variation in rates of admissions for ACS conditions may be very helpful in selecting those geographic regions of our state which suffer from primary care delivery deficits. This will assist us in targeting primary care initiatives. Additionally, the ability to translate variation in hospital admissions for ACS conditions into cost variation will also be a useful tool, especially in highlighting the great expense associated with the potentially preventable hospitalizations for these conditions. Finally, ACS condition admission rates may serve in the evaluation of the impact of these conditions.

Nevertheless, much more needs to be known about how health services are used by the poor, and about the relationship between lack of insurance and the costs of medical indigency. Until that time, it will be difficult to design more sweeping strategies to provide everyone with access to affordable health care.

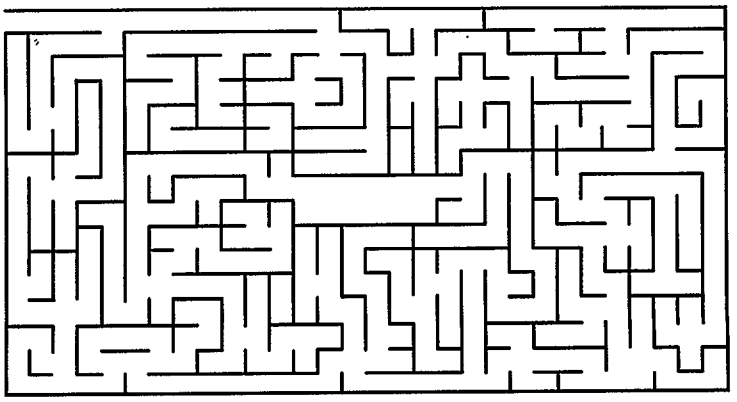
(NOTE: The authors would like to thank John Billings and the Codman Research Group for their tireless assistance.)

Footnotes

1. US Bureau of the Census, Current Population Survey, March 1990.
2. Final Report, Governor's Commission on Health Care Costs, Trenton, New Jersey, October 1990.
3. Billings, J. and Hasselblad, V., "A Preliminary Study: Use of Small Area Analysis to Assess the Performance of the Outpatient Delivery System in New York City", Health Systems Agency of New York City, November 1989.

Session H

Assessing Quality of Care



MEDICAID MANAGEMENT INFORMATION PROVIDES A FRAMEWORK FOR MONITORING QUALITY OF CARE

Mary E. Stuart, Sc.D.
Maryland Department of Health and Mental Hygiene

(Not available for publication)

ASSESSMENT OF OB/NEONATAL QUALITY OF CARE ON A NATIONAL BASIS

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National Perinatal Information Center, (NPIC)

A major developmental activity currently underway at the Joint Commission of Accreditation of Healthcare Organizations (JCAHO) will have significant implications for obstetric and newborn services in American hospitals. The *Agenda For Change* calls for a radically revised approach to JCAHO assessment for the 1990's. The goal of this initiative is to develop outcome oriented monitoring and evaluation which will enhance the efforts both of the Commission and of providers to improve the quality of patient care.

During this decade, more than 5,000 hospitals will be asked to participate in this new process as a condition of participation under JCAHO. The *Agenda For Change* will require hospitals to supply JCAHO with significant amounts of data relative to patient outcomes, e.g., morbidity, mortality and complications of care. The AHA has estimated that over three-quarters of all patient discharges and over one-third of all patient days may eventually come under JCAHO scrutiny as part of this initiative.

The first JCAHO module to be implemented will be for obstetric/newborn care. Perinatal indicators have already been field tested in 17 pilot sites; the original indicator list has been modified and condensed; and beta-site testing is currently being conducted in 450 hospitals nationwide.

The JCAHO obstetrical/newborn indicator list includes both maternal and neonatal factors: cesarean births, successful or failed VBAC, maternal blood loss, eclampsia, neonatal mortality, preterm deliveries, NICU admission/deaths, Apgar scores, birth trauma and seizures. Under the Agend*a For Change*, hospitals will be asked to submit data relative to all cases meeting JCAHO definitions.

The National Perinatal Information Center (NPIC) has completed a preliminary evaluation of these screening indicators from two perspectives:

- First, to what extend can these indicators be measured with currently available hospital discharge data systems, avoiding the considerable financial and manpower costs of purchasing and implementing new custom-tailored data collection instruments and computer programs?
- Second, what problems are hospitals and the Joint Commission likely to face in terms of accurate analysis and interpretation of these indicators?

Careful scrutiny of the original and revised JCAHO indicator lists reveals that most hospitals will be able to measure only some of these items with existing data systems. However, adding a very limited number of perinatal specific data elements to the standard discharge data set should make it possible to measure nearly all the indicators.

As to potential problems, our preliminary analyses of the NPIC Representative Hospital Panel Data Base indicate that tertiary centers in particular may be extremely vulnerable to negative assessments unless they have analyzed their own data carefully and compared these results to other similar institutions in advance of a review from an outside organization.

The Representative Hospital Panel Data Base is a stratified random sample of 50 urban hospitals with greater than 900 births and offering all levels of care. The data base was constructed over a one and half year period and reflects primarily 1985 data. The data are patient specific and contain clinical and financial data on 250,000 perinatal events (mothers and babies). The data base has valid birthweight on approximately 85% of all neonates.

NPIC grouped the 50 hospitals by level of perinatal care and intensity of clinical services using its self-designed Level of Care Survey. The survey measures such variables as number of neonatologists, number of perinatologists, duration and types of mechanical ventilation offered, availability of other clinical interventions, (i.e., ECMO), teaching status, availability of transport services, and whether the hospital performs outreach education.

The fifty hospitals fell into four groups (A-D) ranging from those delivering the least complex care (A) to the most complex (D). As would be expected, the hospitals varied by average number of births, number of special and NICU beds, percentage of VLBW cases, transfer patterns and utilization by high risk neonates (Tables 1 & 2).

TABLE 1

SIZE & VOLUME

Indicator (N)	HOSPITAL GROUPS A (12)	B (8)	C (10)	D (20)
Average # Of Births	1,895	2,418	2,696	3,271
Average # of Special Care Beds	3.5	11.0	23.0	28.5
Average # of NICU Beds	0	2.1	13.3	20.5

TABLE 2
Case Mix Analysis
VLBW Neonates (500 - 1500 g)

	HOSPITAL GROUPS			
	A	B	C	D
Average # VLBW	11	11	56	97
% VLBW	56%	46%	2.1%	2.9%
Discharge Status:				
Transferred	40%	33%	7%	12%
Died	5%	14%	28%	25%
LOS (Days):				
All VLBW	6	24	47	41
Transferred	2	4	36	28
Died	1	8	18	10

Analysis of the revised JCAHO indicators by level of care show distinct differences across the four hospital groups. The indicators showing the greatest variation between the Level D hospitals and the other three levels include: eclampsia, seizures in term infants and neonatal deaths (Tables 3 - 5).

TABLE 3
% ECLAMPSIA BY LEVEL OF CARE

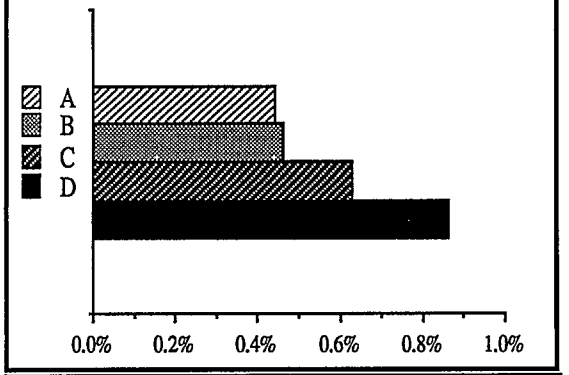


TABLE 4
% TERM INFANT SEIZURES BY LEVEL OF CARE

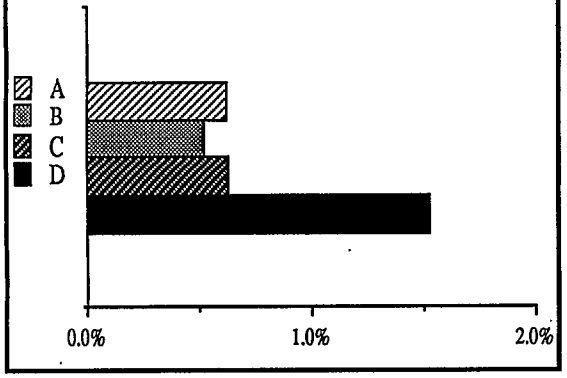
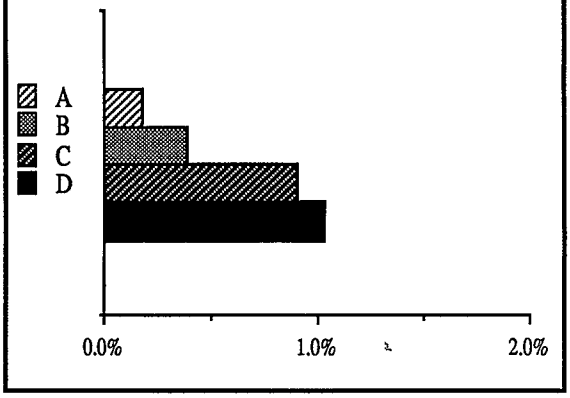


TABLE 5
% NEONATAL DEATHS BY LEVEL OF CARE



The overriding concern for hospitals which treat high risk caseloads therefore, is whether outcome oriented assessments are capable of adequately accounting for differences in patient severity. As shown, the JCAHO obstetric/newborn indicators analyzed by hospital level of care show differences of several hundred percent between smaller hospitals as compared to major tertiary centers. Community hospitals look better on most measures of morbidity and mortality. The neonatal indicators are particularly susceptible to measuring underlying risk rather than quality of services because of the highly significant differences in outcomes by birthweight. Proper risk adjustment will be essential if these assessments results are to be correctly interpreted.

It is very difficult for hospitals to assess their position vis-a-vis outcome indicators unless they have access to a flexible data base of comparable institutions. Measuring the performance of a single institution in isolation means little without access to the sorts of comparisons that assessment agencies will employ to draw conclusions regarding relative performance. Hospitals should begin now to prepare for the demands of JCAHO and others by gaining familiarity with current indicator lists, collecting the necessary OB and newborn data, participating in a large comparative data base of similar institutions, analyzing their results, taking necessary corrective actions, and implementing continuous monitoring and quality improvement procedures.

IMPLEMENTING AN OUTCOMES-BASED QUALITY ASSURANCE PROGRAM FOR VERY LOW BIRTH WEIGHT INFANTS: METHODS AND RESULTS

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Katherine R. Jones, Janet C. Thomas

INTRODUCTION

This year's conference's theme is to define the interactions between the Nation's health agenda for the coming decade and the health statistics needed to plan and monitor these public health programs. In the field of perinatal-neonatal medicine, the goal is to reduce neonatal mortality to less than 4.5/1000 live births. Since very low birth weight infants (500-1500 grams birthweight) account for approximately 60% of the total number of neonatal deaths, they naturally are accorded the highest priority.

This paper describes our evolving experience with an outcomes-based quality assurance(QA) program for neonates. While it focuses on the more sophisticated tools which we have developed over time, it should be noted that many of this program's first results were based on simpler, but less reliable, analytic tools. We believe that our experience provides evidence that outcomes-based QA programs can be reliably implemented and that they can objectively identify differences across providers in treatment patterns and outcomes, monitor trends over time and help evaluate the impact of technologic changes. Additional benefits include the capability to demonstrate the results of specific QA activities and to provide models for improving the certainty of physician decision-making.

Measuring outcomes presupposes our ability to describe our goals of care and then to describe whether our patients are proceeding on course or not. Considerable efforts are ongoing to improve the methodologies by which we assess the outcomes of care. Many difficulties confound these assessments, e.g. unstable measurement conditions, interobserver variability, and ambiguous goals to name just a few of the potential biases. But patient variability is perhaps the most important of these confounding factors, and thus has rightly been the target of so much effort to develop methods to adjust outcomes measures for these differences in case-mix (1).

Perinatal services have always attracted attention as a field to initiate outcomes measures, since the birth process and its associated stillbirth and neonatal deaths provide easily ascertainable and unambiguous events. In California, the crude measures of perinatal outcome are subjected to a sophisticated risk-adjustment process. Williams (2) uses indirect standardization to calculate each hospital's perinatal services' performance taking into account four case-mix factors which together account for as much as 70-80% of the variability in the measured perinatal statistics, i.e. fetal, neonatal and perinatal mortality rates. With these data one can make post-hoc comparisons between each hospital and the state averages. The information is disseminated both to the consumer and the professional community. While these data can clearly motivate introspection, they can only very dimly identify specific care delivery problems.

Providers need more concrete feedback on how their practices affect outcomes if they are to be motivated to make meaningful changes in their practices. Thus, our project sought to bridge the gap between aggregated and non-specific outcome indicators and critical care practices by examining major morbidity indicators which can be linked to specific care practices.

METHODS

Setting: The Kaiser Permanente Medical Care Program, Southern California Region, provides perinatal care in a now ten-hospital network. During the years studied, there were over 25,000 live births per year. We expect to deliver more than 37,000 infants this year.

Study Population: The very low birth weight (VLBW) event monitoring project was initiated in 1986 for the purpose of allowing comparison of our clinical outcomes with external standards, such as those available through the published literature, and with internal standards, each hospital's results as compared to others in the network. We chose the VLBW population, which constitutes just a little over 1% of our deliveries, because they generate 60% of the mortality, morbidity and neonatal patient days. We reasoned that, since on average each VLBW infant requires on average at least 1000 hours of nursing, pharmacist, and respiratory therapist time, in addition to physician time, we should be willing to budget an additional five hours per patient to evaluate and improve our care processes and outcomes.

Data: A computerized data base has been created for all infants whose birth weights were less than 1500 grams (N=799). A data abstraction protocol was defined to characterize the case mix, such as birth weight and gender; selected antenatal, peripartum, and neonatal care processes, such as number of prenatal visits and initial duration of each newborn's fast; and neonatal care outcomes, including survival, chronic lung disease, and necrotizing enterocolitis. Experienced neonatal intensive care unit nurses were trained to abstract these data elements. The data were entered into a dBASE-III database management program, validated, and analysed using the CSS (Stat-Soft

by Complete Statistical System) and SAS statistical packages for the personal computer.

Procedures: The analytic process begins with selection of a report from the published literature to serve as the "external standard" or "benchmark." Selection is based on relevance, impact and degree to which the benchmark and Kaiser VLBW datasets overlap. Using a literature based standard has the advantage of building on the credibility, scientific expertise, and judgment of recognized leaders in the field and thereby avoids protracted discussions over aims and methodologies. Benchmark selection is based on the implicit commitment of both our physicians and the organization to achieve what may be termed "best provisional" outcomes, that is, results equal to the best being reported in the field at this point in time.

Analytic Plan: Data selection and physiologic and clinical definitions are driven by the methodologies of the selected benchmark study; where applicable, either approximations are identified or, if justified, additional data may be sought. Outcomes are compared across studies and hospitals in the region, first with regard to the primary hypothesis suggested by the benchmark study. Secondary analyses are undertaken as other aims present themselves or as additional data allow. Care processes are analyzed and identified variations are related to outcomes, after adjusting for variations in case-mix. Methods and results are presented both formally and informally to providers for comment and response. Where appropriate, conclusions are reassessed or, if indicated, generate discussion and eventual implementation of alternative clinical practice policies. These corrective actions are then later evaluated for their effectiveness at subsequent time periods.

RESULTS

Three comparison studies have been conducted thus far. The first led to considerable savings in hospital days and cost as a result of changed discharge practices. A second comparison suggested an unexpected relationship between Intralipid therapy and the risk of nosocomial infection that has since been corroborated by another published report. And the third, which is the subject of this more detailed report, examined ventilation practices and outcomes. It perhaps best illustrates our methodology and the many kinds of unexpected results and uses that we have found with this technique.

The benchmark study selected for ventilation practices was the report on "Variability in 28-day outcomes for very low birth weight infants: an analysis of 11 neonatal intensive care units" by Horbar and associates (3), which had deservedly attracted much attention and interest from neonatologists throughout the country. In it, eleven prestigious tertiary neonatal intensive care units (NICUs) reported on the variability of two critical outcome measures of their services, namely survival of very low birth weight infants through the 28th postnatal day and the presence of chronic lung disease, as defined by the continuing need for oxygen therapy on the 28th postnatal day. In brief, Horbar et al (3) found, after developing a logistic regression model to adjust for case-mix differences, that both adjusted survival and chronic lung disease rates were significantly different from unit to unit. They then characterized differences in clinical policy among the units and speculated as to whether the observed differences in outcomes might be attributable to differing clinical practices or unmeasured case-mix variation.

We emulated the benchmark study's methodology by examining the two outcomes in question with their risk adjusting case-mix factors of gender, race and birth weight category. Our richer dataset allowed us to also consider additional measures of respiratory outcome: duration of mechanical ventilation, continuous positive airway pressure and their sum: total days of respiratory assistance. We adopted all of the statistical methods, save the benchmark study's calculation of the rate of supplemented oxygen on postnatal day 28. It had a procedural error, which has subsequently been commented upon by other investigators. We alternatively evaluated those infants recieving supplemental oxygen on postnatal day 28 rather than those not on oxygen.

Figure 1

EXTERNAL COMPARISON: HMO/HORBAR ANALYSIS

OUTCOMES	HMO (651)	HORBAR (1776)
Survival 28 Days %	85	85
No Oxygen Day 28 %	74	60

Figure 1 indicates the comparison's study and our own care program's observed rates of survival and chronic lung disease. Since these reported clinical experiences encompass different spans of time (Horbar: '83-'84 vs Kaiser '85-'87), one should not speculate about whether these differences are either statistically or programmatically significant.

Logistic regression modeling in accord with the benchmark's methodology indicated results which were quite similar (Figures 2A and 2B). As compared to those infants whose birthweights were between 1250 and 1500 grams, smaller birthweight categories were, as expected, significant factors in determining both survival and chronic lung disease. Survival rates were only affected by birth weight category and unaffected by site of care. (This finding is significant to our organization's managers,

Figure 2A

RELATIONSHIP OF BIRTH WEIGHT CATEGORGY AND SITE OF CARE TO RISK OF NEONATAL DEATH: LOGISTIC REGRESSION ANALYSIS

RISK FACTOR	BETA	ODDS RATIO
Intercept	-2.69	-
Birth Category:		
701-800 grams	2.68	14.54*
801-900 grams	2.07	7.96*
901-1000 grams	0.92	2.51*
1001-1250 grams	0.55	1.74*
Site 2	0.48	1.61
Site 3	0.48	1.61
Site 4	-0.37	1.45
Site 5	0.11	1.11
Site 6	0.18	1.19
Site 7	0.30	1.35
Site 8	1.17	3.22
Site 9	0.05	1.05
Female	0.02	1.02
Non-White	-0.07	1.07

* $p < .05$
Reference categories: Level III site; B Wt: 1251-1500 gm
Number of observations = 651; number died prior to 28th postnatal day = 121.

since it indicates that we are accomplishing our goal of providing equally good survival rates throughout the system.) However, like the multi-university study, we found significant variation in the occurrence of chronic lung disease from site to site. (Gender was also noted to be significantly associated with chronic lung disease.)

Our more extensive dataset permitted us to do linear regression analysis on the duration of mechanical ventilation, which is arguably a more sensitive measure of lung disease chronicity than the simpler 28 day oxygen use measure. Figure 3 shows this analysis. It confirmed the birth weight category effect, as well as gender effect, and defined two, rather than just one, sites of care as outliers. We found that this style of formatting results is of more interest to physicians, because it more clearly highlights significant adverse practices, such as an additional week or two of ventilation, and thus can be accepted as clinically relevant and important.

Outcomes analysis also enables one to monitor practice and technologic changes over time. Figure 4 shows that, during the three year study period, the duration of mechanical ventilation fell nearly 25%. Part of this decline was achieved by substituting a less invasive technology, i.e. nasal continuous positive airway pressure, for mechanical ventilation. Overall, the sum of respiratory assisted days fell 20%. Not shown is an analysis that indicates how site variability ceased to be significantly different by 1987.

Figure 2B

RELATIONSHIP OF BIRTH WEIGHT CATEGORGY AND SITE OF CARE TO RISK OF CHRONIC LUNG DISEASE: LOGISTIC REGRESSION ANALYSIS

RISK FACTOR	BETA	ODDS RATIO
Intercept	-0.94	-
Birth Weight Category		
701-800 grams	3.17	23.86*
801-900 grams	3.24	25.61*
901-1000 grams	1.80	6.07*
1001-1250 grams	1.53	4.61*
Site 2	-0.03	1.03
Site 3	-0.14	1.15
Site 4	-0.77	2.17
Site 5	0.96	2.60*
Site 6	-0.22	1.25
Site 7	0.33	1.38
Site 8	0.31	1.37
Site 9	0.17	1.19
Sex: Female	-0.88	2.41*
Race: Non-white	-0.18	1.19

* $p < .05$
Reference categories: Level III site; B Wt: 1251-1500 gm
Number alive on day 28 = 407; number alive and on oxygen on day 28 = 146.

Figure 3

DURATION OF MECHANICAL VENTILATION (DAYS):
LINEAR REGRESSION ANALYSIS*

RISK FACTOR	BETA
Intercept	37.4
Birth Weight Category:	-5.8*
701-800 grams	
801-900 grams	
901-1000 grams	
1001-1250 grams	
Gender: Female	-4.2*
Race: Non-White	0.4
Site 2	6.9*
Site 3	2.2
Site 4	-2.7
Site 5	12.5*
Site 6	-4.3
Site 7	5.1
Site 8	6.8
Site 9	5.5

* $p < .05$
Sample consists of all 651 ventilated infants.

DISCUSSION

Our regional quality assurance effort was initiated in 1986 without having these elegant data analyses available. At that time we utilized clinical reports to identify ventilation practices, viewing them as an opportune area for practice improvement because of their relationship to air leak syndromes, chronic lung disease and even intracranial hemorrhage. Quick and simple quality assessments were instituted to document the existence of problems with ventilation practices. Physicians were primed to consider alternatives to their existing practices through multidisciplinary conferences. Those sessions were designed primarily to heighten awareness and to reorient attitudes, knowledge and skills. Subsequently, many patient records were painstakenly and diplomatically critiqued to gain compliance with an alternative ventilation strategy. Later, we were able to find and develop additional technology to monitor our ventilation technology in real-time, much as the electrocardiogram monitors cardiac function in real-time (4). These efforts have been rewarded by decreasing use of ventilation and decreasing rates of chronic lung disease. Now that we have these more sophisticated clinical outcome meas-

Figure 4

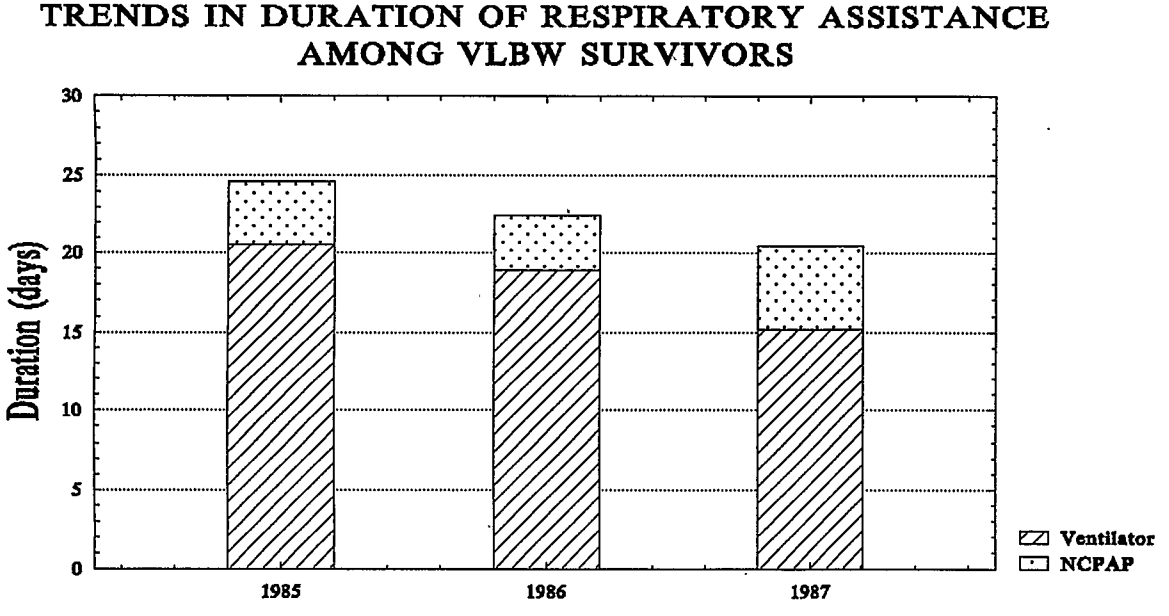
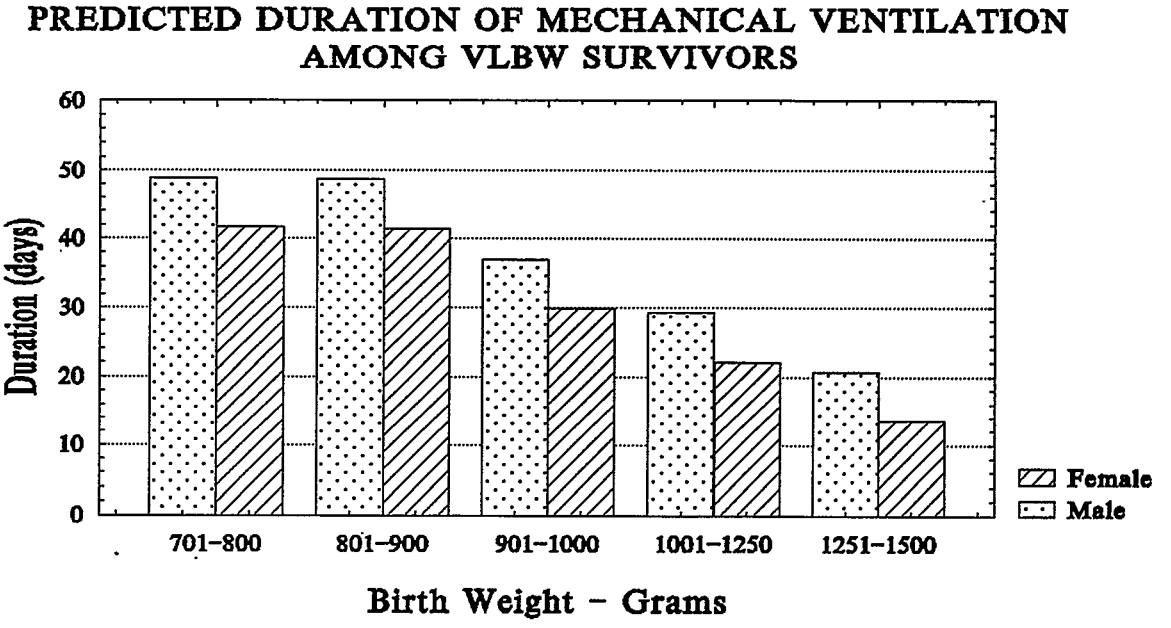


Figure 5



urement techniques, we expect to identify more subtle areas for practice improvement.

THE FUTURE

We believe that predicting clinical outcomes should become another important application of these data models. As shown in Figure 5, we can either simply characterize the predicted use of a technology (in this case, ventilation), or, we can utilize more complex models to predict duration of ventilation, hospital stay, or other items of interest. The ability to define the patient's course, just like the ability to map a ship's course, is the basis for determining whether the patient's care, or the ship, is on or off course, and as to whether the care or ship should be redirected (5). Enhancing certainty about where you are improves decision-making.

CONCLUSION

The realized and potential benefits of an outcomes-based record review are significant. We believe them to include:

1) objective identification of provider and/or site differences;
2) objective identification of trends over time;
3) objective identification of changes required in clinical policy;
4) objective demonstration of quality assurance results; and
5) more confident clinical decision-making by reducing physician uncertainty.

We have concluded that an outcomes-based quality assurance program can provide clinically relevant and useful results.

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A METHOD FOR ASSESSING THE OUTCOMES OF NURSING HOME CARE USING ADMINISTRATIVE DATABASES

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There has been a long-standing concern that nursing homes do not consistently provide high-quality care to their residents. Part of this concern relates to some disagreement about the proper definition and measurement of quality. Measuring quality is difficult in health care since in most cases neither the patient nor provider know what to expect. This is particularly true when dealing with nursing home care, as nursing home residents as a rule are frail, have multiple, chronic health problems, and are often not expected to improve.

Traditionally, we have looked at measures of structure and process to assess quality (Donabedian, 1966). Structure refers to the capacity to deliver care, and involves such things as accreditation, certification, staffing levels, and compliance with safety codes. Process measures evaluate the extent to which written procedures, protocols, and standards are followed. Although it is unlikely that high quality care could be provided where its structural and procedural components are inadequate, they do not guarantee desirable outcomes of care.

In an attempt to improve the regulation of nursing home quality, the Institute of Medicine's Committee on Nursing Home Regulation recommended, among other things, the use of outcome measures as a screen to evaluate the quality of nursing homes (Institute of Medicine, 1986). The recommended strategy was to use standardized measures to develop norms for resident outcomes. The quality assurance method suggested was to compare these outcome norms with actual outcomes on a facility by facility basis. A facility identified as having outcomes below the norm could then be targeted for a second survey.

Norms for outcomes have been difficult to identify. Measures used in the acute care sector, such as complication, rehospitalization, and death rates, are not necessarily appropriate, as these events may occur despite the provision of high quality nursing home care. It is important that a range of potential outcome indicators be evaluated, as no single measure is likely to be appropriate. Additionally, it is important to adjust outcome norms for case-mix -- that is, to recognize and quantify the extent to which different types of residents experience different outcomes.

Analytic methods

This paper presents an example of a method for identification of outcome norms using administrative databases. Four outcome measures are presented: rates of decubitus ulcers, use of physical restraints, rates of urinary tract infections, and change in ability to transfer. Among the characteristics examined for potential relationships with the outcome measures are functional status, age, mental status, and selected primary diagnoses. The data used in this analysis are administrative data from two nursing home systems -- the New York State Department of Health, and the National Health Corporation (NHC). The New York data represent a random sample of 20% of nursing homes in the state. NHC is a chain of 45 proprietary nursing homes in six southern states. The data are used for the planning and management of care, for determination of reimbursement, allocation of staff resources, and for quality assurance. In each system, data are collected by trained assessors, and samples are periodically audited for quality control.

For both data sets, we developed analytic files containing cross-sections of residents in the facility at a particular point in time (time 1), and a second cross-section approximately six months later (time 2). Rates of selected conditions and services -- the outcomes -- were then calculated. The rates were prevalence, incidence, and recovery or discontinuance for services and clinical indicators, or improvement and decline for functional indicators. Dr. Sidney Katz first identified the usefulness of measures of function in activities of daily living (ADL) -- bathing, dressing, toileting, transferring, and eating -- in evaluating the status of those with chronic medical conditions (Katz et al, 1963). For such persons, improvement or decline in function may be a more sensitive and useful indicator than a diagnosis-related measure.

Prevalence was calculated as the number of cases at time 1 divided by the number of residents at risk at time 1. Incidence is the number of new cases identified at the time 2 cross-section divided by the number of time 1 non-cases still in the facility at time 2.[1] Recovery or discontinuance is the

number of time 1 cases resolved (no longer experiencing the condition) by time 2 divided by the number of time 1 cases still in the facility at time 2. Finally, rate of functional improvement is measured as the number of residents dependent at time 1 and independent at time 2 divided by the number of residents dependent at time 1 who are still in the facility at time 2.

With the exception of cross-sectional prevalence, each of the measures is based on those residents still in the facility at time 2. In the NHC sample, 35% of residents measured at time 1 were no longer in the facility at time 2: 24.5% had been discharged, and 10.5% died. Approximately 20% of the New York sample was no longer in the facility at time 2; the data do not provide information about discharge disposition.

In order to evaluate whether it was necessary to adjust these rates for selected resident characteristics, we calculated relative risks for subgroups with those characteristics. For example, adjusting the outcome measure of prevalence of decubitus ulcers for the resident being dependent in transferring and eating, we calculated the relative risk as the prevalence of decubitus ulcers among dependent residents divided by the prevalence of decubitus ulcers among residents independent in these functions. In order to assess the significance of the relative risks, 95% confidence intervals were calculated (Rothman, 1986).

Results

Sample description

The National Health Corporation sample contained 4595 residents at time 1; 65% of residents had a six month follow-up. The New York Sate sample contained 11,795 residents at time 1; approximately 80% had a time 2 assessment.

The NY and NHC systems serve different kinds of residents. The National Health Corporation is Medicare-oriented, with about 20% of residents at the time 1 cross-section covered by Medicare. In the New York system, about 2% of residents are Medicare-covered at time 1 (Table 1). The distribution of lengths of stay at the time 1 cross-section reflects this difference: NHC has a shorter-staying population, with about 30% having been in the facility for thirty days or less at time one, compared to about 2% of the New York sample (Table 2).

Decubitus ulcers

The way in which decubitus ulcers was defined was fairly uniform across the data sets; each was coded on a four-stage scale, with stage 1, the least severe, defined as a persistent reddened area. The similarity in rates reflects this uniformity of definition. The prevalence of decubitus ulcers was 15.65% in NHC and 15.41% in New York (Table 3). The incidence and recovery rates were both higher in New York (9.64% and 51.12%, respectively) than in NHC (5.98% and 45.58%, respectively.)

The relative risks for the three subgroups of residents follow similar patterns across the two data sets. ADL-dependent residents were six to seven times as likely to have prevalent decubitus ulcers, and three to three and one half times as likely to develop incident sores than were ADL-independent residents (Table 4). Comatose residents were about three times as likely to have prevalent ulcers than were non-comatose residents (Table 5). Diabetic residents were 1.22 times as likely as non-diabetic residents to have prevalent ulcers in New York and 1.43 times as likely to have prevalent ulcers in NHC (Table 6).

Physical restraints

The prevalence of restraint use in NHC was 47.18%, while in New York it was 56.9%. The incidence of restraint use was also higher in New York (22.65%) than in NHC (15.48%). The third measure, rate of discontinuance, was twice as high in NHC (15.48%) than in New York (Table 7).

Before making any statements about the level of restraint use, it is important to assess two additional issues. First, are the definitions used in the administrative databases identical? In fact, they are not. The documentation accompanying the New York Patient Review Instrument defines a restraint as "a device used during the daytime during the past four weeks to limit, restrict, or keep patient movement under control ... Restraints include belts, cuffs, mitts, geri-chairs, harnesses, locked doors or gates, nets, full-length side rails and domes." The NHC assessment instrument defines physical restraints as "a mechanical device (such as arm restraints, posey belts) used to limit movement." These definitions suggest that higher rates of restraint use are likely to be identified in the New York data. Despite definitional differences, some of the variation in the prevalence rates may also be attributable to the different mix of residents in the two systems. Addressing this issue requires comparing rates among subgroups of residents for whom the type of restraint and the purpose of restraint use might be similar.

ADL-dependent residents are more likely to have restraints at baseline, are more likely to become restrained during the study period, and are less

likely to have their restraints discontinued than are ADL-independent residents (Table 8). ADL-dependent residents are about two and one half times as likely as ADL-independent residents to become restrained, and one-quarter to one-third as likely to have their restraints discontinued. The direction of the relative risks of prevalence of restraints is the same across the data sets, although the magnitude differs. The relative risk for ADL-dependent residents in NHC was 6.34, while in New York it was 9.22.

It is possible that older residents (those aged 90 or more) may have different rates of restraint use. The relative risk of prevalence of restraints is uniformly elevated in both data sets (1.16 in NHC and 1.14 in New York); the relative risk of discontinuance is 0.56 in NHC and 0.88 in New York, although the 95% confidence interval suggests that the New York rate does not differ significantly from one (Table 9).

Finally, the relative risks of restraint use among disoriented residents in the NHC system suggests the importance of adjusting for this characteristic. Disoriented residents are 6.34 times as likely to have restraints at baseline, 2.56 times as likely to become restrained, and 0.33 times as likely to have their restraints discontinued (Table 9). No comparison between NHC and New York is possible since the New York data do not contain a similar measure of mental status.

Ability to transfer

In both systems, decline in ability to transfer was more common than improvement. During the six month period, 15.91% of NHC residents as 25.12% of New York residents became dependent in transferring (Table 10). Improvement was more common in NHC (7.81%) than in New York (3.72%). Two diagnostic measures were examined with respect to change in ability to transfer: primary diagnosis of stroke and primary diagnosis of hip fracture. Residents recovering from a hip fracture had relative risks of improvement in transferring of 1.44 in NHC and 2.42 in New York (Table 11). Those recovering from a stroke were only half as likely to improve in both systems (Table 12).

Urinary tract infection

This final measure is presented as a cautionary example of data elements that should not be compared due to the variation in definition across the systems. The NHC assessment instrument identifies a urinary tract infection (UTI) only if coded as a medical diagnosis. In New York, UTIs are one of a checklist of conditions, and any symptoms of UTI qualify the identification of that condition; a formal diagnosis is not required. The rates associated with urinary tract infections reflect this disparity in definition: the prevalence rate in New York is more than half again as high and the incidence rate almost eight times as high as that in NHC (Table 13).

Discussion

These results suggest that it may be possible, using some relatively simple measures, to identify some normative ranges for outcomes of nursing home care. When variables are uniformly defined, as is the case with some of the measures defined here, overall rates and relative risks among subgroups are comparable. In making use of this method, it is important to acknowledge that variables must be uniformly defined, and that case-mix is a multivariate phenomenon. With a range of comparably defined measures, it would be possible to measure average outcomes while controlling simultaneously for a number of resident characteristics.

In evaluating outcomes of care using this method, it would be important to include measurements of discharge disposition. With the exception of the prevalence measure, these measurements are based on the proportion of residents still in the facility at the time 2 cross-section. The discharge disposition of those no longer in the facility is an important outcome of care. If data on discharge disposition were collected, ranges of rates of rehospitalization and death for certain subgroups of residents can be compared. This comparison is not made here, as the New York data did not allow us to distinguish among types of discharge.

Measures of average outcomes are not necessarily equivalent to norms for acceptable standards of care. When defined and measured uniformly, these measures will allow long-term care systems to identify and analyze regional variation in resident outcomes, as is possible in the acute care sector. Beginning in 1990, nursing homes began assessing their residents with the federally-mandated Minimum Data Set for Nursing Home Residents (Morris et al, 1991). The use of this instrument will result in a uniform set of core items on which data are collected for all nursing home residents in the country. When these data are available, the assessment of quality of care using methods such as this can be further developed and refined.

1. This definition of incidence may result in a failure to identify some cases which arise and are resolved between observations.

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TABLE 1:
PRIMARY PAYMENT SOURCE AT BASELINE

National Health Corporation, 1983 (48 facilities)			New York State, 1986 (111 facilities)		
	n	%		n	%
Medicaid	2362	51.4	Medicaid	9342	79.2
Medicare	924	20.1	Medicare	274	2.3
Self-pay	1071	23.3	Other	2179	18.5
Other	238	5.2			

TABLE 2:
LENGTH OF STAY AT TIME 1

National Health Corporation, 1983 (48 facilities)			New York State, 1986 (111 facilities)		
	n	%		n	%
<30 days	1409	30.4	<30 days	248	2.1
31-90 days	486	10.5	31-90 days	715	6.1
91-1 yr	1228	26.5	91-1 yr	2247	19.1
1-2 yrs	604	13.0	1-2 yrs	2381	20.2
2-3 yrs	337	7.3	2-3 yrs	1598	13.5
3-10 yrs	548	11.8	3-10 yrs	4042	34.3
10+ yrs	19	0.4	10+ yrs	556	4.7

TABLE 3:
RATES OF DECUBITUS ULCERS DURING SIX-MONTH PERIOD

	PREVALENCE	INCIDENCE	RECOVERY
NHC	n = 4595	n = 2625	n = 351
	15.56%	5.98%	45.58%
NY	n = 11,795	n = 8192	n = 1294
	15.41%	9.62%	51.12%

TABLE 4:
DECUBITUS ULCERS:RELATIVE RISKS AND 95% CONFIDENCE INTERVALS BY SELECTED RESIDENT CHARACTERISTICS

	PREVALENCE	INCIDENCE	RECOVERY
ADL Dependent			
NHC	7.18	3.55	1.15
	(4.85,10.64)	(2.10,6.00)	(0.61,2.15)
NY	6.13	3.17	1.14
	(4.83,7.78)	(2.48,4.05)	(0.90,1.46)

TABLE 5:
DECUBITUS ULCERS:RELATIVE RISKS AND 95% CONFIDENCE INTERVALS BY SELECTED RESIDENT CHARACTERISTICS

	PREVALENCE	INCIDENCE	RECOVERY
Comatose			
NHC	3.09	2.27	0.54
	(2.49,3.83)	(0.98,5.22)	(0.20,1.46)
NY	3.62	1.74	0.65
	(2.71,4.84)	(0.49,6.18)	(0.29,1.45)

TABLE 6:
DECUBITUS ULCERS:RELATIVE RISKS AND 95% CONFIDENCE INTERVALS BY SELECTED RESIDENT CHARACTERISTICS

	PREVALENCE	INCIDENCE	RECOVERY
Diabetes			
NHC	1.43	1.53	0.84
	(1.21,1.69)	(1.04,2.23)	(0.61,1.14)
NY	1.22	1.12	0.99
	(1.07,1.38)	(0.91,1.39)	(0.84,1.16)

TABLE 7
RATES OF PHYSICAL RESTRAINT USE DURING SIX-MONTH PERIOD

	PREVALENCE	INCIDENCE	DISCONTINUANCE
NHC	n = 4595	n = 1544	n = 1432
	47.18%	15.48%	14.80%
NY	n = 7548	n = 2654	n = 3401
	56.90%	22.65%	7.15%

TABLE 8:
PHYSICAL RESTRAINT USE:RELATIVE RISKS AND 95% CONFIDENCE INTERVALS BY SELECTED RESIDENT CHARACTERISTICS

	PREVALENCE	INCIDENCE	DISCONTINUANCE
ADL Dependent			
NHC	6.34	2.56	0.33
	(5.16,7.78)	(1.92,3.42)	(0.24,0.46)
NY	9.22	2.68	0.24
	(7.65,11.11)	(2.23,3.23)	(0.17,0.34)

TABLE 9:
PHYSICAL RESTRAINT USE:RELATIVE RISKS AND 95% CONFIDENCE INTERVALS BY SELECTED RESIDENT CHARACTERISTICS

	PREVALENCE	INCIDENCE	DISCONTINUANCE
Age 90+			
NHC	1.16	1.09	0.56
	(1.08,1.25)	(0.81,1.48)	(0.38,0.83)
NY	1.14	1.11	0.88
	(1.09,1.19)	(0.94,1.31)	(0.66,1.16)
Disoriented			
NHC	6.34	2.56	0.33
	(5.16,7.78)	(1.92,3.42)	(0.24,0.46)

TABLE 10:
CHANGE IN ABILITY TO TRANSFER DURING SIX-MONTH PERIOD

	DECLINE	IMPROVE
NHC	n = 748	n = 2228
	15.91%	7.81%
NY	n = 2030	n = 7456
	25.12%	3.72%

TABLE 11:
ABILITY TO TRANSFER:RELATIVE RISKS AND 95% CONFIDENCE INTERVALS BY SELECTED RESIDENT CHARACTERISTICS

	DECLINE	IMPROVE
Hip Fracture		
NHC	1.15	1.44
	(0.47,2.83)	(0.92,2.26)
NY	1.28	2.42
	(0.72,2.27)	(1.42,4.11)

TABLE 12:
ABILITY TO TRANSFER:RELATIVE RISKS AND 95% CONFIDENCE INTERVALS BY SELECTED RESIDENT CHARACTERISTICS

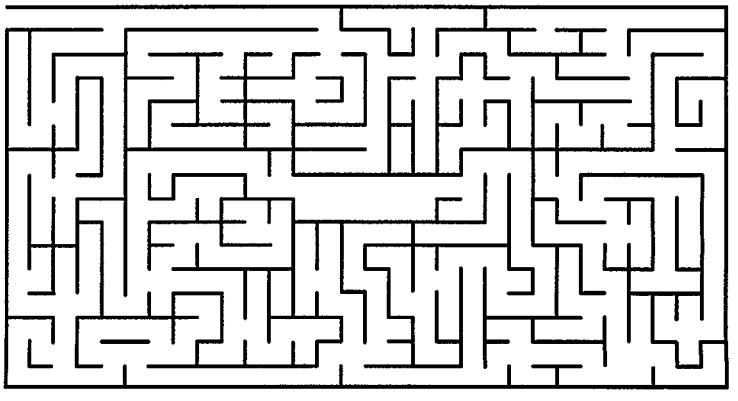
	DECLINE	IMPROVE
Stroke		
NHC	0.95	0.57
	(0.42,2.17)	(0.36,0.90)
NY	1.14	0.50
	(0.78,1.64)	(0.31,0.80)

TABLE 13:
RATES OF URINARY TRACT INFECTIONS DURING SIX-MONTH PERIOD

	PREVALENCE	INCIDENCE	RECOVERY
NHC	n = 4595	n = 2734	n = 242
	7.97%	1.72%	16.53%
NY	n = 7543	n = 5291	n = 759
	13.02%	8.62%	70.09%

Second Plenary Session

Assessment of Community Health



POVERTY IN THE NEW AMERICAN ECONOMY

Norman Fainstein, Baruch College, CUNY

You know better than do I the interconnections between low income, health, and health care--interconnections that stem from the behavioral attributes, geographical location, and employment situations of the low-income population. So this morning I want to take a step back in the chain of causality and talk mainly about the determinants of low income itself in the new American economy that has emerged since 1973.

As we'll see in a moment, that economy has been characterized by stagnation in the average American income, by rising inequality in its distribution, and by the need for two earners in many households in order to maintain a standard of living achieved by one earner in the previous generation.

During these last two decades, the American economy has also been restructured--in part because of the very loss of world domination reflected in our reduced standard of living. Manufacturing industries have declined in relative importance; service industries have expanded. High tech firms have grown while the old bread and butter industries like autos and steel have sharply contracted. This industrial reorganization has been accompanied, as we all know, by geographical shifts out of old central cities and whole regions--shifts that have hurt various segments of our less-mobile, low-income population.

But of greater importance, I think, has been the internal reorganization of businesses in our more competitive and less regulated economy. The character of work has become more unequal, with expansion in high-paying jobs and even greater expansion in low-paying jobs--leaving the middle behind. At the same time, firms have sought to free themselves from union restrictions and to become more flexible in their organization of the production process and in their treatment of labor. This turn toward flexibility has characterized manufacturing businesses as well as service firms. The result is that more and more workers with relatively low skills find themselves employed by contractors and subcontractors, with little security and few benefits--particularly health care. Thus, the janitor who once worked for General Motors at a good wage now works for a cleaning firm at a low wage with no benefits; the cleaning firm is a contractor to a local GM plant.

Add to this, the growth in the so-called informal economy of daycare workers, household servants, gypsy cab drivers, immigrant sweat shops, homeworkers in the garment industry, street vendors, not to mention drug dealers and others engaged in illegal work--I could go on. The "hollowing out" of the corporation and the informalization of parts of the labor market have put more and more households with relatively lower levels of education and skill in an ever more precarious position. These households face an economic system with increasing numbers of less desirable slots.

Economic restructuring has been accompanied since 1981 by national governmental policies that have substantially contributed to an upward redistribution of power and income. These policies included a shifting to the states of targeted programs for the poor, which were initially maintained, but then declined significantly with the state-government fiscal hardship of the last several years. It should, therefore, hardly come as news to those of us who daily encounter the homeless, that declining incomes at the bottom have been accompanied by the elimination of virtually all federal low-income housing programs. In the name of establishing a safety net, benefits for low-income citizens just **above** the poverty line were decimated. Here, for example, the federal government contributed to the declining college graduation rates of blacks and Latinos, as it withdrew support from college scholarship programs. Tax policy has reduced the importance of progressive personal and corporate income taxes in favor of flat or regressive Social Security and Medicare payroll taxes. Similarly, contraction in federal aid to states and localities has meant that more of their activities are now financed by the less progressive part of the national tax system. Finally, the courts and the national administration have seriously reduced the effectiveness of labor unions in all industries. Together, these governmental actions and non-actions substantially magnified the tendencies toward greater inequality already inherent in economic restructuring.

I've avoided the subjects of poverty or the poor up to this point because I want you to think about them within the context of our changing political economy. For nearly a decade discourse about economic deprivation have been framed in quite a different

way. Maybe I should say that there have been two discourses--rather distinct bodies of literature, speeches, conferences, and the like. One set of researchers--mainly political economists--has been talking, as I have been here, about income distribution, economic restructuring, wages, the disappearing middle class, the declining competitive position of African Americans and Latinos. The other--mainly sociologists and anthropologists--has been talking about the "underclass"--

> that heterogeneous grouping of inner-city families who are outside the mainstream of the American occupational system. Included in this population are persons who lack training and skills and either experience long-term unemployment or have dropped out of the labor force altogether; who are long-term public assistance recipients; and who are engaged in street criminal activity and other forms of aberrant behavior.

It's no wonder with words like these of William Julius Wilson (1985: 133) that the idea of the underclass has captured the American imagination. After all, there are many people who **do** fit this description, and not just in Spike Lee's films. So, too, has the concept of the underclass framed numerous academic studies and been the subject of conferences here and abroad.

In brief, scholars working within the paradigm of the underclass have emphasized the isolation of this population from middle class households and role models, the tangle of pathology associated with out-of-wedlock births and female-headed households, and the increasing concentration of the poor in inner-city neighborhoods, where they are spatially isolated from employment opportunities, for which their low skill levels have left them relatively unqualified in any event.

Serious debate have arisen among those focusing their attention on the underclass with regard to the relative importance of culture and economic opportunity, the significance of spatial isolation and concentration, the contribution of public policy to so-called welfare dependency, and the importance of gender in maintaining and reproducing the underclass. Indeed, recent studies have discredited many key assumptions about the underclass.

For example, Massey and Eggers (1990), in a definitive review of evidence from the 1970s, have shown that the increasing spatial concentration of poverty in city neighborhoods is **not** produced by middle class people moving out of the ghettos--leaving only the desperately poor behind. Rather, they finds persistently high levels of housing segregation has kept better-off minority households in relatively close spatial contact with the urban poor.

Other studies (Fainstein, 1987, Waldinger 1989) have demonstrated the empirical weakness of claims that the service economy requires higher levels of skill than did manufacturing--skills which the poor do not have. They have instead shown the continuing importance of race and gender in channeling the poor into the bottom of an employment structure generating an increasing proportion of low-skill, low-wage jobs in every sector.

The jury is still out on testing all the hypothesis associated with various versions of the underclass paradigm. Suffice it to say, however, that the debates about the underclass have tended to displace interest in the broader subject of economic deprivation and its sources in our evolving national political economy.

Undoubtedly there is an underclass. But I would argue that it is only a fraction of those who fall beneath the poverty line, just as the set of households officially defined as in poverty encompasses only a fraction of those with low incomes. A conservative guess is that the attributes associated with the so-called underclass fully apply to less than 10 percent of U.S. households with low incomes, and perhaps 20 percent of those under the federal poverty line. Of course we should study households with multiple social liabilities, as well as the experiences of people living in desperately poor and drug-ridden neighborhoods. Attention to the underclass has broadened our understanding of the individual and communal attributes of those who have dropped out of our economy. But as University of Pennsylvania historian Michael Katz has noted in his recent book, <u>The Undeserving Poor</u> (1989: 196), obsession with the underclass has deflected attention "away from the more intractable, growing, and potentially subversive problems of the working poor: increasing income inequality and the bifurcation of America's social structure."

In my view, it is simply impossible to explain economic and social failure without a structural analysis of the

conditions that establish economic risk, as well as those which make certain individuals and groups more likely to succumb to it. From this perspective, it is the economy and governmental policy which increase or decrease risk at the bottom. When there is no economic growth and increasing income redistribution upward, then there will be more low-income households, more households under the poverty line, and more out of the system altogether. To see who falls into each category, of course, we have to take a more fine-grained look at factors like race and geography.

It is simply bad social science to examine the underclass in isolation from the larger economic forces that create it, just as it is bad social science to look at the homeless without examining incomes, housing prices, urban redevelopment, and national housing policy; or to try to explain typhoid fever in terms of the beliefs and life styles of its victims, without paying due attention to water supply and sewerage treatment.

Let me now quickly show you some data that illustrate the diversity of low-income households, the growth of income inequality, the continued employment disadvantage of women and minorities, and the increasing tendency of our economy to generate low-wage jobs.

EXHIBIT 1. While it is certainly true, as you heard from Dr. Pappas, that poverty has become increasingly feminized, it is also the case that an important share of **in-tact** families live in poverty. These married-couple families generally do not receive welfare benefits, do not fall into the behavioral category of the underclass, and are usually in the labor market. In this exhibit, it is worth noting the racial differences among poor families--the similarity of Hispanic and white families as compared with black families. I should note that 32 percent of non-poor black families were female-headed in 1989.

EXHIBIT 2. Most poor families, including those that are female-headed, participate in the labor market, with about a fifth of whites and Hispanics working full-time, year round--but at "poverty" wages. Here, again, black families showed somewhat lower levels of work history. Still, in none of these categories can we assume that being poor can be equated with being outside of the labor market.

Exhibit 3. Here we see first that real median family income barely changed for anybody during the last two decades, and that it noticeably decreased for Hispanic families, possibly as a result of recent immigration. Second, the percentage of families with very low income, less that $14,999, increased for every racial group. Third, the percentage of American families with incomes of less than $25,000, or 73 percent of median family income, comprised over 31 percent of white families, 58 percent of black families, and almost 53 percent of Hispanic families. While the official poverty rate stood at 10.3 percent of families in 1989, clearly a much larger fraction of our citizens lived under conditions of economic hardship. Most of these families were not even officially defined as poor.

Exhibit 4. Since 1973 overall economic inequality has grown substantially, as income has been distributed upward in a basically stagnant economy. Many indicators point in the same direction, including the Gini coefficient and measures of both pre- and post-tax income shares. In this exhibit we see a rather striking demonstration of economic bifurcation by comparing the mean incomes of the wealthiest fifth of families to the poorest fifth, controlling for family size. This ratio of inequality increased by more than a third--remember again--during a period of unchanged real incomes.

Exhibit 5. Now I would like to look at wages. The upper panel shows the earnings of full-time white, black, and Hispanic women workers as a percentage of the average earnings of all men in a given year. Notice that the earnings of Latinas and black women rose substantially until the 1970s, when they converged with those of white women. Yet the earnings of all women have always remained substantially below those of men--with white women, the best paid group, now earning about 65 percent of male wages. For women, gender matters more than race in determining earnings.

The lower panel presents average earnings of black and Hispanic men as a percentage of those of white men. By the seventies, black and Hispanic males had similar earnings. Both groups earned much less than white men, and their relative position deteriorated after 1973. Among male earners, the economic disadvantage of minority men has intensified. Remember, again, that these are fully employed workers, not

the official poor, and certainly not the underclass. Their situation is actually even worse than we see here, because average white earnings declined absolutely during the period. The last exhibit will give you a better look at what has happened.

Exhibit 6. Harrison and Gorham (1990) have shown that the new American economy is generating jobs for men with lower real average earnings than in the past, in large part because of increasing inequality in the distribution of wages; on top of that, more low-wage jobs are being created than high wage jobs. The exhibit before you divides jobs into classes by their average wages as a fraction of the prevailing official poverty line for a family of four, about 12,000 "1987" dollars. We see that for both black and white men of prime age, low-wage jobs expanded in the 1980s and high wage jobs contracted. From the perspective of some economists and business leaders, this trend meant that American workers were becoming more competitive with low-wage workers in much of the Third World. For others of us, our society was in fact joining the "third world," becoming more economically unequal and ethnically divided.

Let me close by observing that although in the past, economic growth was always accompanied by inequality, real well-being increased for nearly everyone. Now, growth is much more difficult to achieve in a competitive world. A combination of business decisions and government policy has resulted in an American approach to competition that has emphasized increasing the absolute supply of labor--through the entry of women and immigrants into the work force--while driving down wages (Levy and Murnane, 1991). Other countries have been much more successful at keeping up wages; they have increased work force productivity by prudent investment encouraged through government policy. They have both grown more rapidly than us and kept inequality in check. We would do well to consider as a nation the likely consequences of our path to competitiveness--an ever more unequal distribution of wages and income--not just for the health of the poor left behind, but even more for those of us who have prospered.

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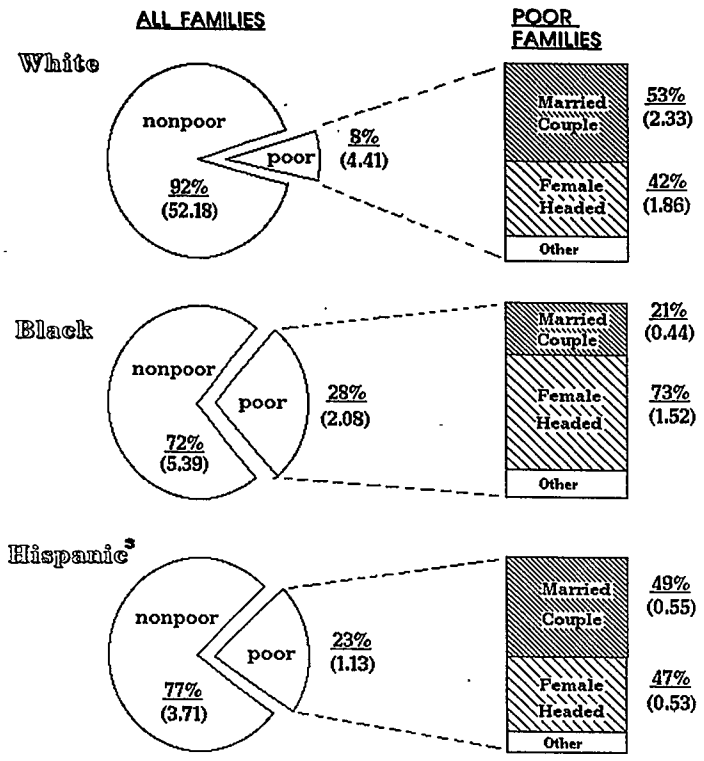
Exhibit 1

Family Composition[1] and Poverty,[2] 1989

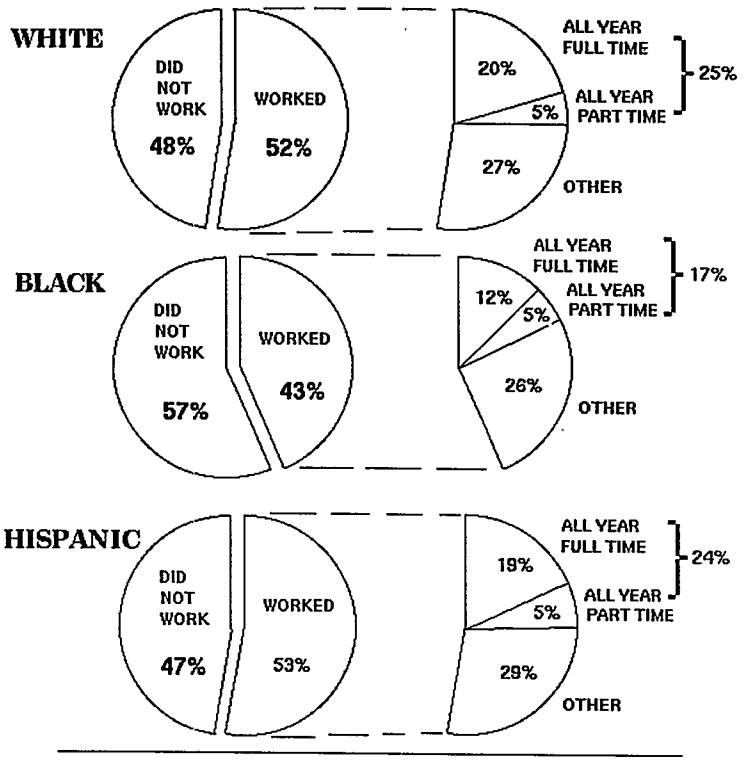


1. Millions of families in parentheses.
2. The poverty threshold for a family of four was $12,675 in 1989.
3. Hispanics may be of any race.

Source: U.S. Bureau of the Census, Current Population Reports, Series p-60, No.168 (September, 1990), Table 9.

Exhibit 2

Work Experience of Householder for Families in Poverty, 1989



Source: U.S. Bureau of the Census, Current Population Reports, Series P-60, No. 168 (September, 1990), Table 23.

Exhibit 3

Very-Low-Income and Low-Income Families as Percentage of All Families in Each Category, 1973 - 1989

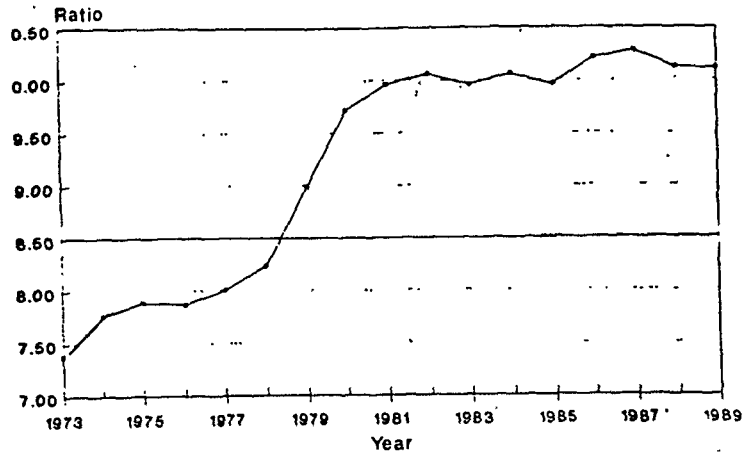
	Income[1]	1973	1979	1984	1989
WHITE	Less than $14,999[2]	14.3	14.6	17.4	15.2
	$15,000 to $24,999[3]	16.7	17.7	17.8	16.4
	Median	$35,175	$34,910	$33,042	$35,975
BLACK	Less than $14,999	37.8	38.5	42.6	38.5
	$15,000 to $24,999	22.7	21.7	20.9	19.5
	Median	$20,301	$19,768	$19,344	$20,209
HISPANIC	Less than $14,999	26.1	28.0	26.7	30.7
	$15,000 to $24,999	25.2	23.9	21.2	21.9
	Median	$24,339	$24,200	$22,475	$23,446

1. Income expressed in 1989 CPI-U adjusted dollars.
2. Less than 44 percent of 1989 U.S. median family income. We consider families in this category to receive very low incomes.
3. Between 44 and 73 percent of 1989 U.S. median family income. We consider families in this category to receive low incomes.

Source: U.S. Bureau of the Census, Current Population Reports, Series P-60, No. 168 (September, 1990), Table 8.

Exhibit 4

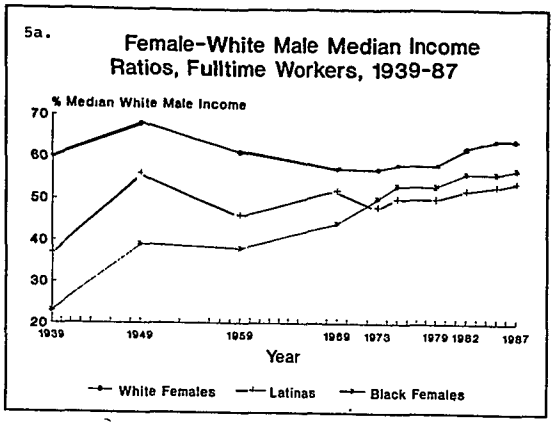
RATIO-AVERAGE INCOME OF RICHEST 20 PERCENT COMPARED TO THE POOREST 20 PERCENT, 1973-89



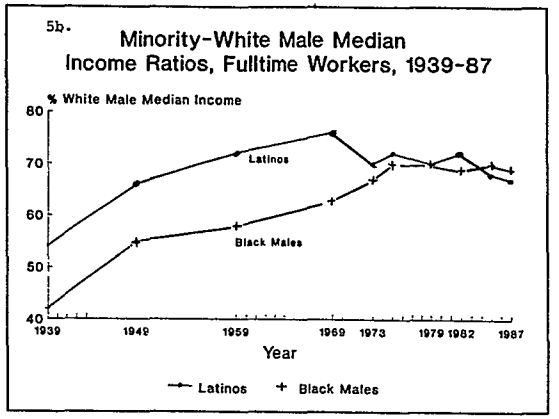
Source: U.S. House of Representatives, Committee on Ways and Means, Overview of Entitlement Programs, 1991 Green Book, 1991, p. 1191.

Exhibit 5

5a.



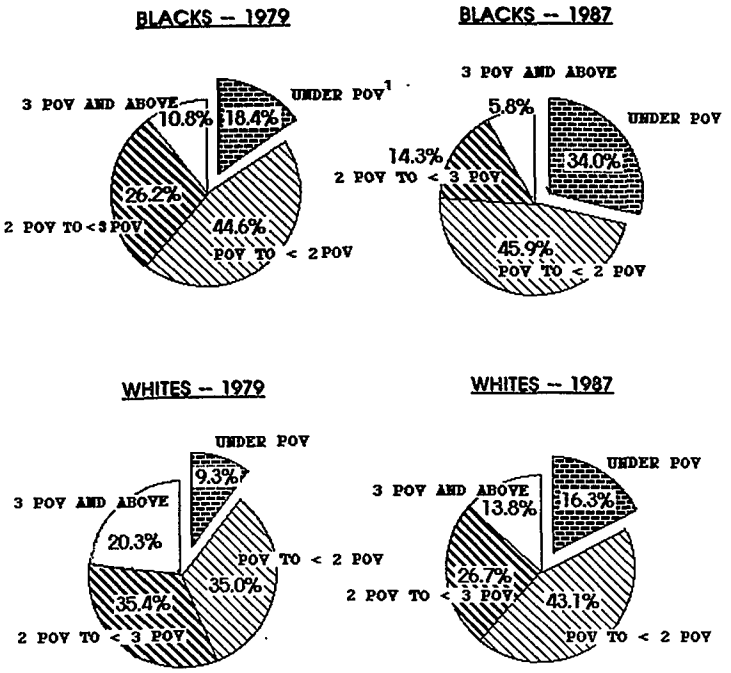
5b.



Source: Martin Carnoy, Hugh Daley, and Raul Hinojosa Ojeda, Latinos in a Changing U.S. Economy, Research Foundation of the City University of New York, 1990.

Exhibit 6

Dist. of Employment by Full Time Equivalent Wages
Men Aged 25 - 34



1. About $12,000.
Source: Bennett Harison and Lucy Gorham, Growing Inequality in Black Wages in the 1980s and the Emergence of an African-American Middle Class, School of Urban and Public Affairs, Carnegie Mellon University, 1990.

FAMILIES, POVERTY AND THEORIES OF CULTURE

Ida Susser, Hunter College

The term "underclass" (Wilson 1987) and its relationship to the 1960's concept of "culture of poverty" has been a source of controversy. In the view of this writer, neither term adequately summarizes the plight of the urban poor, for each implies in different ways a separation between poor and not poor, which is illusory. The argument developed in this paper is that whereas the term "underclass" connotes social isolation of displaced workers and people without homes, it is precisely the social interaction and active intervention of government institutions, schools, health care, police and as I shall argue shelters, which structures the lives lived by the poor, whether we label them unemployed working class, urban poor or "underclass".

Much of the discussion of underclass and poverty and its causes centers around the family or household structure: questions of female headed household, teenage mother, absent fathers, abandoned and neglected children. The research presented here suggest that these life pattern are based on interaction with mainstream institutions as they affect members of different classes within complex society.

This is not a new argument: it has been ongoing for some time in literature concerning poor and minority families in the U.S. However, in examining the shelter system in New York City we see the re-emergence of old patterns in new institutions.

On the basis of a study of household structure and gender as found in the New York City shelter system between 1987 and 1991, this paper examines the institutional processes which have led to the present situation and which maintain current conditions (along with structural unemployment in the formal sector for men, low paid service sector jobs for women and general patterns of racial discrimination (which are documented elsewhere by other researchers). In discussing the poor who have lost or are losing their homes, this analysis emphasizes their interaction with government institutions rather than their exclusion from participation to explain gender socialization and household patterns over the lifestyle.

History of Homelessness in New York City

The shelter system: divisions by age and gender

People's access to Shelters in New York City is largely determined by sex, age, mental status and family structure. "Single" men are usually assigned to large barracks in the city's armouries. In such places up to 700 cots are lined up in the main hall. "Single" women without children are assigned to other armouries. Such single adults have no access to the hotels and voluntary agency settings to which families are sometimes assigned. Men are not allowed in women's barracks and women are not even allowed to walk across the hall to where the men sleep.

Women with young children are also assigned to large congregate sleeping shelters, but this is supposed to be a temporary measure. If they are fortunate women with young children may be sent to stay in homeless hotels, or if even more fortunate, they may be allocated "transitional" housing run by voluntary associations. In the transitional housing, which is the most humane currently offered, multiple restrictions determine access. One such institution houses only mothers with daughters under 18, sons under 12. Men were allowed to visit at certain hours in the basement. They were never allowed in women's rooms. Another transitional facility only houses women with children under 9 years old. In this facility, there are no visiting hours for men and they are not allowed to enter the institutions at all, unless as employees. Visiting female relatives, such as grandmothers were not allowed into the shelter unless they had scheduled an appointment. Women and children stay in these facilities from six months to over a year.

In the homeless hotels financed by the city, similar restrictions are enforced, although many more men are in evidence. Women with children are officially allocated rooms in these hotels and the private management is paid by the city. If husbands are listed as recipients of public assistance in the household, they too are allowed to stay in the hotel. However, frequently, due to the complexity of public assistance

regulations, men are not listed on a household budget and therefore not entitled to enter hotels with women and children. One major difference between hotels and transitional housing is the level of security. It is possible for men not officially listed as residents to find their way into hotels whereas this is highly unusual in transitional housing.

Thus, the main institutions created for homeless people where men and women can live together with their children are privately managed, for-profit hotels, which have little to recommend them in any other way. Even in this case, most men have to sneak into the rooms against regulations. It is in fact these poorly maintained buildings from which people were being removed by the city to be placed into transitional housing, or apartments.

It is significant in light of general arguments about absent fathers and irresponsible young boys which abound in discussions of the underclass, that the institutional separation and exclusion of males from the household structure starts at an early age in the shelter system. In transitional housing, teenage girls may be allowed to stay with their mothers, but not teenage boys may not. If a woman accepts such housing she must give up her older boys to foster care or the supervision of relatives. Private hotels have no such regulations. However, in the course of field work in one hotel, a researcher was informed that the "manager" (the private businessman) who runs the hotel, "doesn't allow teenagers". This rule clearly referred to young boys as there were numerous teenage mothers permitted to live in this hotel.

In fieldwork in the Hotel in the fall of 1989, fathers were observed picking children up from the day care center in the hotel, staying with children in their rooms while the mother was out, meeting children at school and bringing them back to the hotel, caring for babies and children when their mother was sick and in general assisting in family life.

In spite of their official absence from statistics and measures of households among the poor, men were much present among the families of the homeless. As soon as women we worked with were relocated to apartments, men were in evidence. But within the institutions, both hotels and transitional housing, men and young boys were relegated to the status of criminals and reduced to sneaking in illegally (in the hotels) or shut out all together (in the transitional housing).

Research in a shelter for "single" men suggests that many men spend weekends visiting girlfriends, wives and children, (Susser and Gonzalez, 1991). However, the overall impact of the shelter system is to separate households and undermine whatever cooperation or dual responsibilities may be developed between men, women and children.

The exclusion of young boys and men from the family has been documented in public assistance programs since AFDC was implemented in the 1930's. In my own work concerning poor residents of New York City, 1975-78, I documented the exclusion of young men from public assistance and the harassment of young men when they applied for relief. Young boys and men were in fact supported by households on public assistance, but women were unable to list them for fear of problems with their own eligibility. Even boys 12 years of age were dropped from public assistance rolls because of bureaucratic hurdles (Susser, 1982). I am suggesting here, that first, as in the extreme case of homelessness, the young boys are excluded by regulations which, while confusing and varied, follow regular patterns. Boys are subject to a variety of pressures which separate them from household and family and, unlike their sisters, they cannot expect assistance for rearing children. Later on, boys are portrayed as absent fathers, or seen as unmotivated in terms of marriage and family commitments. However, these portrayals cannot be clearly understood without an analysis of the ways in which boys have already been excluded from participation in family life and the regulatory hurdles which men must surmount in order to take on fatherhood.

Static labelling involved in discussions of underclass and culture of poverty fails to capture the dynamic processes which create and recreate families and households in the U.S. today. Any category which situates people outside the ongoing pressures of the government regulations and changing employment structure implies that only personal characteristics and motivation could lead to such conditions. In fact, data from the shelters suggest that consistent barriers exist here against formation of nuclear households among the poor in the U.S. I would not in anyway advocate the removal of services for the poor under current conditions, but rather a more in depth examination of why social services continue to replicate the patterns of the past in consistent, gender-specific ways.

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ASSESSMENT OF COMMUNITY HEALTH
DISCUSSANT

Gail F. Fisher, Ph.D., National Center for Health Statistics

Today's sessions following this plenary deal with improving our capacity to assess community health. Look at some of the problem areas - substance abuse - AIDS - homicides -They are difficult problems to measure and they are complex.

Dr. Fainstein and Dr. Susser have started this day by sharing their perceptions of factors - particularly poverty - which are impacting on the health of urban populations. I listen to their discussions with an ear to what we need to know to improve public health and health care programming today.

It is only by looking ahead and applying the best product of the skills and insights, not only of health professionals - but also of social scientists - that we can hope to assure that data relevant to the issues will be available. I welcome the presentations this morning as they contribute to that process.

I am a firm believer that you cannot solve a problem that you do not understand. I continue to be appalled that so many of our health leaders on the firing line of program development and management must decry the lack of information upon which they base their decisions and actions. It is an unacceptable situation.

I serve in a variety of capacities in which I listen to or participate in discussion of gaps in data, needs for data, and projections for the future. I have long been involved in planning for NCHS programs, I serve as Executive Secretary to the NCVHS and my office coordinates NCHS activities with many different organizations. We have recently provided staff support to the 22.1 committees's work on health indicators. Based on those experiences and listening to our speakers yesterday, and this morning, it is clear that we, and when I say we I mean the broader community of public health and statistics, must define and measure more effectively what is going on in problem areas and in populations with unique problems that affect health behavior and health outcomes. If you will, we need to be studying small pockets of people and the social health problems that are somewhat unique to their situation -- a relevant term is community assessment. Our capacity to measure health problems and trends at the national level is solidly based; improvements in methods are at least keeping pace with emerging health problems; and the needs for expansion in the future are fairly well defined and feasible. Our capacity to study small population subdomains is much weaker.

We should leave these sessions with an awareness for the 1990's, in consonance with the year 2000 objectives, that we will be focusing on small area statistics with increased emphasis. We will be conducting community assessments with sufficient sophistication to permit the development and evaluation of specific and effective health programs. When we speak of community assessment we should not just be speaking of statistics for a large metropolitan area, several large counties or regions of a state. We should have the capacity, when it is required for programmatic purposes, to measure what is going on in particular subgroups within those larger areas, whether they be identified by minority status, socio-economic status or other relevant descriptors. We need to be able to describe the health problems of those in poverty, the homeless and those living in areas characterized by violence. The documented changes in health patterns and program needs are moving us in this direction. So many of our health problems are not evenly distributed throughout our population and communities today.

Many of the standard measurements remain important: age, race, sex, income, education and occupation - but the complexity of the problems we are dealing with require much more. Changing demographics, changing family structure and new profiles of health problems stretch our imagination for ways to count, measure, quantify, and analyze. Dr. Susser's presentation highlights the problems of responding to and identifying family structure and inter-personal relationships relevant to social, economic and emotional support among the homeless. The usual classifications for family structure become irrelevant in populations where the norm varies greatly from the population as a whole or from the way that we, as statisticians and health workers, expect it to be.

Dr. Fainstein presents in a profound manner the interconnectedness of the problems we are facing. He highlights the

need to understand the problems where they happen in real communities.

As health workers we need to know on some kind of continuing basis how individuals and families cope with economic crises as related to the need for health services. Indicators of family income, economic status and the existence of some form of health insurance won't answer all the critical questions. We need indicators to identify the support mechanisms used by individuals and especially for children where "traditional" family ties are inappropriate. What descriptor do you use as a child moves from one geographic location to another in a city as care shifts among more distant relatives and associates on a day to day or week by week basis. How do individuals and families cope, or not cope, with child care needs in specific environments?

What models do we accept for prediction and measurement of progress? The smoking model is an example of one we understand and accept - a fairly simple model - the behavior of smoking is addressed as predictive of subsequent expectation of lung cancer. What models work for child abuse? for illicit drug abuse? for suicide?

Looking at today's topics, the subject of today's sessions - the models will be much more complex in the future.

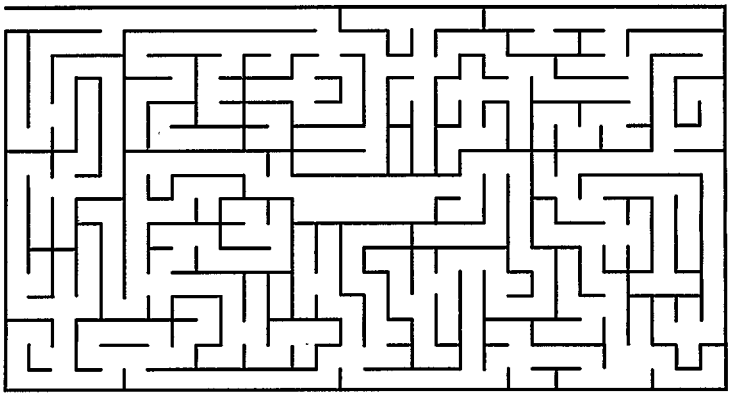
Dr. Susser addressed the problems of the homeless. Consider, as an example, the homeless in terms of public health programming needs. The requirements for services differ greatly among the varying components of the homeless population. A community public health leader needs to know how many homeless are in the community; how many have severe mental, emotional and substance abuse problems, and of what nature? How many are families in difficulty economically on a temporary or long term basis? Also, the health leadership needs some assessment of the future in terms of predictive trends in the size of the various components of that population. What are the economic forecasts for that community? I know that some will say - we don't have the tools to provide precise data for such difficult problem areas. I have more faith in the combined skills of health statisticians and social scientists. We can provide data sufficiently adequate to guide programs. Ineffective programs are very wasteful. The benefits of well designed programs based on factual data and sound models will more than offset the costs of obtaining the data.

Yesterday, Dr. Hussein indicated that we could not develop good programs on the basis of hearsay. Good data guides good programming. I applaud the Year 2000 activity in which communication between program directors, statisticians and epidemiologists was enhanced and the importance of good data was recognized and publicly endorsed.

It will take the combined efforts of many to address the complex problems we face. We need the insights and experience of social scientists as we develop new and improved methods and approaches. They assist greatly in identifying populations in trouble and developing sound models upon which to base health and other social action programs. We thank Dr. Susser and Dr. Fainstein for their contributions this morning and look forward to the sessions following this plenary.

Session I

Infant Mortality, Reproductive Health, and Birth Outcomes



A SYSTEMATIC APPROACH FOR TARGETING RESOURCES AND INTERVENTION STRATEGIES AGAINST INFANT MORTALITY

George H. Walter
Maternal and Child Health Bureau

(Not available for publication)

THE EFFECTS OF WIC AND MEDICAID PARTICIPATION ON PREGNANCY OUTCOME

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INTRODUCTION

Infant mortality and low birth weight remain difficult problems in the U.S. and especially in Georgia. There the infant mortality (IM) rate ranked 50th in 1988, just ahead of the District of Columbia[1]. The determinants and consequences of IM and LBW and the special effects of poverty on pregnancy outcome have been extensively described[2-10]. The contribution to healthy babies made by health services, including the amount of prenatal care and the receipt during pregnancy of nutritional, health education, and other non-medical services that support good outcomes, depends on the availability of such services to pregnant women. Low-income mothers often must depend on the public sector for these services, if they receive them at all. Under conditions of constrained public resources, assuring the availability of these services depends in part on demonstration that these services are effective. Do public programs that provide prenatal care and other pregnancy support help the recipients of those programs to have healthier babies?

The Medicaid program, which pays for health services for some of the poor, and the WIC program (Special Supplemental Food Program for Women, Infants, and Children), which provides food, health education, and screening for nutritional risk for low-income women and children, are two such programs. The record that prenatal care received under Medicaid is effective is mixed[11,12], but prenatal care in general has been shown to be associated with better outcomes, and similar prenatal care provided by the Medicaid program is likely to be similarly effective. WIC's effectiveness has been the subject of two national studies[14,15] and several state studies[16-19]. In the national studies, WIC participation was associated with higher birthweights, modest reductions in LBW rates, and variable reductions in neonatal mortality as well as cost savings to Medicaid for health care of the infants. The state studies, which were smaller and employed a variety of different controls, generally show modest reductions in LBW rates and IM. The results vary with locale, as do those of the national studies when individual states are reported.

METHODS

Data sources:

The data come from three sources: Georgia vital records (birth and linked infant death files), Medicaid paid claims, and WIC administrative data. Medicaid claims records were searched for the appropriate procedure code (ICD9 or CPT) or the appropriate revenue code (which indicates site of service provided) that indicate newborn delivery. False labor claims were removed and duplicate records deleted. All claims for nine months prior to the date of delivery (child's date of birth) were appended to create a unique record of paid claims and dates of service for every woman whose delivery was paid for by Medicaid. A file describing WIC participation was created from WIC administrative records for 195,820 women served in the program from April 1984 through May 1989. These are unique longitudinal records that contain information about program participation dates and eligibility status (as a prenatal or post-partum client) for each participant. These were matched to a corresponding certificate of live birth in a manner described below. Infant birth and death record linkage is done routinely in Georgia, providing information about infant deaths.

Record linkage:

In 1987, Medicaid paid for 23,778 births in Georgia. These were matched to 105,788 births to all mothers in Georgia in an iterative process that used identifiers common to both files. These included Social Security number (SSN), followed by combinations of the mother's birthdate, first name, maiden name, current last name, previous last name, county of residence, and the name of the physician who performed the delivery. At each step an identifier was created from selected combinations of these elements and the record was brought into the match against the opposite file if the combination was unique (no other record with the same combination of mother's birthdate and first name, for example). If a match was found it was verified by checking that a separate identifier also matched in the two records, and the matched record was output to a file. The flow of this process and its yield is described in the appendix, Table A. Overall, 92% of the Medicaid records were matched, the great majority by use of the SSN (80%). Non-singleton Medicaid records (113 pairs of twins) were matched separately; 84 of these (74%) were matched successfully (not shown).

A similar process was followed to match WIC records to these same 105,788 births. Unlike the Medicaid file, in which the universe of Medicaid births in 1987 is known, WIC records do not always specify who may be expected to have delivered a baby in 1987. In the majority of cases, a mother returns to the WIC office after delivery to receive post-partum benefits for herself and her child, and provides the baby's date of birth at that time. By this method, 21,388 women were known to have delivered in 1987. The flow of this match and its yield is described in the appendix, Table B. Overall, 91.7% of these records were matched to their corresponding birth certificate. Non-singleton births were matched separately and are included in this total.

In order to find those women who participated in WIC as prenatal clients but did not return to provide the baby's Date of Birth, a separate match of all 195,820 WIC records for women who participated at any time between March 1984 and May 1989 was run, yielding 24,628 matched records (Table C, appendix). These were searched for records that had not already been matched (13,597 non-duplicate matched records), and these were added to the 19,614 records already matched, yielding 33,211 matched records. Without knowledge of the baby's date of birth this match can proceed through only three iterations and is incomplete; from Table 2 it can be seen that after these same three steps a 71.4% match rate had been achieved. This allows an estimate that when these match results are pooled an approximate match rate of 83.4% is achieved (19,614 records matched at a 91.7% rate and 13,597 records matched at a 71.4%).

Sample Selection:

After record linkage was complete, Medicaid participation was further defined as receipt of some Medicaid-paid service during the nine months preceding the date of delivery. This

caused reclassification of 3954 births (22%) in which the only Medicaid-paid services during that pregnancy were received at the time of delivery or post-partum. All Medicaid recipients were Georgia residents. Similarly, 5061 WIC births (15.6%) were reclassified because the mothers either did not participate in WIC during the 1987 pregnancy, (matching because of previous or subsequent WIC participation), or because the mothers participated for less than a single month, failing to return to pick up food vouchers after an initial certifying visit to the WIC office, or they participated only post-partum. Finally, only births to Georgia residents (as indicated on the birth certificate) were analyzed, excluding 124 matched records. The final sample totaled 28,026 WIC births.

Logistic regression was used to estimate odds ratios in separate models for two outcomes, infant mortality and low birth weight. Both models included age (classified as < 20 years), race (white, non-white), education (High School graduate, non-graduate), and the adequacy of prenatal care (calculated by the Kessner Index - adequate, all other) as well as the two variables of interest - Medicaid and WIC participation. All possible interactions between age, race, education, prenatal care, Medicaid participation, and WIC participation were explored, and significant interactions (Wald statistic $p<.05$) were retained in the final models. Confidence intervals (95%) for odds ratios are calculated using variance and covariance estimates as described elsewhere[20]. Regression coefficients, standard errors, and covariance estimates are not provided here but are available from the author upon request. Estimates for odds ratios are presented at each level of risk determined by age, educational attainment, race, and prenatal care.

RESULTS

In 1987 there were 102,486 births to Georgia residents (Table 1). Of these, 17,363 were to women who spent part or all of their pregnancy on WIC, 7,125 to women who received some medical services paid for by Medicaid in their pregnancy prior to delivery, and 10,663 who received both benefits. Additionally, there were 67,335 births to other women, i.e., those who had neither benefit. Table 1 also shows that the distribution of the four risk factors for poor pregnancy outcome used in the analysis is unequal across these four groups. Medicaid women with or without WIC are at highest risk; compared to women on neither program, Medicaid mothers are roughly 3 times as likely to be teenagers or non-white, or non-high school graduates and are at nearly twice the risk to have had inadequate prenatal care. The group of WIC-only mothers has a level of risk between Medicaid and the non-WIC, non-Medicaid group. Table 2 shows the unadjusted number of infant deaths and low birth weight births and the corresponding rates. The unadjusted risk of death for babies of Medicaid-only mothers is over twice that of other groups, and the risk of low birth weight is between 1.4 and 1.7 times higher. Babies born to WIC mothers, with or without Medicaid, have slightly lower risk of death and a slightly higher (1.3 and 1.1 respectively) unadjusted risk of low birth weight.

Table 1
SELECTED RISK FACTORS BY WIC AND MEDICAID PARTICIPATION

	TEEN (%)	RACE NON-WHITE (%)	DIDN'T GRADUATE HS (%)	INADEQUATE PRENATAL CARE (KESSNER)	N	%
OTHER	9.4	22.7	14.5	27.2	67335	65.7
WIC ONLY	28.4	48.8	40.4	47.3	17363	16.9
WIC & MEDICAID	34.8	70.5	50.7	52.6	10663	10.4
MEDICAID ONLY	28.2	70.1	51.4	58.0	7125	7.0
				TOTAL	102486	100.0

Table 2
INFANT MORTALITY AND LOW BIRTH WEIGHT RATES BY WIC AND MEDICAID PARTICIPATION (unadjusted)

	DEATHS	RATE	LOW BIRTH WEIGHT	%
OTHER	788	11.7	5028	7.5
WIC ONLY	193	11.1	1529	8.8
WIC & MEDICAID	122	11.4	1013	9.5
MEDICAID ONLY	165	23.2	925	13.0
ALL	1268	12.4	8495	8.3

Separate logistic regressions were run for IM and LBW. With IM as the outcome, the relevant interactions are between the Medicaid term and age, and between the Medicaid term and prenatal care. There were no interactions between WIC and any term, including Medicaid. Chi-square for the deviance of this model (-2 times the log likelihood ratio) with 8 degrees of freedom was 354 ($p=.0001$).

The interaction pattern with LBW as the outcome is more complex. There are interactions between WIC and race,

and between WIC and education. Age, prenatal care, and race showed interactions with the Medicaid term. There was no interaction between WIC and Medicaid. Chi-square for the deviance of this model with 11 degrees of freedom was 1737.6 ($p<.0001$).

Table 3 presents adjusted odds ratios and confidence intervals for each combination of the risk factors for both IM and LBW. Odds ratios are expressed as the ratio of the odds of the outcome (infant death or low birth weight) among participants to the odds among non-participants. An odds ratio of less than 1.0 indicates a reduction in risk for program participants. For uncommon events (IM occurs approximately 1-2%, LBW approximately 10%), odds ratios are good estimates of relative risk. An appropriate interpretation of the odds ratio for IM among WIC participants from Table 4 (.58) is that such women are only 58% as likely (or 42% less likely) as non-WIC participants to suffer an infant death. The pattern seen in the table is that the largest reductions in risk for both IM and LBW associated with Medicaid and/or WIC participation are achieved by women at the highest risk - those who are teenage mothers, non-white, with low educational attainment, and inadequate prenatal care. Lesser risk reduction is achieved by lower risk women, so that for some combinations of age, race, education, and prenatal care, risks for IM or LBW are actually greater for Medicaid and WIC participants.

In general, WIC participation without Medicaid is associated with a reduction in IM at all levels of risk, and with a reduction in LBW for all but white high school grads, for whom the odds ratio is statistically indistinguishable from 1.0. Medicaid participation* without WIC is associated with a reduction in IM for teenagers with inadequate prenatal care, and with an increase for non-teenagers with adequate care; for others the odds ratio is statistically indistinguishable from 1.0. Medicaid without WIC is associated with a reduction in LBW for mothers with three or four of the risk factors, and with an increase for those with one or none. Generally, mothers with two risk factors show odds ratios statistically indistinguishable from 1.0. Finally, participation in both programs is always associated with lower IM (at any combination of risk factors) and with lower LBW, except for women with none of the four risk factors and for women with any one, for whom odds ratios are statistically indistinguishable from 1.0.

Table 4 shows that the 81% of the women in the sample with either Medicaid or WIC have 2-4 risk factors, and therefore the majority of women eligible for either program might be expected to experience the reductions in IM or LBW shown for high risk women in this study.

Table 3
Odds Ratios and 95% Confidence Intervals for IM and LBW by Program Participation

AGE	RAC	EDU	PNC	WIC		MEDICAID		WIC & MEDICAID	
				IM	LBW	IM	LBW	IM	LBW
+	+	+	+	.58(.54-.63)	.59(.54-.65)	.64(.49-.85)	.72(.64-.81)	.38(.28-.51)	.43(.37-.49)
-	+	+	+	.58(.54-.63)	.59(.54-.65)	.95(.77-1.16)	.90(.82-.98)	.55(.43-.70)	.53(.47-.60)
+	-	+	+	.58(.54-.63)	.80(.72-.88)	.64(.49-.85)	.85(.73-.98)	.38(.28-.51)	.67(.57-.79)
+	+	-	+	.58(.54-.63)	.80(.74-.86)	.64(.49-.85)	.72(.64-.81)	.38(.28-.51)	.58(.51-.67)
+	+	+	-	.58(.54-.63)	.59(.54-.65)	1.07(.78-1.47)	.96(.84-1.09)	.63(.45-.87)	.57(.48-.66)
-	-	+	+	.58(.54-.63)	.80(.72-.88)	.95(.77-1.16)	1.05(.92-1.19)	.55(.43-.70)	.83(.72-.97)
+	-	-	+	.58(.54-.63)	1.08(.98-1.19)	.64(.49-.85)	.85(.73-.98)	.38(.28-.51)	.92(.77-1.08)
+	+	-	-	.58(.54-.63)	.80(.74-.86)	1.07(.78-1.47)	.96(.84-1.09)	.63(.45-.87)	.77(.66-.89)
-	+	+	-	.58(.54-.63)	.59(.54-.65)	1.58(1.25-2.00)	1.18(1.07-1.31)	.92(.71-1.18)	.94(.82-1.09)
-	+	-	+	.58(.54-.63)	.80(.74-.86)	.95(.77-1.16)	.90(.82-.98)	.55(.43-.70)	.72(.64-.80)
+	-	+	-	.58(.54-.63)	.80(.72-.88)	1.07(.78-1.47)	1.12(.96-1.31)	.63(.45-.87)	.89(.75-1.05)
-	-	-	+	.58(.54-.63)	1.08(.98-1.19)	.95(.77-1.16)	1.05(.92-1.19)	.55(.43-.70)	1.13(.96-1.31)
-	+	-	-	.58(.54-.63)	.80(.74-.86)	1.58(1.25-2.00)	1.18(1.07-1.31)	.92(.71-1.18)	.95(.84-1.07)
-	-	+	-	.58(.54-.63)	.80(.72-.88)	1.58(1.25-2.00)	1.38(1.22-1.58)	.92(.71-1.18)	1.10(.94-1.28)
+	-	-	-	.58(.54-.63)	1.08(.98-1.19)	1.07(.78-1.47)	1.12(.96-1.31)	.63(.45-.87)	1.21(1.02-1.43)
-	-	-	-	.58(.54-.63)	1.08(.98-1.19)	1.58(1.25-2.00)	1.38(1.22-1.58)	.92(.71-1.18)	1.50(1.30-1.72)

Age= <20yr Rac= Non-White EDU=Non-HS Graduate PNC=Inadequate Prenatal Care Risk Factor Present=(+) Risk Factor Absent=(-)

DISCUSSION

Publicly funded programs like WIC and Medicaid are continually at risk of inadequate funding during times of governmental budget shortfalls, both national and state. It is important to measure their contribution to achieving intended goals so that their value can be judged in comparison to other social needs. However, this is not directly possible, since the randomization scheme required for a proper trial would deny some participants in such a trial program benefits and would be unacceptable at this time. Observational studies such as this one can never fully answer the question at hand, 'Does WIC (or Medicaid) produce better pregnancy outcome?' It is impossible to separate program effect from other forces at work in the real (not experimental) world, such as self-selection and unmeasured, confounding risk.

Self-selection in this study probably introduces a bias away from the null (larger program effect), since by seeking WIC or Medicaid, women exhibit one positive behavior that may indicate a tendency toward other favorable behaviors (such as avoiding cigarettes, alcohol, or drugs). On the other hand, unmeasured risk, especially income, probably has an opposite effect on the measured odds ratios. WIC and Medicaid are both means-tested programs, and it is likely that even at the same level of the other sociodemographic variables used here (age, race, and education), WIC and Medicaid women are poorer than non-WIC and non-Medicaid women. Poor women are at greater risk of adverse pregnancy outcomes than non-poor, so that even a relative risk of 1.0 suggests a beneficial program effect, since we expect worse outcomes in program participants. And, while not absolute proof, risk reductions of the magnitude seen here, especially for the most at-risk women, suggest that there is some true program effect to reduce IM and LBW.

In Georgia, where about one-third of all pregnant women receive some or all of their care in county health departments, WIC is the 'glue' that holds this care together. Its main benefit, roughly $25-30 per month of food, is an inducement to an early visit to the health department (where WIC is administered), in turn leading to referral to prenatal care and other programs available through the health department designed to produce good pregnancy outcome. With an average participation of 5 months and administrative costs of 20%, the average cost to government is $150-180. If the actual risk reduction is even close to that measured here, especially for the highest risk groups (48% reduction in IM, 41% in LBW), the program would be cheap at twice the price.

Medicaid and WIC exert independent and additive effects on pregnancy outcome in this study. At the time of this study, the threshold for benefits under the Georgia Medicaid program was 35-45% of the federal poverty level, depending on eligibility status. In recent years Medicaid has been expanded to cover all pregnant women in families with incomes up to 133% of the federal poverty level. WIC continues to use 185% as its threshold, but since the Medicaid program counts the unborn baby in determining family size and WIC does not, the actual thresholds are closer. This means that nearly all women eligible for one program ought to eligible for the other. The effect of this is to 'push' all participants to the right-most column of Table 3, where outcomes are best and where odds ratios are less than 1.0 for all but the few women with one or no risk factors. This study supports the concept that dual eligibility and dual participation in WIC and Medicaid can lead to improvements in IM and LBW for the majority of eligible mothers.

Table 4:
Distribution of Risk Factors Among WIC and Medicaid Participants

NUMBER OF RISK FACTORS	N	(%)	CUMULATIVE PERCENT
4	2430	6.9	6.9
3	11561	32.9	39.8
2	14534	41.3	81.1
1	6060	17.2	98.4
0	566	1.6	100.0

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APPENDIX

Table A:

Medicaid - Birth Record Match
Number of Medicaid Records Matched to the Corresponding Birth Record and Cumulative Percent at Each Match Identifier

Identifier(1)	Matched(Cumul Pct)	Check Item (2)
Start	23,778 (0)	
SSN	19,036 (80.1)	MCLMO = BLMO or MCLMO = BLFA or MCLMO = BLFA or MPLMO = BLMO
Mother's DOB (MMDDYY) + 1st 3 letters of Mother's first name +	2,507 (90.6)	MCLMO = BLMO or MCLMO = BLFA or MPLMO = BLMO
1st 3 letters of Mother's first name + 1st 6 letters of Mother's last name + Mother's county of residence	185 (91.4)	Mother DOB
1st 5 letters of Doctor's last name + 1st 3 letters of Mother's first name	14 (91.4)	Mother DOB
MATCHED	21,742 (91.4%)	
UNMATCHED	2,036 (8.6)	
TOTAL	23,778 (100%)	

(1) The manner in wich dates are used is expressed in MMDDYY notation: MM(month), DD(day of month), YY(year, eg 52 for 1952)

(2) MCLMO is Medicaid Current Last name of the Mother BLMO is Birth record Last name(Maiden) of the Mother BLFA is Birth record Last name of the Father; MPLMO is Medicaid Previous Last name of the Mother

(3) In the Medicaid file, Mother's Last name is her previous Last name, or if missing, her current name; in the Birth records file it is her maiden name.

Table B:

WIC- Birth Record Match
Number of WIC Records Matched to the Corresponding Birth Record and Cumulative Percent at Each Match Identifier
WIC records with Date of Delivery (Baby's DOB) in 1987.

Identifier	Matched(Cumul Pct)	Check Item(1)
Start	21,388 (0)	
SSN	1,025 (4.8)	WLN = BLMO or WLN = BLFA
Mother's DOB (MMDDYY) + 1st 3 letters of Mother's first name	13,978 (70.1)	WLN = BLMO or WLN = BLFA

Mother's County of residence + 1st 3 letters of Mother's first name	269 (71.4)	WLN=BLMO or WLN=BLFA
Mother's DOB (MMDDYY) + Baby's DOB (MMDD)	2,791 (84.%0	WLN=BLMO or WLN=BLFA
1st 3 letters of Mother's first name + Baby's DOB (MMDD)	233 (85.5)	WLN=BLMO or WLN=BLFA
Mother's DOB (MMDD) + Baby's DOB (MMDD)	69 (85.9)	WLN=BLMO or WLN=BLFA
SSN from other years	181 (86.7)	NONE
Baby's DOB (MMDD) +	981 (91.3)	WLN=BLMO or
1st 3 letters of Mother's first name + Mother's DOB (MMDD)		WLN=BLFA or Mothers DOB
UNMATCHED	177 (8.3)	
TOTAL	19614 (100%)	

(1) In the WIC file, a single unspecified last name is provided for the Mother; this may be her maiden name or any of her married names. In the Birth Records file, her maiden name as well as the name of the baby's father are provided.

WLN is the WIC last name. **BLMO** is Birth record Last name (Maiden) of the Mother
BLFA is Birth record Last name of the Father
Mother DOB is the Mother's Date of Birth expressed as MMDDYY.

Table C: Supplemental WIC - Birth Record Match
Number of WIC Records Matched to the Corresponding Birth Record and Cumulative Percent at Each Match Identifier
All WIC records from 3/84 to 5/89

Identifier	Matched	Check Item(1)
Start	195,820	
SSN	3,162	WLN=BLMO or WLN=BLFA
Mother's DOB (MMDDYY) + 1st 3 letters of Mother's first name	21,001	WLN=BLMO or WLN=BLFA
Mother's County of residence + 1st 3 letters of Mother's first name	465	WLN=BLMO or WLN=BLFA
MATCHED	24,628	

(1) In the WIC file, a single unspecified last name is provided for the Mother; this may be her maiden name or any of her married names. In the Birth Records file, her Maiden name as well as the name of the baby's father are provided.

WLN is the WIC last name. **BLMO** is Birth record last name (Maiden) of the Mother. **BLFA** is Birth record Lastname of the Father. **Mother DOB** is the Mother's Date of Birth expressed as MMDDYY.

DEVELOPING AND UTILIZING "COMMUNITY HEALTH PROFILES" BASED ON LINKED INFORMATION FOR ADVERSE REPRODUCTIVE OUTCOMES

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Introduction. Adverse reproductive outcomes (AROs) such as very low and low birthweight, infant and perinatal mortality, and congenital anomalies, among others, are both early and costly health outcomes (Edmonds et al., 1981 and Flynt et al., 1987). Because of this, assessing and analyzing their occurrence are important considerations in the development and evaluation of health plans. This presentation briefly describes how a cooperative agreement between the New Jersey Department of Health (NJDOH) and the U.S. Centers for Disease Control (CDC) enabled the State to utilize "community health profiles" as part of an ecologic, or correlational, study to provide insights into possible associations between environmental exposures and AROs. In large part, the profiles are based on information collected through long-standing, population-based data systems, particularly vital records. Since there have been recent efforts to improve and standardize their content and collection, this means that some of the most important health indicators for realizing YEAR 2000 and other health-related objectives may already be available.

Several types of health-data needs can be addressed through the judicious use of community health profiles for geographic areas. These include: (1) describing characteristics of areas and their populations, incorporating such components as (a) demography, (b) physical environment, (c) community resources and facilities, and (d) health outcomes; (2) examining historical trends, particularly in providing backgrounds for the assessment of changes due to programmatic interventions; (3) inspecting results across a range of outcomes that might otherwise be mutually exclusive at the individual level of analysis; and (4) assisting in cluster investigations (e.g., Fulcomer et al., 1988).

Definition of "Community Health Profiles". For this presentation, a community health profile is defined as the planned linkage of comprehensive sets of aggregated health-related variables for a community. Such a profile could be viewed as the meaningful juxtaposition of several health-related measurements for a well-defined geographic area, particularly reflecting careful planning efforts in the choices of health indicators to be included. Similarly, the term juxtaposition is meant to emphasize the linkage or matching of information from different sources. The phrase several health-related measurements is included to convey the importance of comprehensiveness. Finally, referring to a well-defined geographic area points to the need for such data representations to reflect the aggregation of information to meaningful units such as minor civil divisions (county/municipalities), zip codes, or census tracts.

This definition of a community health profile borrows heavily from the literature on testing individuals' mental abilities, dating back to some of the early work in psychological testing, and there are many well-known examples (e.g., see Cronbach, 1960). In general, there are four major types of values that are displayed in such profiles: (1) original (i.e., raw) scores; (2) deviation scores (i.e., comparisons to a fixed value); (3) standardized scores (i.e., variations of z- or T-scores, with predetermined means and standard deviations, allowing easy cross-variable comparisons); and (4) normative values (i.e., percentiles).

It is important to note that the invariance characteristics of linear transformations in parametric analyses make it possible to conveniently re-scale the specific variables included in a profile without affecting the intercorrelations among profile variables (up to reflection, if the scale points are reversed) or between a profile's variables and external criteria. Thus, just as it is possible to present IQ profile scores with predetermined means (usally 100) and standard deviations (typically 15-16), a profile of a community's health status can be used to: (1) display relative positions along several dimensions simultaneously; (2) facilitate comparisons between different communities or groupings of communities; and (3) allow the application of normative statements (e.g., percentile point in a probability distribution) by making assumptions about the underlying form(s) of the distributions of the variables (e.g., normality). Viewing community health profiles as aggregated versions of composite "individuals" (i.e., communities) makes it possible to apply powerful statistical techniques such as regression analyses and to study emerging health policy and planning issues quickly and effectively, possibly with preexisting data. In fact, the analysis of this type of data makes so much sense that it has apparently been independently "rediscovered" numerous times and appears in the literature under several different adjectives (e.g., demographic, social area, ecologic, correlational, small-area, and context analysis, among others); a history of some of these applications is given by Struening, 1975).

Environmental Concerns. At the present, little is known about the relationships between environmental exposures and AROs. Fortunately, because they can be based on the aggregation and linkage of already existing information, community health profiles can be especially helpful in situations in which the collection of such data might otherwise be prohibitively expensive and time-consuming if undertaken through individual-based, case-control studies. Furthermore, even when studies have obtained

individual-level data, they often have also suffered from poor statistical power. Therefore, for the present study, a few previously-unexamined environmental variables were also included in the profiles to reflect our special concerns about the potential relationships between possible exposures and adverse reproductive outcomes in the nation's most densely-populated state.

Public concerns about the quality and safety of air and drinking water are quite understandable in light of New Jersey's having the largest number of toxic sites in the U.S. (over 100 on the National Priority List, or NPL, along with over 1300 other sites in various stages of investigation and remediation). Moreover, despite its population density, New Jersey still has large areas devoted to farming, leading to questions about the possible impact of agricultural applications of pesticides. As part of a national effort to enhance states' capabilities in the surveillance of AROs (Edmonds et al., 1988), the cooperative agreement allowed New Jersey to develop and apply several different methods of analysis to this emerging topic area, including large case-control, ecologic, and cross-sectional studies (Fulcomer et al., 1987).

As part of that effort, the present ecologic study combined results from New Jersey's Birth Defects Registry and from its vital records with census data for 561 municipalities. The profiles also incorporated environmental results derived from the N.J. Agricultural Pesticide Survey, the U.S. EPA Toxic Release Inventory, and the CERCLIS database, the information system for CERCLA (the Comprehensive Environmental Response Compensation and Liability Act). In turn, treating municipalities as the unit of analysis made it possible to obtain early results from multiple and partial regression analyses of a comprehensive set of environmental data.

Methods. The study population included in our analyses of the community health profiles covered 327,015 live births and 3,548 fetal deaths that occurred in 561 of New Jersey's municipalities during 1985 to 1987 (another 6 municipalities were dropped because of small population sizes). Three major sets of variables were used in the regression analyses. The first set of variables contains 12 sociodemographic characteristics, six drawn from the 1980 U.S. Census and the remaining six aggregated from the birth certificates for use as risk factors. The means and standard deviations of these 12 variables, based on the weighting of each community's data by the number of live births, are given in Table 1. In terms of well-known risk factors, it is interesting to note the high level (27.93%) of inadequate prenatal care.

Table 1. Descriptive statistics for the sociodemographic variables

Variable	Mean	Std. Dev.
A. From 1980 U.S. Census		
1. Per capita income in dollars	7707.31	2241.49
2. Mostly rural (>50% in rural areas-yes/no)	.10	.30
3. Population density (persons/sq. mile)	6529.88	7169.77
4. Crowded housing (% > 1.0 persons/room)	4.00	3.43
5. Old housing, i.e., built before 1960 (%)	65.10	21.52
6. Female-headed hshlds. in poverty with children < 6 (%)	1.31	1.57
B. From Birth Certificates		
1. Average age of mothers	27.12	2.06
2. % mothers over age 35	9.05	4.43
3. % mothers with less than H.S. education	16.29	13.71
4. % primiparous mothers	44.85	4.58
5. % white mothers	78.75	22.57
6. % inadequate prenatal care	27.93	14.66

The second set of variables encompasses three groupings of potential exposure surrogates. The first grouping includes four variables describing the State's toxic waste sites. There are two indicators of the presence/absence of NPL sites or CERCLIS sites (of which the NPL sites are a subset) in a community and two so-called "dump-density" variables. Note that, while NPL sites occur in only 15.86% of the municipalities, CERCLIS sites are more widely-scattered (60.25%). Based on weighting by the number of births in a community, the average densities of NPL and CERCLIS sites per square mile are 0.0337 and 0.9963, respectively.

A second grouping of exposure surrogates were derived from the federal EPA's Toxic Release Inventory (TRI) for 1987. The eight variables contained in this grouping were used to characterize the dispersal of 39.5 million pounds of chemicals throughout New Jersey. Table 2 lists the per cent of affected communities and the total pounds for each of these variables. [The densities in pounds per square mile were actually used in the analyses.]

Table 2. Exposure surrogates from the Toxic Release Inventory

Variable	% of Communities	Millions of Pounds
Total chemicals	37.61	39.50
Inorganics	24.78	2.60
Known or suspected teratogens	26.56	22.72
Suspected carcinogens or mutagens	19.96	4.52
Lead, arsenic, and vinyl chloride	6.42	.22
Organic solvents	27.63	30.91
Hydrocarbons	21.03	11.67
Halogenated hydrocarbons	16.40	5.02

The third grouping of exposure surrogates consisted of six variables derived from NJDEP's (N.J. Department of Environmental Protection) 1986 survey of agricultural pesticide applications. Table 3 indicates the per cent of affected communities and the total pounds for each pesticide variable. [Again, densities in pounds per square mile were actually used in the analyses.]

Table 3. Exposure surrogates from the NJ Agricultural Pesticide Survey

Variable	% of Communities	Millions of Pounds
Total pesticides	44.03	1.59
Thalidomide analogs	23.53	.09
Organophosphates	40.11	.18
Carbamates	38.32	.19
Herbicides	14.44	.01
Halogenated organics	30.30	.05

Finally, the third set of variables included two distinct groupings of adverse reproductive outcome variables. The first grouping of eight variables was derived from vital records. An inspection of the mean rates (based on weighting by a community's live births) shown in Table 4 makes it clear that, while some of these are indicators of tragic health events, they still fall into the category of "rare" outcomes and, thus, somewhat complicate traditional analyses. The second grouping of 13 overlapping categories of birth defects, for which descriptive results are also listed in Table 4, represents even rarer outcomes than those obtained from vital records.

Table 4. Descriptive statistics for the outcome variables

Variable*	Mean	Std. Dev.
A. From vital records		
1. Preterm births (%)	9.88	3.89
2. Small-for-gestational age (%)	11.15	2.19
3. Very low birthweight rate (< 1500 grams)	12.91	7.53
4. Low birthweight rate (< 2500 grams)	68.74	27.23
5. Neonatal death rate (< 28 days)	6.71	4.07
6. Post-neonatal death rate (up to 1 year)	3.19	2.66
7. Total infant death rate	9.90	5.58
8. Fetal mortality rate	7.69	4.32
B. Birth defects outcome		
1. Down syndrome	1.19	1.62
2. Neural tube defects	2.05	2.05
3. Eye defects	.20	.64
4. Selected severe cardiac defects	1.29	1.57
5. Oral clefts	1.26	1.55
6. Reduction deformities	.42	.88
7. Chromosomal anomalies	1.83	2.00
8. Total congenital anomalies	27.09	13.56
9. Major anomalies	20.65	10.97
10. Minor anomalies	6.44	4.96
11. Central nervous system defects	2.31	2.18
12. Heart defects	5.40	3.86
13. Musculoskeletal defects	8.16	5.55

* All rates are per 1,000 live births.

In addition to univariate and bivariate descriptive statistics (which are not presented here in detail because of space considerations),

the principal analytic strategies included multiple and partial regression analyses. These methods were chosen to provide systematic and logically progressive explanations to the possible exposure-outcome relationships that concern the public and the media. Thus, while simple univariate and bivariate results may raise the prospect of "apparent" relationships, it requires, at a minimum, the application of multiple regression to account (or "control") for known risk factors before possible associations can be addressed by partial correlations.

However, before presenting a few results, Table 5 below is included here to point out some considerations and limitations related to the utilization and analysis of community health profiles. A few of these items are self-explanatory and do not require further elaboration here. Others such as spatial autocorrelation and weighting are quite technical and are well beyond the scope of this presentation (e.g., see Wartenberg, 1985 and Pocock et al., 1981).

Table 5. Some considerations in developing and utilizing community profiles

1. Coordination and parsimony in selecting variables
2. Data quality issues (e.g., accuracy, completeness, comparability)
3. Timeliness of data
4. Cooperation in acquiring data
5. Choice of geocoding units (e.g., blocks, census tracts, cities, zip codes)
6. Mechanics of record matching, linking, and aggregation
7. Designing and maintaining accessible and informative computer files
8. Establishing periodic reviews
9. Weighting areas with different numbers of births
10. Temporal stability
11. Collinearity
12. Spatial autocorrelation
13. Multiple comparisons
14. Ecological bias

Because careful planning efforts are central to the notion of profiles, the first consideration of selecting a parsimonious set of variables deserves special emphasis. In particular, it is important to avoid the temptation to "load-up" profiles with too many indicators. Encumbering profiles with superfluous variables causes further complications in designing accessible computer files (i.e., the seventh consideration). As a way of emphasizing that profile generation efforts are perhaps better suited to ongoing activities (vs. representing one-time demonstrations), the seventh point also highlights the importance of <u>maintaining</u> such files.

Two of the considerations raised in Table 5 are especially relevant to concerns about exposure-outcome relationships. [Clearly, others such as the so-called "multiple comparisons problem" are also relevant.] The first of these to stress involves data quality (the second item in the list), specifically the extreme crudeness of the exposure surrogate variables; the second involves the potential for ecological bias (the fourteenth item) and the associated need to constantly warn others of the dangers inherent in making inferences about individuals from social-area data.

<u>Results.</u> The presentation of results begins with a straight-forward enumeration of the unadjusted (i.e., simple) exposure-outcome correlations, based on weighting by the number of births in a community. For each of the three groupings of exposure-surrogate variables (rows), Table 6 shows the per cent of significant correlations (at $p<.05$) for the two types of outcome variables (columns). For example, there are 32 pairings of exposure-outcome relationships between the four toxic waste site variables and the eight outcomes derived from vital records, of which 21 (65.62%) are significant. With respect to the toxic waste site and air emissions (i.e., TRI) variables, the significant correlations with the outcomes derived from vital records provide some early indications of potential exposure-outcome relationships. In contrast, the smaller proportion of significant correlations involving those two environmental surrogates and the birth defects outcomes demonstrates the difficulty in establishing associations within that category of AROs. Although the general absence of pesticide-outcome relationships probably attests more to data quality issues (e.g., the restriction to agricultural applications alone and the absence of computerized information on commercial uses which is especially relevant to many of the State's more-populated areas) than rules out "true" associations, it actually points to a benefit of using community health profiles in the initial, cost-effective analysis of existing information to highlight apparent data gaps before precious resources are squandered prematurely on individual-based studies with insufficient power.

Table 6. Per Cents of significant, simple exposure-outcome correlations.

Type of Exposure Variable	Type of Outcome Variable: Vital Records	Birth Defects
Toxic Waste Sites	65.62% (21/32)	23.08% (12/52)
Toxic Release Inventory	60.94% (39/64)	5.77% (6/104)
Agricultural Pesticide Applications	0.00 (0/48)	1.28% (1/78)

Table 7 shows the per cents of variance explained in the outcome variables by multiple regression analyses using the 12 sociodemographic variables as predictors. For the outcomes based on vital records information, all of the proportions of variance explained are significant. But more importantly, the values are of sufficient magnitude to make them helpful for deliberations on program planning and placement. In contrast, for the birth defects, the regression results are much less predictive. However, given the general absence of consistent findings from studies of birth defects at the individual-case level, it is hardly surprising that results for such outcomes at the social-area level would demonstrate a similar lack of strong associations.

Note that the present study also calculated partial correlations between the exposure-surrogates and the outcome variables after the influences of the 12 sociodemographic variables had been removed. However, there is not sufficient space to adequately describe those results here and, instead, they will be presented elsewhere. A complete treatment of the partial correlations will be included as part of the final report of the cooperative agreement with CDC.

Conclusions. This paper has discussed the development, use, and limitations of community health profiles for approaching health planning activities in general and for addressing some emerging concerns about environmental issues in particular. Clearly, our profiles contain variables that explain major portions of variance in some of the AROs and demonstrate considerable promise for designing and locating services. For our special concerns about the health consequences of potential environmental exposures, the successful implementation and maintenance of community health profiles may be an important, cost-effective alternative for working with existing environmental and health data, especially as results from the analyses of such data may allow agencies to direct their efforts in individual-based studies to those content and geographic areas likely to have the greatest yield. Furthermore, maximizing the use of in-place reporting systems makes good economic sense in light of current budgetary constraints faced by virtually all levels of government.

Table 7. Per cents of variance explained in outcomes by sociodemographic variables

Variable	Per Cent
A. From vital records	
1. Preterm births (%)	86.96**
2. Small-for-gestational age (%)	52.33**
3. Very low birthweight rate (< 1500 grams)	58.33**
4. Low birthweight rate (< 2500 grams)	83.42**
5. Neonatal death rate (< 28 days)	29.70**
6. Post-neonatal death rate (up to 1 year)	42.46**
7. Total infant death rate	49.13**
8. Fetal mortality rate	23.96**
B. Birth defects outcome	
1. Down syndrome	3.24
2. Neural tube defects	6.05**
3. Eye defects	2.24
4. Selected severe cardiac defects	2.56
5. Oral clefts	1.33
6. Reduction deformities	1.52
7. Chromosomal anomalies	2.14
8. Total congenital anomalies	6.08**
9. Major anomalies	6.05**
10. Minor anomalies	9.63**
11. Central nervous system defects	5.25**
12. Heart defects	6.78**
13. Musculoskeletal defects	10.72**

** Significant at p<.01

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DOES PERINATAL REGIONALIZATION WORK? AN ANALYSIS OF A STATEWIDE LINKED DATASET OF BIRTH AND DEATH CERTIFICATE AND NEONATAL INTENSIVE CARE UNIT DISCHARGE SUMMARIES FOR WISCONSIN, 1982-1983

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Since the late 1960's, innovative projects have demonstrated that perinatal regionalization can improve infant outcomes [Committee on Perinatal Health 1977; Butterfield 1977; McCormick et al. 1985]. Perinatal regionalization involves the routine risk assessment of pregnant women with in utero transport to tertiary facilities with maternal-fetal medicine support, and prompt transport of stabilized neonates to neonatal intensive care units (NICUs) with appropriate facilities for the long-term management and treatment of sick neonates.

Most research on patterns of perinatal regionalization has involved one of three general approaches [Kirby and Patton, 1989a]. These are: 1) clinically oriented studies of perinatal or neonatal outcomes at a single facility or NICU [for example: Anderson et al. 1981; Beverley et al. 1986; Modanlou et al. 1979]; regional studies of outcomes in an area served by a single perinatal center [Cordero et al. 1982, 1989; Powers et al. 1988; Miller et al. 1983; Lubchenco et al. 1989; Saigal et al. 1982, 1984]; and 3) population-based analyses of perinatal outcomes, based primarily on birth certificates, death certificates for neonatal deaths, and fetal death records [Paneth et al. 1982, 1987; Ferrera et al. 1988; Goldenberg et al. 1985; Bowes et al. 1985; Gortmaker et al. 1985; Hein and Lathrop 1986; Kirby and Patton 1989b]. The role of vital statistics data in the analysis of perinatal regionalization is reviewed by Kirby and Patton [1989a].

To date there have been no statewide population-based studies of perinatal regionalization incorporating individual data on all birth events and statistical information on NICU stays. This paper presents results from an analysis of a database linking birth certificates, death certificates, and NICU discharge reports for all resident live births occurring in 1982-83 in an area encompassing almost the entire state of Wisconsin. The focus of this report is on the contribution that a more comprehensive database can make to our understanding of the effectiveness of perinatal regionalization. Following a description of the components of the database and the general methodology for record linkage, some examples of trends and comparisons between subgroups of neonates at risk for neonatal mortality are shown. The paper concludes with a discussion of several issues in the collection of NICU data and their uses, and some implications of this study of health data policy in the field of perinatal care.

Materials and Methods

Data sources

Data were obtained from three sources. First, birth certificates for all Wisconsin resident live births for calendar years 1982 and 1983 were used. Second, death certificates for all infant deaths occurring to the Wisconsin 1982-83 resident birth cohort were linked to the respective birth certificates. Finally, data from NICU discharge reports from twelve hospitals were obtained. Birth and death certificate statistical files were obtained from the Center for Health Statistics, Wisconsin Division of Health. NICU discharge reports were obtained from the perinatal database maintained from January, 1982 to May, 1984 by the Wisconsin Association for Perinatal Care (WAPC). The hospitals participating in the WAPC perinatal database were: Madison General Hospital (Madison), St. Mary's Medical Center (Madison), La Cross Lutheran Hospital (La Crosse), St. Francis Hospital (La Crosse), Theda Clark Medical Center (Neenah), St. Vincent's Hospital (Green Bay), St. Joseph's Hospital (Marshfield), Milwaukee Children's Hospital (Milwaukee), St. Joseph's Hospital (Milwaukee), Mt. Sinai Medical Center (Milwaukee), Milwaukee County Medical Center (Wauwatosa), and St. Mary's Hospital (Duluth, Minnesota). These hospitals maintained the only NICUs providing tertiary neonatal care in the state of Wisconsin during the study period. With the exception of NICU facilities in Minneapolis and St. Paul, Minnesota, it is unlikely that a more than a handful of Wisconsin resident liveborns received neonatal intensive care in other out-of-state facilities.

Record Linkage

A total of 146,826 resident live births in Wisconsin during 1982-83, and 146,065 live births occurred in the state. In the WAPC database, there were 6,903 NICU discharges of infants born in 1982 or 1983, and 6,535 Wisconsin resident NICU discharges. NICU discharge records were linked to birth certificates through a combination of computer linkage and manual-visual evaluation. The following variables common to both the birth certificate and the NICU discharge form were used to perform the matching process: date of birth, hospital of birth, sex of child, birth weight, maternal age, and one and five minute Apgar scores.

A total of 6,450 out of 6,535 NICU discharge records with Wisconsin ZIP Codes were matched to birth certificates (98.7%). Matched and unmatched records were compared across a number of variables to identify any important differences between the two groups that might indicate a potential bias. It is likely that many of the unmatched NICU cases are rehospitalizations of infants already represented in the dataset. Support for this conclusion is gained from the shorter mean length of stay for these visits (11.2 days compared to 17.3 days for the matched records), the larger birth weights (2896 grams compared to 2570 grams), longer gestations (37.5 weeks compared to 35.9 weeks), and lower infant mortality (1, or 1.2% compared to 419, or 6.5% among the matched NICU records). Other variables which

differed significantly between the matched and unmatched records included race of mother, method of delivery, one minute Apgar score, source of infant and mother, discharge destination, and referral into the WAPC high risk infant follow-up program.

Study Area

Although it would be preferable to use the resident birth cohort for 1982-83 for the entire state of Wisconsin for this study, it is clear that some NICU admissions at hospitals in Minneapolis and St. Paul, Minnesota occurred to infants born to residents of western Wisconsin. The NICU hospitalization rates for Wisconsin counties were mapped (Figure 1), showing a considerable range in the rate of NICU admissions across the state. Whereas the low rates shown for Florence, Forest and Oneida counties in northern Wisconsin result from lack of access (there are no NICU facilities in upper Michigan), those found in western Wisconsin occurred because NICU admissions for these infants were not available for analysis. For this reason, eleven counties in western Wisconsin were eliminated from the study (Barron, Buffalo, Burnett, Chippewa, Dunn, Pepin, Pierce, Polk, St. Croix, Rusk and Washburn counties), leaving the remaining 61 counties of the state of Wisconsin as the study area. Thus, the 136,911 live births occurring in 1982 and 1983 to residents of this area form the basis for this study. The analysis includes 6,213 NICU discharges, and 1,315 infant deaths.

Analysis

In the Wisconsin study area, 35,631 live births occurred at hospitals with NICUs, while 98,874 live births occurred at non-NICU facilities (births occurring outside the state of Wisconsin could not be classified by hospital type). The overall rate of NICU admission was 4.8 per 100 live births. Infants born at facilities with NICUs were significantly more likely to be admitted to the NICU (10.9 % compared to 2.4% among liveborns at non-NICU hospitals, $p < .001$). As shown in Figure 2, live births at NICU and non-NICU facilities have strikingly different distributions by birth weight. Slightly more than fifty percent of all births at NICU facilities weighed 2,500g or more, while virtually all births at non-NICU hospitals were in this birth weight group.

The distribution of NICU admissions by hospital of birth and birth weight is shown in Figure 3. Approximately eighty percent of infants weighing less than 1,500g (VLBW) born at NICU facilities were admitted to an NICU, compared to about 48% among those born at non-NICU hospitals. Similarly, infants of birth weight 1,500-2,499g (MLBW) born at a hospital with an NICU were more likely to be admitted to an NICU than their counterparts born at non-NICU hospitals. Similar patterns (not shown) were also found for infants born very preterm (less than 32 weeks gestation) and moderately preterm (32-35 weeks gestation).

The overall neonatal mortality rate (NNMR) for the study area was 6.17/1,000 live births. By type of hospital, the NNMR for non-perinatal hospital births was 4.19/1,000 live births, and the NNMR for perinatal center hospital births was 11.70/1,000 live births (G-adj=211.965, $p < .0001$). This result is anticipated, as perinatal regionalization should result in sicker infants, especially preterm and very low birth weight infants, being born at the perinatal center hospitals.

When the additional factor of NICU admission is included in the analysis, controlling for birth weight infants born at a perinatal hospital and admitted to the NICU were significantly more likely to survive the first month of life than were infants born at other facilities and transferred (adjusted OR = 0.78, 95% C.I. 0.61-1.00, p=.047). Infants born at perinatal centers and not admitted to the NICU had higher neonatal mortality than did infants born at non-NICU facilities and not transferred (adjusted OR = 1.42, 95% C.I. 1.02-1.87, p=.034). Differences in NNMR by birth weight for the four categories of type of hospital and NICU admission status are shown in Figure 4. Note the near 100 percent mortality for VLBW infants born at NICU facilities but not admitted to the NICU. Most of these infants died within the first hour after delivery, and many may have been non-viable births which must nevertheless be reported on birth certificates.

The linked database can also be used to examine population-based as opposed to single facility differences in NNMR among in-born and out-born NICU patients. Figure 5 shows differences between in-born and out-born NICU admissions by birth weight. The NNMR for VLBW in-borns was slightly but not significantly higher than for out-borns. Neonatal mortality rates were significantly lower among MLBW and normal birth weight infants admitted to NICUs who were born at that facility than among infants born elsewhere and transferred. Similar patterns (not shown) also were found by gestational age.

Some Data Issues Concerning the Linked File

The linked database of live births, infant deaths, and NICU discharges provides a far more comprehensive basis for the analysis and interpretation of patterns of perinatal regionalization. However, some limitations still exist. First, while patterns of neonatal transport can be examined and evaluated, one can only surmise that maternal-fetal transport occurs. Clearly, high-risk neonates (as indicated by VLBW and very preterm delivery) are more likely to be born at facilities with NICUs. What is not known is whether this results from residence in the market area of a particular hospital, or due to a referral for tertiary perinatal care following risk assessment during a prenatal visit. A second issue is the issue of 'convenience' as a contributor to differences in NICU admission rates among infants born at perinatal versus non-perinatal hospitals. Infants born at NICU hospitals were more likely to be admitted with a primary reason for admission given as 'observation'. This analysis could be refined to take account of infants admitted to the NICU for observation only. Also, the results reported here did not consider the possibility of the neonate so

seriously ill or malformed that death occurs prior to a potential admission to the NICU. However, when these issues were examined, the statistical associations described here were still obtained. Third, the issue of rehospitalization of infants admitted to an NICU was not addressed in the linked file structure. Data from only one NICU stay were retained on the linked file, although some infants had as many as five separate NICU discharge records in the WAPC database. Several of these infants were transferred between hospitals with NICUs to receive specific treatments or therapies. Others had readmissions following a discharge to their family's residence. As the primary objective of this project was to analyze patterns of perinatal regionalization taking NICU admission into account, data on readmissions were not examined. Several reports have shown that NICU graduates are at greater risk for serious illness and more likely to require surgery than are infants surviving the neonatal period who were never admitted to an NICU [Combs-Orme et al. 1988; Lynch et al. 1988; Mutch et al. 1986].

Implications for Perinatal Health Data Policy

Vital statistics data perform a necessary but not sufficient role in the analysis of patterns of perinatal regionalization. Additional information is necessary to address important policy concerns. Comprehensive NICU data with identifiers sufficient to correctly link records to birth certificates are essential. Other data sources are also necessary to fully evaluate the status of perinatal care and important maternal and child health indicators on a population basis. As shown in Figure 6, there are four major components in an ideal statewide perinatal database. While focussed on certificates of live birth and fetal death as well as death certificates for infant deaths, two additional types of perinatal data are necessary for a comprehensive perinatal database. Hospital data of more direct clinical relevance, abstracted from medical records by trained personnel, can significantly augment the information reported on birth certificates. These data might include data on maternal and infant length of stay, ante-, intra-, and postpartum treatment, surgery and medications, newborn anthropometric measurements, and other clinical information. NICU discharge data reports similar to those examined in this study form a second essential category of hospital data. The fourth component of an ideal statewide perinatal database is prenatal care provider data, in the form of patient history and risk assessments taken in the first trimester, at about twenty weeks gestation, and late in the third trimester. These data could be used to assess the effectiveness of antepartum risk assessment and maternal-fetal referrals of high-risk mothers, and to identify risk factors for preterm labor, intrauterine growth retardation and other high risk conditions. Neither hospital perinatal databases nor prenatal care provider databases will be easy to implement, yet both are essential elements of an ideal regional or statewide perinatal database.

NICU data are especially important, when integrated with the linked live birth-infant death certificate files now available in most states. Important policy issues, including potential effects of cost-containment programs and modifications of financing arrangements (such as expansion of Medicaid eligibility), and the recent trend toward perinatal deregionalization can be assessed more readily with these data. Hospital discharge survey data are not a reasonable surrogate for these data. Discharge surveys contain little information of direct relevance to perinatal risks, and can be quite difficult to link with birth certificates, especially for neonates with several admissions. There is also an association between data and delivery of health care that makes the implementation of comprehensive perinatal data systems imperative: **quality of health care improves when quality data are used for quality assurance in a positive, mutually supportive health care delivery environment.**

Acknowledgements

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FIGURE 1

NICU HOSPITALIZATION RATE PER 100 LIVE BIRTHS
1982–1983 RESIDENT DATA

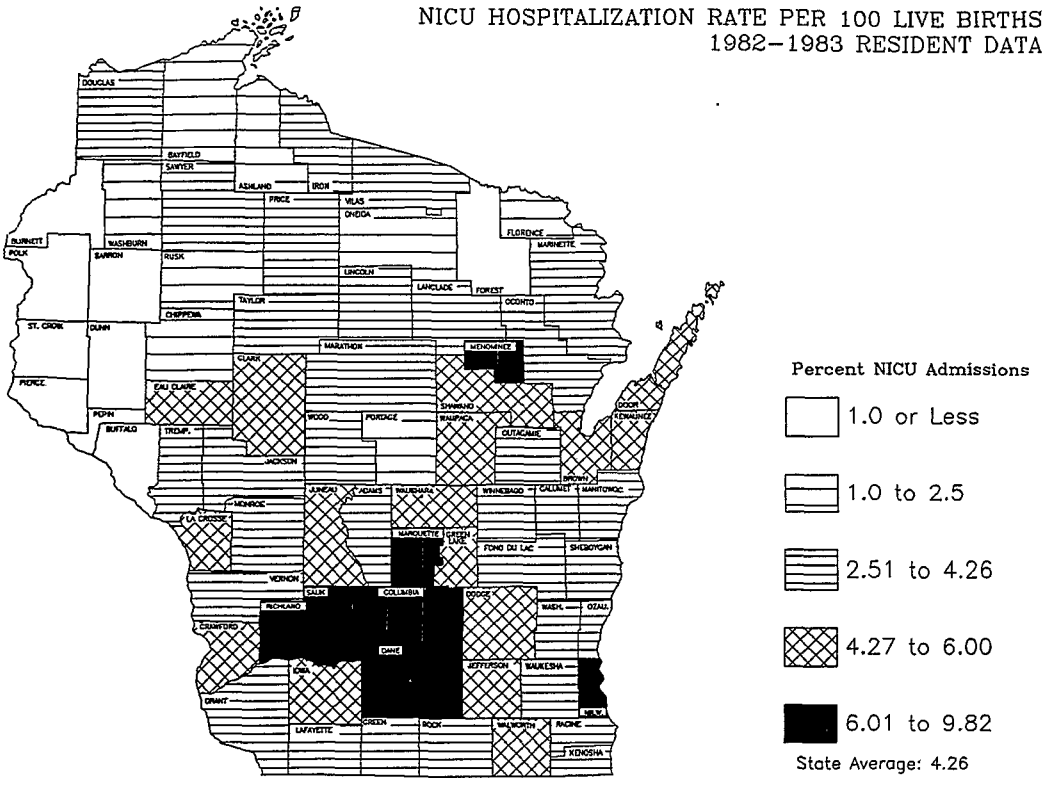


FIGURE 2
BIRTH WEIGHT DISTRIBUTIONS BY HOSPITAL TYPE
WISCONSIN, 1982-83 (61 County Resident Data)

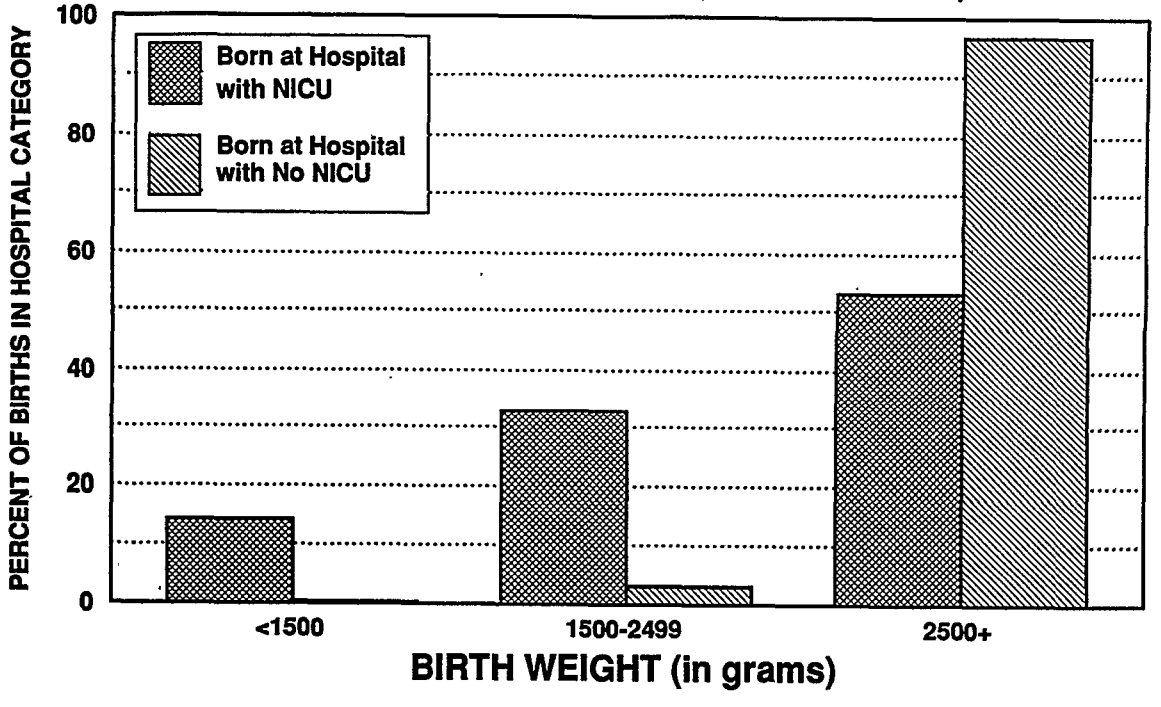


FIGURE 3
BIRTH WEIGHT BY HOSPITAL CATEGORY OF BIRTH
PERCENT OF LIVE BIRTHS ADMITTED TO NICU
WISCONSIN, 1982-83 (61 County Resident Data)

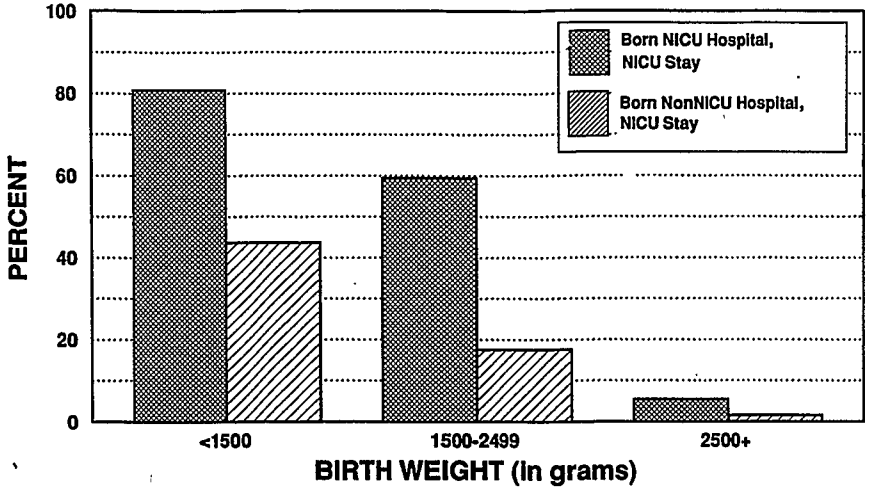


FIGURE 4
NEONATAL MORTALITY RATES BY BIRTH WEIGHT
BY HOSPITAL CATEGORY OF BIRTH AND NICU STATUS
WISCONSIN, 1982-83 (61 County Resident Data)

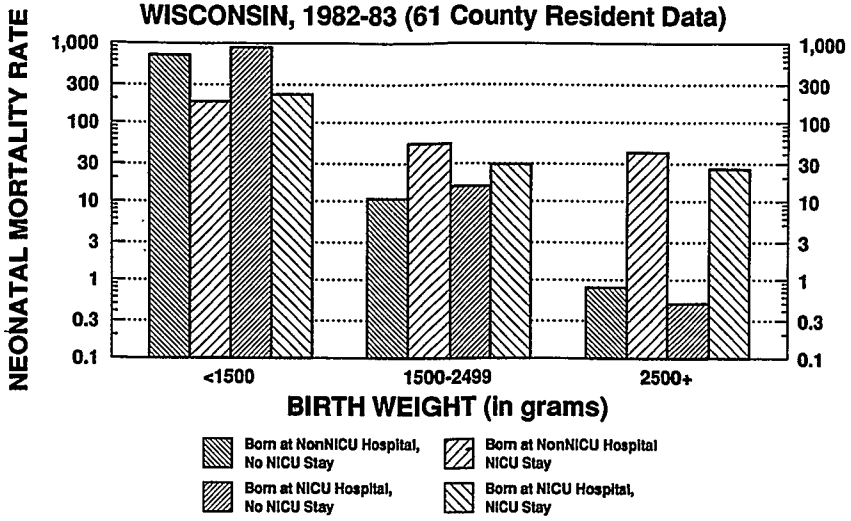


FIGURE 5
NEONATAL MORTALITY RATES
COMPARISON OF IN-BORN AND OUT-BORN INFANTS
ADMITTED TO NICU'S IN WAPC DATABASE, 1982-83

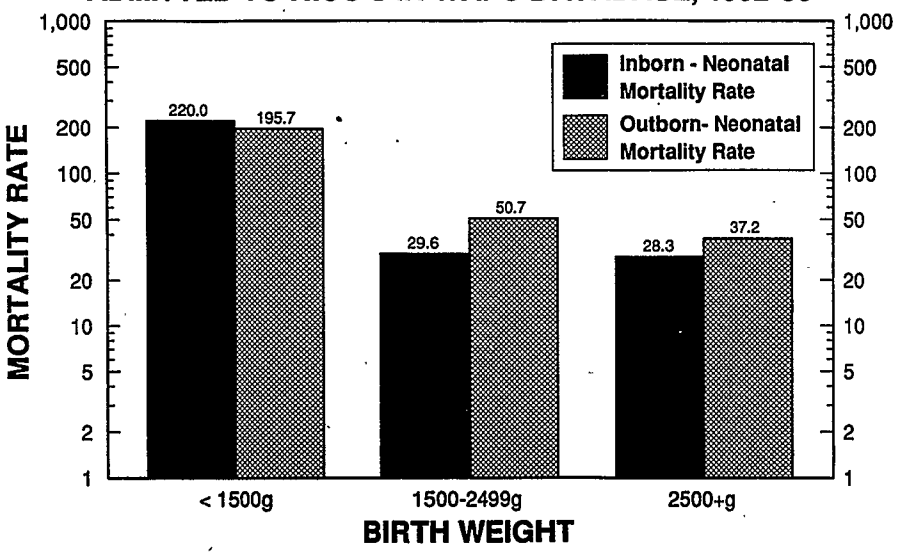
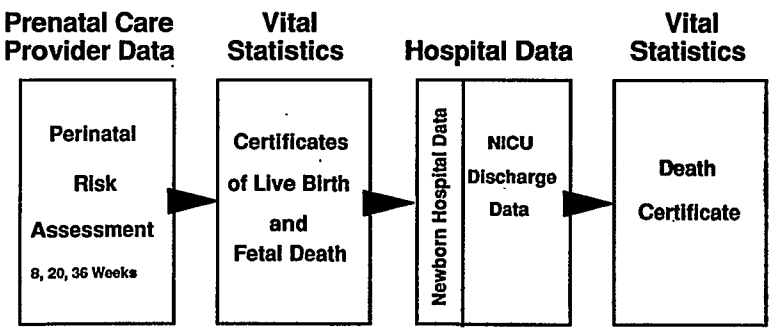


FIGURE 6
COMPONENTS OF AN IDEAL STATEWIDE PERINATAL DATABASE



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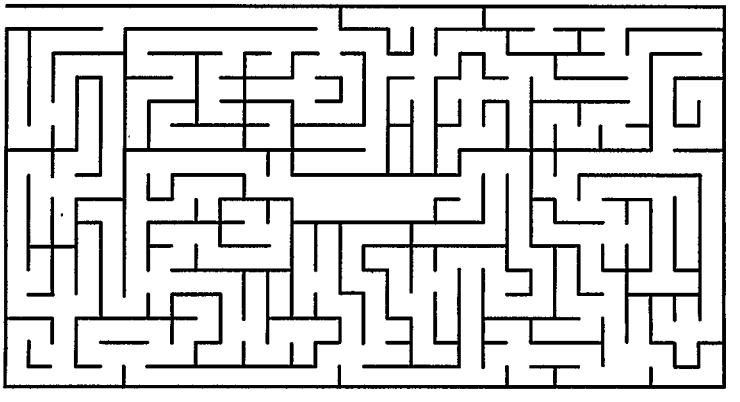
Session J

Adolescent Health



TRENDS IN ADOLESCENT PREGNANCIES IN NEW YORK CITY 1980-1989

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Monitoring progress towards the year 2000 objectives that pertain to adolescent reproductive outcomes requires careful region-, racial/ethnic-, and age-specific trend analyses. This methodology provides an important source of teen pregnancy data, which is needed given the potential biases due to dated, incomplete census information unreported events (especially early spontaneous losses), and selective reporting of induced terminations due to socioeconomic status, method of payment, type of facility where procedures are performed, age of woman and racial/ethnic background. It is also evident that national, state and local statutes including those pertaining to consent procedures seriously impact on the completeness and reliability of the data for adolescents.

Although various activities in the second half of the 1980's may have modified some individual decisions and behaviors, the reporting system and types of facilities have remained relatively stable in that time frame, which supports the efficacy of trend analyses for adolescent pregnancies in NYC. Keeping in mind the potential limitations, the trends in adolescent pregnancies in NYC for the 1980's as reported on the birth, death, fetal death and induced termination certificates received by the NYC Department of Health will be reviewed.

The rate of pregnancies to adolescents 14-19 years old (per thousand female population 14-19 years) remained well above 100 throughout the 1980's (Table I). The pregnancy rates increased with minor fluctations, resulting in a 16.4% increase from a pregnancy rate of 110 in 1980 to 128 in 1989. While the induced termination rates were consistently higher than the birth rates and both increased over the decade, there was a much greater increase in the birth rate. The birth rate increased by about 27%, from 41 to 52, and the induced termination rate increased by 8.3%, from 55 to 60.

Between 1985 to 1989 the pregnancy rates increased among all adolescents regardless of age. Adolescents 18-19 years of age consistently had the highest pregnancy rates and those less than 15 years had the lowest. However, the greatest increase was seen among the very young adolescents, those less than 15 years. These girls had a 12% increase from 25 to 28 pregnancies per thousand population. The pregnancy rate among 15-17 year olds increased by 7.4% from 95 to 102, 51% greater than the 50 pregnancies per thousand teenagers 15-17 years old goal for the year 2000. The 18-19 year olds experienced a 4% increase in their pregnancy rates from 198 in 1985, to 206 in 1989.

Analyses of the absolute numbers of pregnancies reported and proportionate outcomes revealed that consistently more than half of the pregnancies to adolescents ended in induced terminations and less than 5% were fetal deaths. There was a 10.3% decrease in the total number of reported pregnancies to adolescents during the 1980's from 36,355 in 1980 to 32,611 in 1989 (Table I). While the total number of reported pregnancies fell, the number of teens delivering a live birth remained fairly stable during the first three years of the decade at approximately 14,000. It then decreased slightly from 13,892 in 1983 to 13,166 in 1987 and began increasing in 1988 to once again reach the 1980 level, being 14,123 in 1989. Thus, the 10.3% decrease in total pregnancies to adolescents was largely due to a 16.8% decrease in induced terminations from 21,712 in 1980 to 18,056 in 1989.

There were pronounced racial/ethnic disparities in adolescent pregnancies. Nonhispanic Black adolescents had the greatest number of pregnancies (17,571 in 1980 and 16,205 in 1989) and consistently comprised approximately 50% of the adolescents becoming pregnant. The percent of adolescent pregnancies which were to nonhispanic Whites decreased from greater than 25% of all teen pregnancies in 1980 at 9,982 to 4,457, comprising less than 15% in 1989. The proportion of Other Hispanic and Puerto Ricans increased between 1980 and 1989 from approximately one quarter to one third of the pregnant adolescents (1,576 and 6,451 in 1980 to 3,406 and 7,408 in 1989, respectively). Asians consistently comprised less than 2% of these teenagers who became pregnant in NYC during the 1980's.

Over the decade of the 1980's there was substantial improvement in birth outcomes for NYC's adolescents (Table II). The percent of low birthweight (2500g) newborns decreased by 6%, from 12.1% in 1980 to 11.4% in 1989. The infant mortality rate (death 0-365 days per thousand live births) to infants of adolescents fell 30%, from 19.1 in 1980 to 13.4 in 1989. The percent of teenaged mothers who received late or no prenatal care (care starting in the third trimester and no care) fell by 7%, from 1980 to 1987 and dropped to a much greater extent during 1988 and 1989. However, some of the observed decrease in 1988 and 1989 reflected a

revision of the 1988 birth certificate, whereby the question of care now includes the date of the first visit to any provider when pregnant instead of the first prenatal care visit in the institution of eventual delivery.

The proportion of all NYC births which were to adolescents fell by 22% in the 1980s (Table II). There was a gradual, steady decline from 13.2% in 1980 to 10.3% in 1987 where it remained through 1989. However, the percent of births to adolescents varied greatly among the racial/ethnic groups, as is apparent in comparisons from 1985-89 (Figure I). Asian teens consistently accounted for less than 2% of the live births during this 5 year interval. The births to nonhispanic White adolescents comprised approximately 7% of the White births during 1985 to 1987 and fell to less than 4% in 1988 and 1989. However, the proportion of nonhispanic Black births which were to adolescents decreased slightly from approximately 17% in 1985 to about 15% in 1989. The proportion of other Hispanic births which were to teenagers increased from about 7% to about 9%. And, by 1988 and 1989, Puerto Ricans with about 20% of their births to teens had the highest proportion of births to adolescents, reflecting an increase of 15% during 1985 to 1987.

Unlike live births, the proportion of induced termination and fetal deaths which were to adolescents remained fairly stable throughout the decade. Teenagers consistently had about 20% of the induced terminations and less than 5% of the reported fetal deaths.

The age distribution of adolescents giving birth, undergoing induced terminations and with fetal deaths changed little over the decade. 18-19 year olds consistently comprised about 60% of those teenagers with live births, approximately 55% of those undergoing induced terminations and 60% of those with fetal deaths. Adolescents 15-17 years old comprised 35-40% of the teenagers with live births, about 40% of those undergoing induced terminations and approximately 35% of those adolescents experiencing fetal deaths. Those teenagers who were less than 15 years old consistently comprised less than 10% of the adolescents with live births and induced terminations and less than 5% of those experiencing fetal deaths.

There was a 15.6% decrease in the induced termination to live birth ratio for adolescents from 1980 to 1989 as the ratio fell from 1.54 to 1.30 (Figure II). This suggests that, as the decade progressed, the pregnancy outcome for NYC's adolescents was more likely to be the delivery of a live birth. This was observed irrespective of age category. Between 1985 and 1989, young teenagers (less than 15 years old) experienced the sharpest drop in the induced termination to live birth ratio falling 33.1% from 2.78 in 1985 to 1.86 in 1989, but were still the least likely to deliver a live birth. The induced termination to live birth ratio fell 21.2% for 15-17 year olds, from 1.51 in 1985 to 1.19 in 1989. The ratio for 18-19 year olds decreased by 9.0% from 1.22 in 1985 to 1.11 in 1989.

The induced termination to live birth ratios also varied significantly among racial/ethnic groups. Dichotomizing the teens into less than 18 and 18-19 year old categories, the Other Hispanic adolescents consistently had the lowest termination to birth ratios, indicating that their pregnancies were more likely to result in a live birth. They were the only racial/ethnic group with ratios consistently less than 1. The induced termination to live birth ratio for Other Hispanic adolescents less than 18 years old decreased from 0.94 in 1985 to 0.62 in 1989 and for other Hispanics 18-19 years, from 0.63 to 0.51, respectively. Among the younger adolescents (less than 18 years), the pregnant Puerto Rican teens were the next most likely to have live births with ratios ranging from 1.41 in 1985 to 0.83 in 1989. Young Black, White and Asian adolescents, however, were more likely to terminate their pregnancies. The induced termination to live birth ratios ranged from 1.92 in 1985 to 1.71 in 1989 for nonhispanic Blacks less than 18 years, from 1.96 to 2.70 for the nonhispanic Whites and from 2.64 to 1.30 for the Asian, for those same 5 years. Among the older teens (18-19 years), the nonhispanic White and Black adolescents had the highest ratios, both of which increased from 1985 to 1989. The nonhispanic Black ratios ranged from 1.36 in 1985 to 1.41 in 1989, and for nonhispanic Whites the ratios also increased from 1.59 in 1985 to 1.79 in 1989. The older Asian and Puerto Rican adolescents had ratios ranging from 1.13 to 0.95 and 1.27 to 0.94, respectively.

Over the decade, adolescents undergoing induced terminations were more likely to have had a previous induced termination or live birth (Figure III). The percent of adolescents undergoing induced terminations with a history of at least one previous termination increased by 41.0%, from 24.9% in 1980 to 35.1% in 1989. The percent of adolescents undergoing induced terminations with previous live births increased by 34.3%, being 20.1% in 1980 to 27.0% in 1989.

In contrast, the proportion of adolescents giving birth who had previous live births remained fairly stable over the decade (Figure IV). In 1980, 20.9% of the teenagers giving birth had

given birth in the past. By 1989 20.1% had given birth previously. The proportion of adolescents giving birth with a previous live birth peaked at 21.2% in 1986 and reached a low of 19.7% in 1987. The percent of teenagers with live births and a history of induced terminations fluctuated over the decade, increasing from 8.3% in 1980 to 10.8% in 1986, then falling to 8.7% in 1987 and increasing again to 12.3% in 1989.

In summary, results from these trend analyses suggest that close monitoring of region-specific trends all pregnancy outcomes by age- and racial/ethnic-specific subgroups is crucial to assess progress towards the year 2000 objectives. In addition, careful surveillance of the quality of the data, the facilities where adolescents receive services, changes in the reimbursement and consent systems that affect teenagers and the immigration and utilization patterns by adolescents is necessary. It is equally important to analyze past reproductive health outcomes of these young women to better target programs to help prevent unwanted pregnancies.

As the climate changes in the U.S. towards fewer reproductive options, the group of women with the highest ratio of induced terminations to live births is at greatest risk for having poor pregnancy outcomes with all of the short and long term consequences. In order to achieve effective interventions, the data need to be analyzed quarterly, this will assure that increased risks for subgroups of adolescents are identified as early as possible. In turn, the information can be used to support more global efforts to ensure the rights of all women, regardless of age, racial/ethnic background, socioeconomic status or residence.

TABLE I

Pregnancy and Births to Teenagers New York City, 1980-89

Year	Reported Pregnancies	Live Births	Pregnancy Rate*
1980	36,555	14,123	110
1981	35,996	14,014	112
1982	36,191	14,276	118
1983	34,791	13,892	118
1984	32,970	13,339	115
1985	33,666	13,304	119
1986	32,904	13,168	120
1987	33,411	13,166	125
1988	31,527	13,714	122
1989	32,611	14,121	128

*rate per 1000 females 14-19 years

TABLE II

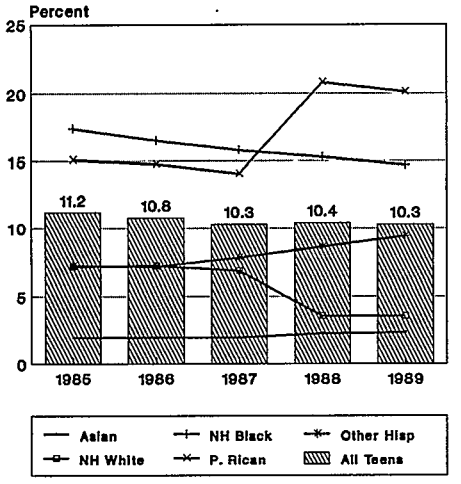
Selected Characteristics of Births to Adolescents (<20 Yrs), NYC, 1980-89

Year	Live Births	% of All LB	LBW <2500g	Late/No Prenat Care	IMR
1980	14123	13.2	12.1	34.7	19.1
1981	14014	12.9	11.6	33.1	16.8
1982	14276	12.8	11.3	36.3	19.8
1983	13892	12.4	11.3	34.2	18.6
1984	13339	11.8	11.3	33.1	16.1
1985	13304	11.2	11.2	30.2	17.1
1986	13168	10.8	11.7	32.9	16.9
1987	13166	10.3	11.4	32.3	14.4
1988	13714	10.4	11.7	20.0*	15.0
1989	14121	10.3	11.4	24.1*	13.4

*Influenced by revision in 1988 certificates

FIGURE I

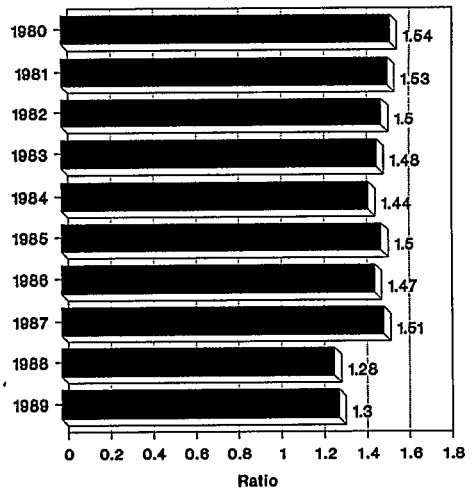
Percent of Live Births to Adolescents by Race/Ethnicity, NYC, 1985-89



Source: BMSFP NYC DOH vital statistics

FIGURE II

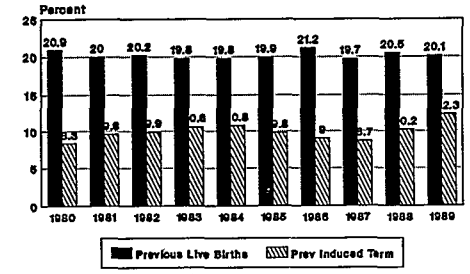
Ratio of Induced Terminations to Births for Adolescents (<20 Years) New York City, 1980-1989



Source: BMSFP NYC DOH vital statistics

FIGURE III

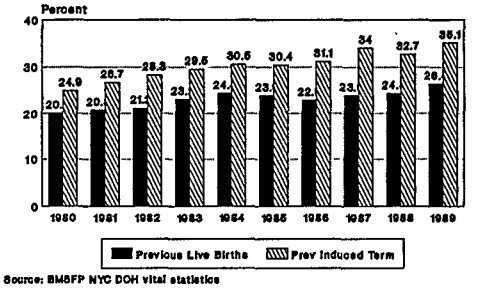
Percent of Adolescents with Live Births with a Previous Induced Termination or Live Birth, NYC, 1980-1989



Source: BMSFP NYC DOH vital statistics

FIGURE IV

Percent of Adolescents Having an Induced Termination with a Previous Live Birth or Induced Termination, NYC, 1980-1989



Source: BMSFP NYC DOH vital statistics

BIRTHS TO TEENAGE GIRLS: A SCHOOL DISTRICT LEVEL ANALYSIS

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Seattle-King County Department of Public Health

Introduction

A broad and comprehensive project titled "The Health of King County" was initiated two years ago to develop an ongoing public health surveillance system for a range of key health indicators. Vital events are a core component of this project. Patterns of occurrence of the indicator events are described geographically, socioeconomically and racially. The data analysis has been planned to facilitate identification of high risk groups. These analyses then become the basis for health department planning of service delivery. Births to teenage girls is one indicator variable obtained from birth certificate analysis. Analysis of this indicator is an example of how these vital statistics data were developed to provide a basis for dialogue between the health department and the schools.

Births to teenage mothers remain an issue of substantial public health significance. After a long and progressive decline nationally, births to girls age 15-17 have shown small increases over the years 1986-88(1). Births among girls in this age group are likely to have been unplanned, are associated with greater likelihood of adverse health outcomes for infant and mother and greatly increase the odds that the mother (and child) will remain in poverty(2,3).

A common point of approach to teens is through the schools. Several studies have demonstrated the effectiveness of school- based health facilities in reducing teen birth rates (4,5). However, development of such facilities requires strong support for these programs from the community. Efforts to develop school-based health services (particularly contraceptive services) frequently are met with vocal opposition from various political and religious groups. Thus, the implementation of school based services requires considerable public education and coalition building to ensure adequate public support and consensus. To pave the way for health department-school system cooperation, the present project was initiated.

Methods

Information regarding all births among King County residents was obtained from computerized birth certificate files. Births from 1986 - 1988 were assigned to a census tract based on maternal residence at the time of delivery. Census tracts were allocated to 19 school districts, based on the school district in which the majority of population of the tract resided. Of the 6122 total teen births, 4 could not be assigned to a school district due to problems with coding of census tracts. Population estimates (by census tract, age, race and sex) were obtained from the National Planning and Decision Corporation. These population estimates are based upon the 1980 census and take into account births, deaths and migration to the extent that the latter is measurable from voter registration, new housing starts, automobile registration, and multiple other public records. Teen birth rates and 95% confidence intervals (6) were calculated for teenage girls age 10-14, 15-17, and 18-20. These age groupings were determined by the availability of denominator data. A minimum of 5 births were required before calculation of birth rates, or inclusion on graphs or charts, to avoid confidentiality violations.

Results

Among girls age 10 - 14, births were too few in number for meaningful comparison among school districts. The birth rate in Seattle was significantly greater than in King County outside of Seattle.

Among girls age 15-17, birth rates ranged from 6.26/100,000 to 34.5/100,000 with statistically significant differences from the county as a whole evident in both directions. Auburn, a small town, low-income, predominantly white area, had the highest birth rate in the county. The Seattle school district (which corresponds to the city boundaries) had the second highest and differences between the two were not significant. The high teen birth rate in Seattle is partially explained by its larger non-white population. The crude relative risk for teen birth (age 15-17) in Seattle compared to the remainder of the County is 2.44; when adjusted for race, the relative risk falls to 1.61. White teens (age 15-17) living in Seattle experienced a birth rate lower than six other school districts outside the city. Several school districts had teen birth rates that were significantly lower than the county as a whole or the county outside of Seattle. All of these districts are relatively affluent suburban districts.

Among girls age 18- 20, differences in birth rates were even greater, from 8.43/100,00 to 108.2/100,000. Statistically significant deviations from the county as a whole were again seen in

both directions. School districts with higher rates generally were in rural and low-income outlying areas of the county. Significantly lower rates were seen in the same affluent suburban communities as were observed for 15 - 17 year olds. Surprisingly, Seattle birth rates for 18 - 20 year olds were lower than birth rates for the county outside of Seattle. Some of this phenomenon may be due to the shifting demographics that result when 18-20 year olds move to Seattle for a college or university education.

Discussion

Presentation of data by school district is helpful when the goal of the analysis is to strengthen the role and response of the schools to the issue of teen pregnancy. School districts have made use of these data to apply for grants, including one which would have funded school-based clinical services. A health department liaison to the schools is actively initiating discussions between the health department and school districts regarding access to clinical care for adolescents and sexuality education. Existing teen pregnancy coalitions, some representing concerned community members, and others representing service providers, have found these data helpful and supportive of their efforts to educate community members. A sexuality education committee was formed in one moderately high-risk community to help develop a sexuality curriculum for use in the schools. Another high-risk district has approached the health department for help in developing school-based health services.

This small area analytic approach may be useful in following the results of a given intervention over time. Pregnancy rates can be compared between districts which do implement curriculum changes or add new services and districts which do not make such changes. The wide range of teen birth rates has generated much discussion regarding potential factors contributing to high rates in certain districts. Health educators and members of local teen pregnancy coalitions associate teen birth with:

- poverty and the associated limited educational and employment opportunities. Without such opportunities, having a child at a young age is not a obstacle to career advancement.
- residence in rural areas
- acceptability of contraceptive use
- availability of abortion
- community values regarding parenting and family

Conclusions

Substantial variation between school districts is evident when teen birth rates are examined by school district of residence. These variations appear to follow patterns which correspond to socioeconomic and demographic features of the population in those districts. Small area data analysis can strengthen and support efforts by the schools to address the issue of teen pregnancy and provides a point of common discussion between the health department and the schools. In addition, effects of school district level innovations may be gauged.

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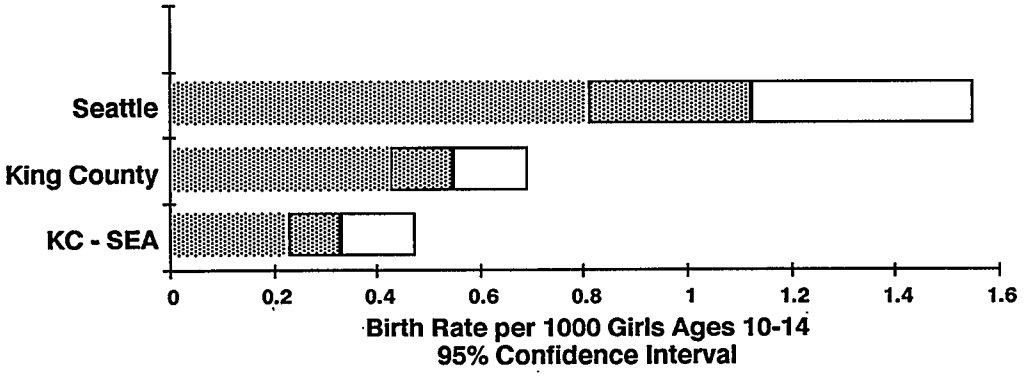
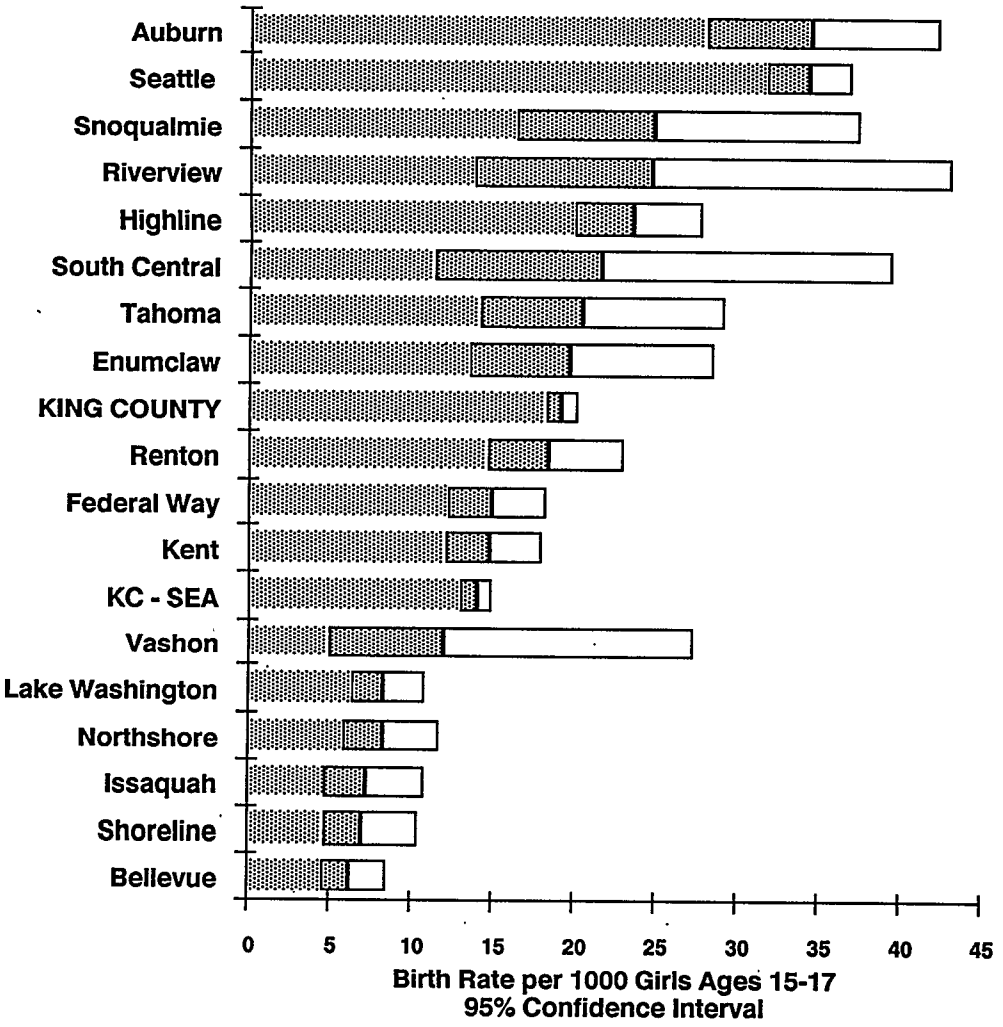
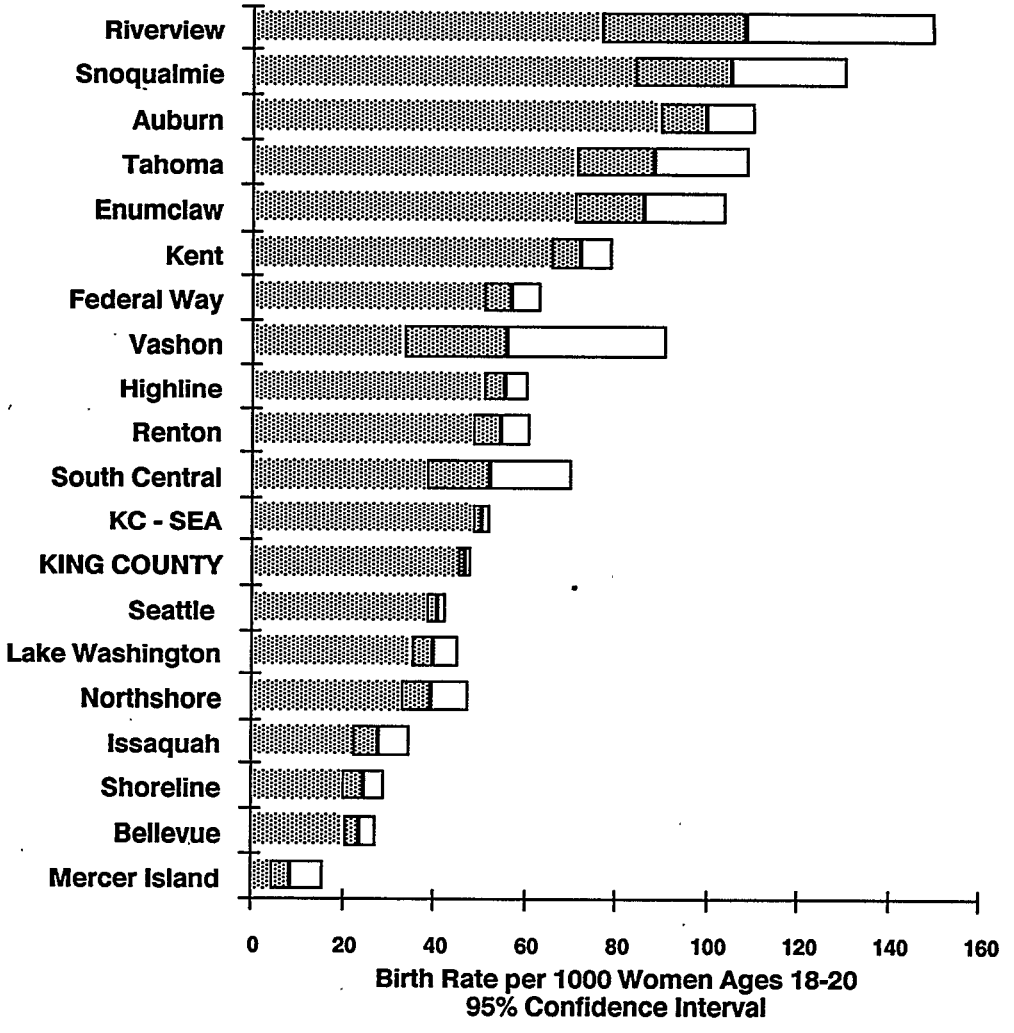
Birth Rates for Girls Ages 10 to 14
By School District Residence
1986-1988
May 1991 Revision



Birth Rates for Girls Ages 15-17
By School District Residence
1986-1988
May 1991 Revision



Birth Rates for Women Ages 18 to 20
By School District Residence
1986-1988
May 1991 Revision



Birth Rates for Girls Age 10-14
By School District Residence
King County, Washington: 1986-88
May 1991 revision, correction

	Total		White		Black	
	Births	Rate	Births	Rate	Births	Rate
Washington (1987)		0.74				
US (1987)		1.30		0.6		4.7
King County	70	0.55	35	0.33	23	2.8
Outside Seattle	31	0.33	25	0.29		
Seattle	39	1.12	10	0.45	19	2.9

Note: Rate per 1000 girls age 10-14
No rates reported for districts with number of births less than 9

Birth Rates for Girls Ages 15-17
By School District Residence
King County, Washington: 1986-88
May 1991 revision, correction

	Total		White		Black	
	Births	Rate	Births	Rate	Births	Rate
Washington (1987)		30.91				
US (1987)		31.80		24.10		72.90
King County	1501	19.21	946	14.35	342	73.41
Outside Seattle	820	14.03	702	13.21	49	52.80
Seattle	675	34.28	244	19.11	293	78.53
SCHOOL DISTRICTS						
Auburn	92	34.50	79	31.51		
Bellevue	43	6.26	31	4.99		
Enumclaw	29	19.74	20	14.60		
Federal Way	98	14.97	92	15.74		
Highline	145	23.59	112	20.85		
Issaquah	24	7.22	23	7.34		
Kent	100	14.84	93	15.36		
Lake Washington	59	8.34	52	7.83		
Northshore	34	8.32	30	7.84		
Renton	80	18.42	60	15.76		
Riverview	13	24.76	12	24.39		
Seattle	675	34.28	244	19.11	293	78.53
Shoreline	26	7.02	22	6.68		
Snoqualmie	24	24.87	22	23.66		
South Central	11	21.57	10	22.47		
Tahoma	31	20.42	30	20.82		
Vashon	6	12.05	5	10.42		

Rates per 1000 girls ages 15-17.
No data are shown for school districts whose number of births is less than 5.

Birth Rates to 18-20 year olds
By School District Residence
King County, Washington: 1986-88
Revised May 1991,correction

	Total		White		Black	
	Births	Rate	Births	Rate	Births	Rate
Washington (1987)		48.06				
US (1987)		91.60		79.43		144.83
King County	4551	46.82	3301	40.14	704	137.15
Outside Seattle	2913	50.44	2548	48.31	137	128.52
Seattle	1602	40.61	733	24.85	567	139.41
SCHOOL DISTRICTS						
Auburn	330	99.40	303	95.67		
Bellevue	177	23.82	154	22.78	6	45.80
Enumclaw	101	85.88	88	82.55		
Federal Way	324	56.78	285	54.73		
Highline	479	55.39	390	50.15	37	169.72
Issaquah	82	28.04	75	27.16		
Kent	423	72.14	380	71.77	14	112.00
Lake Washington	238	39.84	202	36.63		
Mercer Island	10	8.43	9	8.38		
Northshore	112	39.55	96	35.82		
Renton	274	54.48	228	50.97	27	133.66
Riverview	33	108.20	31	107.27		
Seattle	1602	40.61	733	24.85	567	139.41
Shoreline	112	24.50	99	24.31		
Snoqualmie	76	105.12	73	103.55		
South Central	43	52.31	32	44.2		
Tahoma	81	88.14	75	86.01		
Vashon	16	55.94	16	59.04		

Rates per 1000 women ages 18-20.
Washington and US are estimates: rates usually reported for women ages 15-19.
No data are shown for school districts whose number of births is less than 5.

MONITORING THE PREVALENCE OF PRIORITY RISK BEHAVIORS AMONG YOUTH: DATA FROM THE 1990 YOUTH RISK BEHAVIOR SURVEILLANCE SYSTEM

Laura Kann
Centers for Disease Control

(Not available for publication)

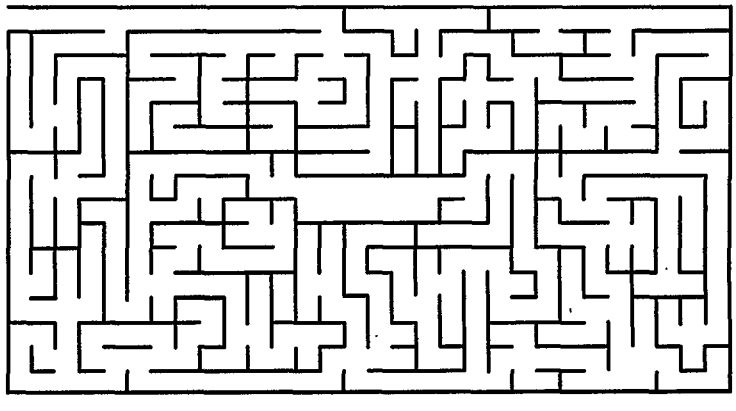
ADOLESCENT CONDOM USE AND ITS RELATIONSHIP TO HIV RISK STATUS

Charles Warren
Centers for Disease Control

(Not available for publication)

Session K

Women's Health



DIFFERENCES IN CHRONIC CONDITIONS BETWEEN HOMEMAKERS AND OTHERWISE EMPLOYED WOMEN FOR THE PERIOD 1970-1987

T.D. Sterling, Simon Fraser University
J.J. Weinkam
D.A. Sterling

Public use tapes of the U.S. National Health nterview Survey for 18 years are used to compute standardized Morbidity Ratios for homemakers with a variety of health conditions including Bed Days, Restricted Activity Days, Chronic Disease Symptoms Acute Disease Symptoms and for specifically diagnosed diseases including Cancer, Heart Disease and Other Diseases. For the majority of chronic diseases, homemakers have significantly higher Standardized Morbidity Ratios than women otherwise employed. With the exception of prevalence of Cancer, these differences can be explained by possible selection bias by which women who suffer from chronic disease may be self selected for homemaking. However, the risk of cancer remains significantly elevated even after adjustments are made for differences between chronic disease ratios of homemakers and women employed outside the home. Coupled with the observation that homemakers may be exposed to many carcinogens in their workplace, very often in poorly ventilated spaces, the conclusion seems plausible that homemakers are at an increased risk from cancer compared to women in other employment.

UTILIZATION OF SCREENING MAMMOGRAPHY IN CALIFORNIA, 1987-1990

CI Perkins, California Department of Health Services,
WE Wright, GA Kaplan, ND Kohatsu, D Littlefield

Introduction

Breast cancer is a leading cause of morbidity and mortality among women in the United States. In California, more than 16,000 women were diagnosed with invasive breast cancer in 1988, and more than 4,000 died (1). Although lung cancer has outstripped breast cancer as a cause of death, breast cancer is the most commonly diagnosed cancer among women. The American Cancer Society estimates that one out of nine women will be diagnosed with breast cancer during her lifetime (2). Despite improvements in diagnosis and treatment and increases in survival rates, breast cancer mortality rates have, in fact, increased by about 0.2% per year over the past 15 years, with larger increases among women aged 50 and older and among black women (3).

Since there is no known way to prevent breast cancer, early diagnosis and treatment are essential to reduce breast cancer mortality. Over 90% of women diagnosed with localized breast cancer survive for five years, compared to only 18% of women diagnosed with metastasized cancer (3). Considerable evidence shows that mammographic examination of asymptomatic women can detect breast cancer in earlier stages than physical exam alone (4). Screening mammography has been shown in large, randomized studies to reduce mortality by up to 40% among women aged 50 and older (5, 6). Although there has been considerable controversy over the optimal age to begin breast cancer screening with mammography, there is now general agreement on guidelines. Exams every one to two years are recommended for women aged 40-49, and annual exams are recommended for women aged 50 and older (7).

The Year 2000 Objectives focus on breast cancer screening as a crucial element in reducing overall cancer mortality (8). The objectives are for 80 percent of women aged 40 and older to have had at least one mammogram and clinical breast exam, and for sixty percent of women aged 50 and older to have been screened in the past two years. Specially targeted populations are black and Hispanic women, women from households with annual incomes of less than $10,000, women with less than a high school education, and women aged 70 and older.

Surveys conducted in the late 1970's indicated that only 15-20% of women aged 40 and older had ever had a mammogram (9, 10, 11). Considerable effort has been made at the national, state and local levels to increase screening mammography. This paper assesses changes in the utilization of screening mammography in California from 1987 to 1990, using data collected as part of the California Behavioral Risk Factor Surveillance System (BRFSS).

Methods

The BRFSS is a collaborative project between the California Department of Health Services and the Centers for Disease Control (12). It is a random-digit dial telephone survey of adults aged 18 and older, using Waksberg methodology (13). Its purpose is to collect state-specific information on a wide variety of health-related behaviors. Bilingual interviewers conduct the survey in Spanish on request. At the present time, 250 interviews are conducted each month, and response rates are about 80%.

In 1987, a series of questions on mammography were added to the survey. Women were asked if they had ever had a mammogram, and if so, how long ago it was done and the reason for having it done. About ten percent of women aged 40 and older responded that their most recent mammogram was performed because of a breast problem or cancer. These women were excluded from the analysis in order to better assess screening, rather than diagnostic, mammography. The denominator can be described as women without an identified breast problem or cancer, or "asymptomatic" women.

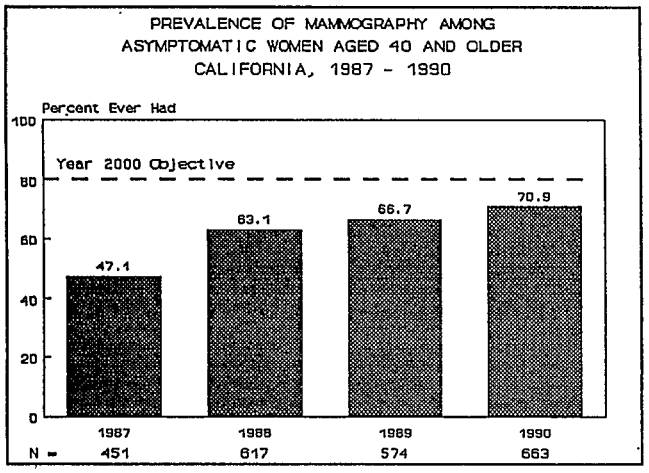
More than 2,300 asymptomatic women aged 40 and older were interviewed over the four-year period. All analyses were weighted to reflect the age-, sex-, and race-specific distribution of the 1986 California population. Approximately 21% of the sample was nonwhite, 16% had less than a high school education, and 19% came from households with annual incomes less than $10,000.

Results

There was a dramatic and significant increase in the utilization of screening mammography in California from 1987 to 1990 (Figure 1). In 1990, 71% of asymptomatic California women aged 40 and older reported ever having had a mammogram, a 50% relative increase from the rate of 47% in 1987. The majority of the increase took place between 1987 and 1988. Compared with 1987, each of the subsequent years had significantly higher mammography prevalence rates.

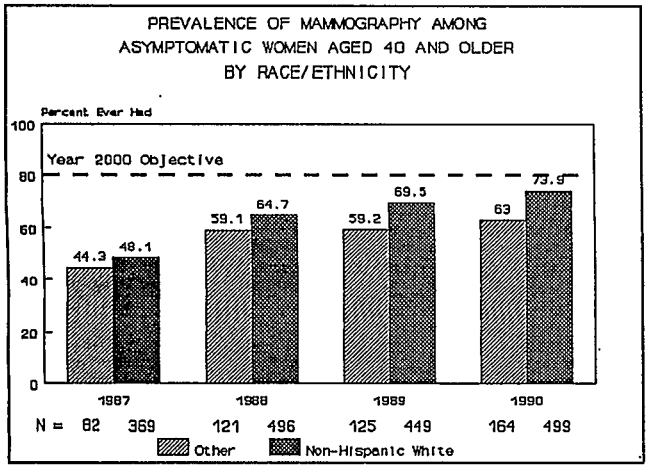
Changes in utilization of screening mammography were examined in some of the population groups targeted in the Year 2000 Objectives. When comparing changes over time among non-Hispanic white women

Figure 1



to all other women (black, Hispanic and "other" combined), both groups showed increases in utilization over the four years, but non-Hispanic white women consistently reported higher utilization than other women (Figure 2). If anything, the difference between the two groups appears to be increasing, and is statistically significant in 1990, when 74% of non-Hispanic white women and 63% of other women reported ever having had a

Figure 2



mammogram.

Very similar trends are seen when comparing women with less than a high school education to women with more education (Figure 3). In 1990, 60% of women aged 40 and older with less than a high school education had had a mammogram, compared to 73% of women with more formal education.

The greatest relative increase in reported utilization was among women from households with annual incomes less than $10,000 (Figure 4). Among this group, mammography increased from 32% in 1987 to 62% in 1990, a 90% relative increase. However, poor women are still less likely to report having screening mammograms than women with more income.

Figure 3

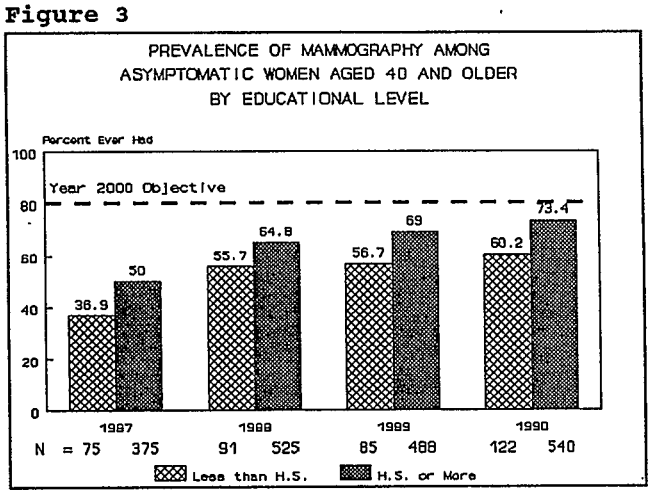
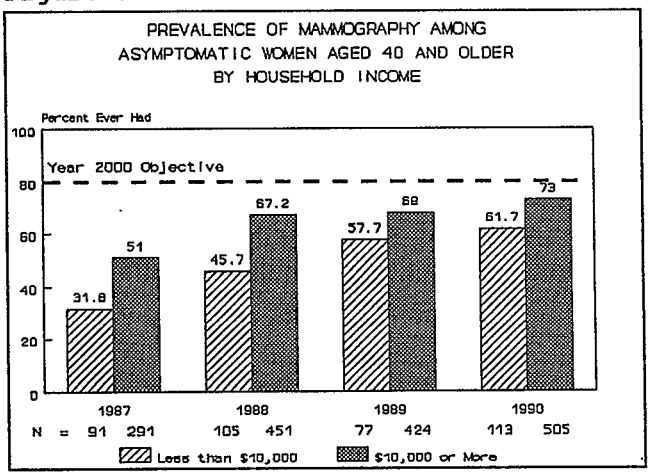
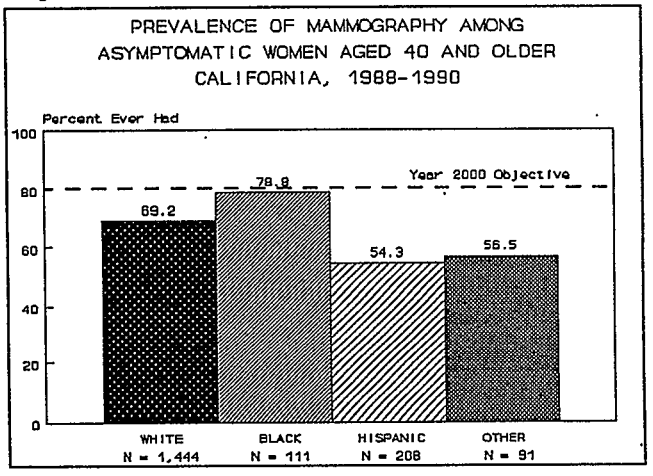


Figure 4



In the next analyses, data were aggregated over three years, 1988-1990. Although this causes some loss of precision in the point estimate, it allows adequate sample sizes to examine more meaningful categories for race/ethnicity.

Figure 5



Aggregating over the three years, 79% of black women aged 40 and older reported having had a mammogram, compared to 69% of white women and 54% of Hispanic women

(Figure 5). Despite the relatively small sample sizes, the differences are statistically significant.

In order to better assess these differences, logistic regression was performed on the aggregated data to assess which variables were independently associated with mammography utilization. Two dependent variables were examined: ever having had a mammogram, and having followed the age-specific guidelines for screening mammography, that is, within two years for women aged 40-49 and within one year for older women.

Table 1

PREDICTORS OF SCREENING MAMMOGRAPHY
INDEPENDENT VARIABLES

	N (%)	%Ever Had	%Guidelines
Race/Ethnicity			
White	1,292 (82)	69.7	53.8
Black	97 (6)	77.1	61.1
Hispanic	179 (11)	55.2	39.7
Education			
≤ H.S.	716 (46)	64.7	47.5
> H.S.	852 (54)	71.5	57.1
Income			
< $15,000	484 (31)	59.4	42.6
≥ $15,000	1,084 (69)	71.9	56.5
Marital Status			
Married/Couple	804 (51)	71.9	57.3
Not	764 (49)	62.7	45.1
Age			
40-49	566 (36)	63.3	57.5
50-59	320 (20)	74.0	52.7
60 +	682 (44)	68.2	48.6
Routine Checkup			
In last year	1,238 (79)	75.0	60.4
Longer	330 (21)	41.9	21.6
Breast Self Exam			
Monthly	946 (60)	71.2	56.2
Less often	622 (40)	63.1	46.2
Employment Status			
Employ/retired	1,253 (80)	69.3	52.5
Not	315 (20)	64.2	51.8

The independent variables were: race/ethnicity (white, black, Hispanic); educational level (HS or less vs. more); income (less than $15,000 vs. more); marital status (married or unmarried couple vs. other); age (40-49, 50-59, 60+); employment status (employed or retired vs. not); routine physical checkup (within the last year vs. not); and breast self-exam (perform at least monthly vs. not). Note that slightly different cutpoints were used for education and income than in the Year 2000 objectives in order to make the number of subjects in the categories more equal. Women of "other" race/ethnicity (not white, black or Hispanic) were excluded from the analysis due to small sample sizes. Sample sizes and unadjusted prevalence rates for both dependent variables are shown in Table 1.

Table 2

PREDICTORS OF SCREENING MAMMOGRAPHY
ASYMPTOMTATIC WOMEN AGED 40 AND OLDER

Results of Logistic Regression

	Odds Ratios	
	%EVER	%GUIDELINES
Routine Checkup	4.2*	6.0*
Age 50-59	1.8*	0.8
Married/Couple	1.5*	1.6*
> $15,000	1.4*	1.2
Hispanic	0.5*	0.5*
Monthly BSE	1.3	1.4*
More than H.S.	1.2	1.3
Employed/Retired	1.2	1.0
Age 60 +	1.2	0.6*
Black	1.1	0.8

*$p < 0.05$

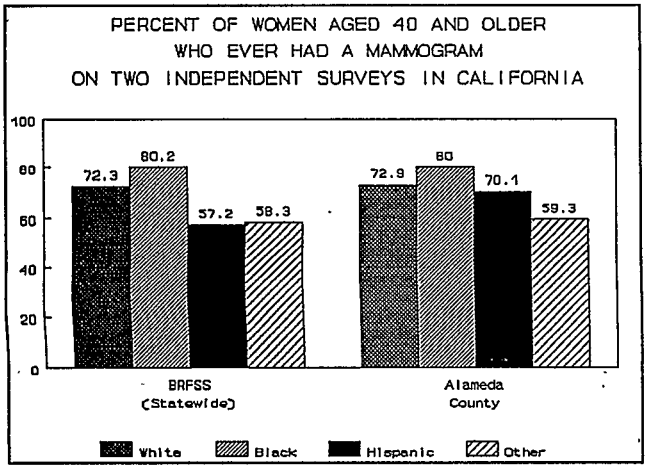
Although the results of the logistic regression analyses are fairly similar for both dependent variables, there are some interesting contrasts (Table 2). In both models, the largest odds ratio is for women who have had a routine physical checkup in the last year. All other factors in the model being equal, women who report having had a routine physical exam in the last year are significantly more likely to report having ever had a mammogram or to have followed the age-specific guidelines. In both models, married or cohabiting women have significantly higher odds of having a mammogram (OR = 1.5 and 1.6 in the first and second model, respectively) than women who are not living with a partner, and Hispanic women are at significantly lower odds (OR = 0.5 in both models) than white women. Utilization among black women was not significantly different from white women in either model.

An important dissimilarity in the models is apparent when looking at the effects of increasing age on utilization of mammography. Women aged 50-59 and 60 and older are more likely than 40-49 year olds to have had at least one mammogram; the odds are significantly higher for 50-59 year olds (OR=1.8), and somewhat lower and not significantly different for women aged 60 and older (OR=1.2). However, women aged 40-49 are the most likely to have met the guidelines for their age. Women aged 50-59 are less likely, but not significantly less, to have met the guidelines (OR=0.8), and women aged 60 and older are the least likely to have met the guidelines (OR=0.6, $p < 0.05$).

Discussion

The finding that black women in California are more likely to have had a mammogram than non-Hispanic white women is contrary to previous reports in the literature. For example, the National Health Interview Survey Cancer Supplement in 1987 estimated that nationwide, about 40% of white women and 31% of black women aged 40 and older had had at least one mammogram (14).

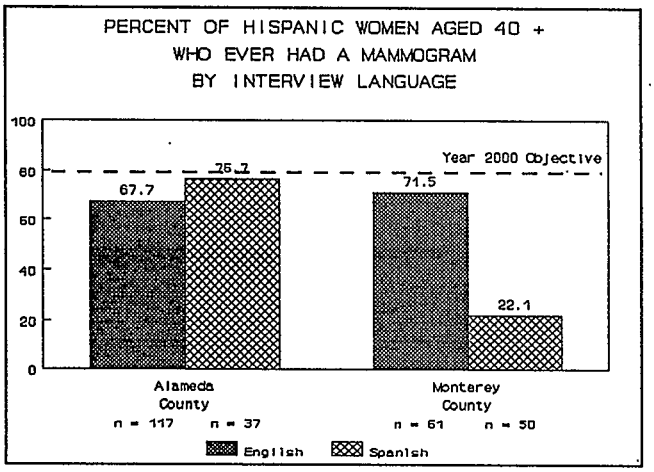
Figure 6



The finding reported here is consistent, however, with other data collected in California. Using very similar methodology to the BRFSS, the Department of Health Services Human Population Laboratory conducted a telephone survey of adults in Alameda County between March 1989 and June 1990. In this survey, women were not asked the reason for their most recent mammogram, and rates therefore reflect both diagnostic and screening mammography. When similar rates were calculated for the BRFSS (i.e., among all women, not just "asymptomatic" women), nearly identical results are found in the two surveys for non-Hispanic whites, blacks, and women of other race/ethnicity (Figure 6). In both the Alameda County survey and BRFSS, about 80% of black women reported ever having had a mammogram, compared to about 72% of white women and 59% of women of "other" race/ethnicity. However, in Alameda County, an urban area, Hispanic women reported higher rates of utilization (70%) than in the state as a whole (57%).

Another telephone survey with similar methodology was conducted in 1989 among Hispanics in Monterey County, a rural, agricultural area. Mammography rates among Hispanics in the Alameda County and Monterey County surveys were calculated by interview language as a surrogate for acculturation. While in the urban area acculturation had no discernable impact on utilization, it appeared to have a major impact in a rural area (Figure 7). In rural Monterey County, only 22% of women

Figure 7



whose survey was conducted in Spanish reported ever having had a mammogram, compared to 72% of those who chose to be interviewed in English.

These results demonstrate that screening mammography has increased significantly in California over a fairly short time period. The large increase between 1987 and 1988 coincided with implementation of legislation requiring MediCal (California's MediCaid program) and group and private health insurance plans to cover screening mammography.

In 1990, about 70% of asymptomatic women aged 40 and older in California reported having had at least one mammogram during their lifetime. Continued efforts will be needed to reach the Year 2000 Objectives for breast cancer screening, especially among the targeted populations. Notably, Hispanic women were significantly less likely to have had screening mammography than white or black women, especially those who are less acculturated and live in rural areas. Income was a significant predictor for screening mammography, despite legislation requiring coverage of screening mammography by medical insurance carriers. Women aged 60 and older were less likely than younger women to follow the screening guidelines, despite the fact that breast cancer incidence increases dramatically with age.

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THE HEALTH RISKS AND BENEFITS OF CONTRACEPTIVE USE IN THE UNITED STATES

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Americans, on the whole, want small families, yet they have one of the highest unintended pregnancy rates among developed countries. More than half (56.5 percent) of the approximately six million pregnancies that occur in the United States each year are unintended. As a result, the United States also has one of the highest abortion rates and one of the highest rates of unintended births in the developed world.

The 1988 National Survey of Family Growth shows that two-thirds of the 57 million American women in their reproductive years (ages 15-44) are currently sexually active and do not want to have a baby now, but are physically able to do so (this includes those women who would be able to have a baby if they were not relying on contraceptive sterilization, an extremely effective but not foolproof method of contraception). Ninety percent of these women use some method of birth control, leaving ten percent who use no method at all. The ten percent of couples who do not use contraceptives account for 53 percent of the 3.5 million unintended pregnancies that occur annually. The most common reason women give for not using contraceptives is the fear of side effects and potential health problems. Often, media coverage of research findings emphasizes dangers and risks which exacerbates that fear. As a result, the public may be receiving a distorted view of the health effects of contraception.

In addition, little public attention is given to the role of contraception in the prevention of sexually transmitted diseases (STDs) or to the effect of STDs on women's reproductive health. Many people are aware of AIDS but are less knowledgeable about other STDs. Like AIDS, these other STDs continue to spread in the United States, with more than 12 million new cases estimated in 1989. As the incidence of STDs rises, so does the incidence of upper genital tract infections and ectopic pregnancy, potential consequences of STD infection that can lead to infertility. Today, because more and more young women and men are postponing childbearing until the middle or later years of their reproductive lives, preventing infertility has become an important companion goal to postponing pregnancy.

This paper is drawn from a recently completed study that compared the health benefits and risks of the use of contraceptive methods and of no method among American women (Harlap, Kost and Forrest, 1991). We use simulation models to measure the implications of the various observed risks that women face for their health and fertility. The purpose of these models is to examine current knowledge in a framework that allows us to compare contraceptive options in light of the various risks faced by sexually active women. Like all models, these include assumptions that greatly simplify the real world and do not take into account all of the factors that can affect the outcomes for individual women. Most of our comparisons involve estimates of the number of adverse health events that will occur in groups of 100,000 women using each method over a period of time, usually a year. We compare such large groups because most effects, fortunately, are quite rare. The rates we present here cannot be used to predict what will happen to an individual woman; instead they indicate the likely effect of each method on a large group of women. Thus, these results will be most useful for policy makers and family planning program providers because they demonstrate the potential impact of contraceptive use on the public's health.

The methods we discuss are those currently available and being used in the United States, including one just recently approved by the Food and Drug Administration (NORPLANT), as well as long-acting injectable hormonal methods, such as Depo-Provera, that are used in many other countries and may have been used by women now living in the United States.

The Simulation Models

To estimate the impact of method differences on pregnancy rates and on the risk of infertility, we used a decision-tree analysis program that allowed us to calculate the number of unintended pregnancies, live births, induced abortions, spontaneous abortions, ectopic pregnancies, upper genital tract infections and cases of infertility that would occur in a hypothetical cohort of 100,000 women within a specified period of time, given a set of probabilities for each outcome. Monthly probabilities of the various events included in the models were calculated from estimates of annual risks obtained by combining information from an extensive review of previous studies as well as analyses of national data sources. The probabilities of pregnancy, including contraceptive failure, are based on previous analyses of the 1982 National Survey of Family Growth. The probabilities of upper genital tract infection were estimated using the 1987 National Hospital Discharge Survey and those for ectopic pregnancy were calculated using estimates of their incidence from the Centers for Disease Control. Estimates for pelvic inflammatory disease (PID) were assumed to vary according to whether the women were at a low or high risk of exposure to sexually transmitted diseases. In addition, the computer program enables us to vary the risks of ectopic pregnancy and infertility according to the events a woman has already experienced. (The models, and the calculation of all values of the estimates, are explained more fully in Harlap, Kost and Forrest, 1991).

The models we use simulate the reproductive experience of a population of women on a month-to-month basis by using estimates of the probability of each event's occurring in a given month. For example, at the start of the simulation, all 100,000 women are assumed to be sexually active, nonpregnant and to have no known impairments to their fecundity. In the first month of the simulation process, all women are subject to specific risks of conception and of developing

upper genital tract infections. Thus, in the second month, some proportion of the women will be pregnant, some will have an upper genital tract infection and the remainder will continue to be exposed to the risk of conception and infection.

To obtain annual estimates of events, we took the distribution in the population of all temporary conditions (e.g., uterine pregnancy, ectopic pregnancy and infection) in the last month of the 60-month simulation process and multiplied by 12. We used the five-year distribution for two reasons: The distribution after only one year is greatly affected by the starting assumption that none of the women entering the model are pregnant, and the distribution after five years, although somewhat arbitrarily chosen, allows enough time for the population to experience the various risks. To obtain an estimate of the number of women who would become infertile each year, we divided the final number of women who became infertile by five.

We have limited ourselves to comparisons of methods as they affect three major objectives -- preventing pregnancy, preserving future fertility and protecting health.

Preventing Pregnancy

Table 1. Estimated number of births and abortions per woman using one method for 30 years, by method

	Births	Abortions
No Method	18	35
Periodic Abstinence	3	4
Withdrawal	3	4
Condom	2	3
Diaphragm/Cap	3	3
Sponge	4	4
Spermicides	5	6
IUD	0	1
Pill	1	1
Implants	0	0
Injectables	0	0
Tubal sterilization	0	0
Vasectomy	0	0

Note: estimates are rounded; zero indicates that the value is 0.5 or less.

Table 1 presents results from the simulation models and illustrates the effect of contraceptive use on women's fertility. The models estimate the number of births and abortions women would have if they used no method for 30 years or if they used any one of the methods for 30 years. The assumption that each woman would not change her contraceptive behavior for 30 years is extreme and is used for purely illustrative purposes.

For one group of women, we assume that they will never use a method of birth control, will be subject to a constant risk of pregnancy and will never have an abortion. Under this set of assumptions, the average woman would have about 18 births over the course of 30 years. Alternatively, if these same nonusers ended every pregnancy with an induced abortion, they would have, on average, about 35 abortions. The assumptions for these 2 sets of models -- that all women in a population would never have an induced abortion or that they would always have one -- are also extreme. And the high numbers of births and abortions are affected by the assumption that these women would be exposed to the risk of pregnancy every month they were not pregnant nor immediately postpartum and would not experience declining fecundity over the 30 years. Although these assumptions may not be useful for predicting the future reproductive experiences of actual women, the model provides a clear illustration of the substantial effects of both contraceptive use and abortion on women's fertility.

Women who use no method would have far fewer births than abortions because a woman spends 9 months pregnant for every live birth and only about 2 months pregnant for an induced abortion; she could have far more pregnancies over the course of time if she used no method and terminated all pregnancies in an induced abortion. These numbers contrast sharply with the number of births and abortions contraceptive users would have. Women who use contraceptives will have far fewer births and abortions over the course of their reproductive lives than if they had used no method simply because they will not become pregnant as often as women who use no method.

Even the least effective methods will prevent substantial numbers of pregnancies. In addition, whether the pregnancies of contraceptive users end in a live birth or in induced abortion will make very little difference to the total number of pregnancies they would have since they have so few pregnancies. Thus the use of any method substantially reduces the risk of pregnancy.

Protecting Future Fertility

Sexually transmitted diseases (STDs) have reached new epidemic highs during the past decade. Each time a person has a new partner, they face the risk of contracting an STD. The majority of U.S. women have more than one sex partner in their lifetime, and a sizable proportion have sex with more than one partner over a short period of time (see Harlap, Kost and Forrest, 1991).

As shown in Table 2, about 8% of sexually active U.S. women aged 15-19 report having had more than one sex partner in the past 3 months.

Table 2 Percentage of women who had more than one partner in the past 3 months among all women who had intercourse in past 3 months.

Age	> 1 partner
15-19	8.2
20-24	5.6
25-29	3.5
30-34	2.0
35-39	2.2
40-44	1.9

New cases of STDs occur most frequently in the youngest men and women, since they change partners

most frequently.

For women, one consequence of STDs is pelvic inflammatory disease (PID). Each year in the U.S., about 1% of sexually active women between the ages of 15 and 44 receive treatment for PID. Because the risk of developing PID is closely associated with the risk of contracting STDs, PID is also most common among the youngest women (see Table 3 and Harlap, Kost and Forrest, 1991).

Table 3 Annual number of PID infections per 100,000 women who have ever had intercourse.

Age	PID Infections
15-19	2200
20-24	1600
25-29	1300
30-34	1000
35-39	600
40-44	500

Some contraceptives -- such as barrier and spermicide methods or the pill -- can provide strong protection against PID.

One consequence of having PID -- or any other upper genital tract infection -- is that if a woman subsequently becomes pregnant, she faces a greater risk of ectopic pregnancy than women who have never had such an infection. The more times she has had a tubal infection, the greater the risk that future pregnancies will be ectopic. By preventing infections, contraceptive use can decrease the risk of ectopic pregnancies, perhaps many years later, when the methods are not even being used.

In addition, when women become pregnant while actually using a contraceptive, the method

Table 4 Percentage of pregnancies following a contraceptive failure that are ectopic.

Method	Ectopics
Copper IUD	3
Progestin IUD	16
Progestin-only pill	6
Implants	14
Injectables	13
Tubal Sterilization	50
All Other Methods	1

that fails may contribute to an ectopic pregnancy. As Table 4 shows, the likelihood of an ectopic is 1% or less for women who become pregnant while using combined oral contraceptives, periodic abstinence, withdrawal, barrier or spermicide methods or vasectomy, but it can be as high as 13-16% of failures among women using progestin-only long-acting hormonal methods or progestin IUDs, or, as high as 50% of pregnancies occuring to women who have had a tubal sterilization. However, the fact that women using these methods experience a contraceptive failure so much less frequently than women using less effective methods means that they actually experience fewer ectopic pregnancies even though the risk per pregnancy is increased.

One consequence of upper genital tract infection and of ectopic pregnancy is a raised probability of tubal infertility. The more often a woman has been infected and the more times she has had an ectopic, the more likely she is to become infertile. Table 5 shows estimates of the number of women in the simulated population who would acquire tubal infertility over a 5-year period of contraceptive use or nonuse.

Table 5 Estimated number of women developing tubal infertility over a five-year period per 100,00 women aged 15-44 (from simulation models).

Method	Number infertile
Low Risk of STDs	
No Method/Birth	400
No Method/Abortion	740
Periodic Abstinence	190
Barriers/Spermicides	110
IUD	280
Pill	80
High Risk of STDs	
No Method/Birth	3810
No Method/Abortion	6370
Periodic Abstinence	4450
Barriers/Spermicides	1980
IUD	7070
Pill	2240

The upper panel in Table 5 compares nonusers and users of different contraceptives among women who are at low risk of STDs, and the lower panel compares nonusers and users at high risk of STDs. There are four important points made in this table. First, we can see that a major determinant of the risk of tubal infertility is the level of exposure of the woman to the risk of STDs. Again, as the number of sexual contacts of the woman or her partner increases, her risk of contracting an STD also increases. Second, tubal infertility will be most common in women using no method of birth control because of their lack of protection against upper genital tract infections and ectopic pregnancy. Third, contraceptive choices are very important among women at high risk of STDs. Among these women, there is a substantial preventive effect attributable to barrier and spermicide methods and to oral contraceptives, compared with women using no method or using a method that offers no protection against infection, such as periodic abstinence or the IUD. Fourth, the IUD, which may add cases of tubal infertility in women at high risk of STDs, actually prevents tubal infertility among women at low risk of STDs, compared with those using no method of birth control. This preventive effect is due to the low risk of pregnancy among women using the IUD and therefore a lowered risk of experiencing an ectopic pregnancy.

Contraceptive use can have a large effect on the risk of developing tubal infertility. Among women at low risk of STDs, estimated rates of tubal infertility for women using any

contraceptive are lower than those for women using no method. Among women at high risk of STDs, the estimated rates of infertility are lowest in the group of women using barrier and spermicide methods.

Protecting Health

In our study, we estimate the preventive effect of pill use on ovarian and endometrial cancer, and how this balances against a possible increased risk of breast and liver cancer among pill users (again, for explanation of the calculation of our estimates, see Harlap, Kost and Forrest, 1991). We conclude that the average woman who has ever used the pill is less likely to get cancer -- and to die as a result --before age 55 than a woman who has never used the pill.

Table 6 Estimated annual number of newly diagnosed cases of ovarian cancer per 100,000 women who never used the pill and per 100,000 women who used the pill for 10 years or longer.

Age	Never Used	Used 10+ Years
15-19	2	0
20-24	3	1
25-29	4	1
30-34	6	1
35-39	10	2
40-44	17	3
45-49	27	5
50-54	33	7

Table 6 shows our estimates of ovarian cancer rates in each five year age group among women who never used the pill compared with women who used the pill for ten years or more, or, from age 15 if they are under 25.

Pill use for ten years or more reduces the probability of ovarian cancer to about one-fifth -- and this preventive effect benefits substantial numbers of women as they become older, in their late 40's and 50's. The pill also helps to protect against endometrial cancer; women who have used the pill for ten years or more are about 40% as likely to experience this cancer as women who have never used the pill. The preventive effect of the pill on both ovarian and endometrial cancers continues for many years into the future, even after the woman discontinues use, and is an important side benefit of oral contraceptive use that is not usually taken into account in studies that focus exclusively on younger women.

The relationship between oral contraceptive use to breast cancer is not completely clear, with several studies presenting inconsistent results. We have tried to organize current knowledge and make some sense of it, drawing on results from the three largest studies in the U.S., New Zealand and the United Kingdom, and reviewing other studies with comparable data. Table 7 shows the number of breast cancer cases diagnosed among women who used the pill for ten years in each of the three studies, as compared to women who never used the pill.

Current evidence shows that women in their 30's and early 40's who used the pill for prolonged periods are having more breast cancer diagnosed, while at older ages long-term pill users have less breast cancer diagnosed. Breast cancer, however, is less common in the youngest age groups, while it is much more common among older women. When all ages are considered together, women who ever used the pill -- even for prolonged periods -- have the same rate of breast cancer as nonusers.

Table 7 Estimated annual number of newly diagnosed cases of breast cancer per 100,000 woman who have never used the pill and per 100,000 who have used the pill for 10 years or longer; 3 studies in the United States, New Zealand and the United Kingdom.

	Never Used	Used 10+ Years		
Age	U.S.	U.S.	New Zealand	U.K.
15-19	0	0	0	0
20-24	1	1	2	0
25-29	6	9	29	11
30-34	21	30	97	37
35-39	61	68	52	*
40-44	112	123	94	*
45-49	188	169	180	*
50-54	210	189	202	*

*No information for older women.

In Table 8 we consider all cancers affected by pill use together, contrasting women who used the pill for ten or more years to never users. We estimate that there may be about 1 more case of cancer per 100,000 pill users per year at ages 25-29 and 30-34, but at older ages, the number of cases of ovarian and endometrial cancer prevented by the protective effect of the pill outweighs the number of cases of breast and liver cancer. Our assessment of the current evidence, therefore, shows a net protection against cancer by the pill.

Table 8 Estimated annual number of newly diagnosed cases of ovarian, endometrial, breast and liver cancers combined per 100,000 woman who never used the pill and per 100,000 women who used the pill for 10 years or longer.

Age	Never Used	Used 10+ Years
15-19	2	0
20-24	4	2
25-29	11	12
30-34	31	34
35-39	80	76
40-44	148	137
45-49	252	192
50-54	299	228

Mortality

Finally, we have calculated updated estimates of mortality associated with contraceptive use. Table 9 shows combined pregnancy-related and method-related mortality for each of the methods, and compares hypothetical cohorts of 100,000 women who choose to give birth

-- the first column -- with those who choose to have induced abortions -- the second column. This table shows first, that induced abortion saves lives. Second, the use of a contraceptive method -- any method -- is less likely to lead to death than using no method.

Table 9 Estimated annual number of pregnancy- and method-related deaths per 100,000 woman aged 15-44, by method used and pregnancy outcome.

Method	Birth	Abortion
No method	5.3	1.2
Periodic abstinence	1.0	0.1
Withdrawal	1.0	0.1
Condom	0.7	0.1
Diaphragm/Cap	0.8	0.1
Sponge	1.1	0.1
Spermicides	1.5	0.2
IUD	0.2	0.1
Pill	1.3	< 0.1
Long-acting hormonals	0.5	< 0.1
Tubal sterilization	1.2	0.1
Vasectomy	0.1	< 0.1

Table 10 shows the number of deaths related to pregnancy or childbirth and to cardiovascular disease averted by current use of barrier and spermicide methods and of the pill. In every age

Table 10 Estimated annual difference in the number of deaths related to pregnancy and childbirth or cardiovascular disease between 100,000 women who use the method and 100,000 who use no method.

Age	Barriers/ Spermicides	Pill
15-19	3.8	3.9
20-24	4.0	4.1
25-29	3.9	3.7
30-34	5.1	4.5
35-39	10.2	10.7
40-44	17.9	18.7

group, contraceptive use averts deaths. For example, 100,000 30-34 year-old current users of barrier and spermicide methods experience 5 fewer deaths each year than women who use no method of contraception. The number of deaths prevented by current use increase at the older ages because the risk of death from pregnancy and childbirth increases with age.

Not only do contraceptives save lives in the present, but they also avert deaths in the future (Table 11). We calculated how many future cancer deaths would be prevented by ever use of these methods, compared with women who never used them. The deaths prevented are for cervical cancer (prevented by barrier and spermicide methods) and for ovarian and endometrial cancer (prevented by the pill) and we calculated how many deaths would be prevented from the age at which the women began using the method until they reach age 45. For

Table 11 Estimated difference in the number of cancer deaths before age 45 between 100,000 women who ever used and 100,000 who never used the method.

Age	Barriers/ Spermicides	Pill
15-19	60	23
20-24	60	21
25-29	58	19
30-34	49	15
35-39	33	16
40-44	12	10

example, 100,000 women who use a barrier and spermicide method in their late teens will avoid 60 cervical cancer deaths by the time they reach age 45. Similarly, women 15-19 years old who use the pill will prevent 23 cancer deaths by the time they reach age 45.

In addition, many more cancer deaths will be prevented between ages 45 and 54 and probably later. Ever use of barrier and spermicide methods and the pill saves lives in the future, and this saving continues even if the women stop using the method.

Conclusions

The riskiest contraceptive choice a sexually active woman can make is to use no method at all. Consistent and correct use of a birth control method not only prevents unintended pregnancy but helps a woman preserve her ability to have children in the future and to safeguard her health. The health dangers associated with the use of birth control methods are far fewer than those associated with an unplanned pregnancy. Barrier and spermicide methods and oral contraceptives also save lives by preventing reproductive cancers and preserve women's ability to have children in the future by protecting them against sexually transmitted diseases or against developing pelvic infections from these diseases. For women who are at risk of unintended pregnancy, then, using a contraceptive method -- any method -- is a far more certain way of maintaining good health than using no method. The sexually active woman who uses no method not only is at a greatly increased risk of an accidental pregnancy, but also has no opportunity to gain from the benefits of contraceptives.

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THE ULTIMATE MEASURE OF WOMEN'S HEALTH: MATERNAL MORTALITY

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The ultimate measure of the health of reproductive-aged women is the level of maternal mortality. Since 1940, the number and ratio of maternal deaths in this country have declined dramatically. With the advent of antibiotics, intravenous fluids, blood transfusions, prenatal care, and modern obstetrical techniques, many maternal deaths have been prevented. However, maternal deaths still occur, and they affect different subgroups of the population differently.

The 1990 health objectives for the nation included maternal mortality as a priority area that could show improvement. A specific goal of no more than 5 deaths per 100,000 live births was set for any ethnic group or county.[1] This goal was not achieved for all women.[2] A new goal calling for further reductions in this preventable cause of death was stated for the Healthy People 2000 objectives.[3]

To better understand the risk factors and leading causes of maternal death, the Centers for Disease Control, in collaboration with the Maternal Mortality Special Interest Group of the American College of Obstetricians and Gynecologists (ACOG), the Association of Vital Records and Health Statistics, and state and local health departments, initiated National Pregnancy Mortality Surveillance in 1988.[4] This system has two major components: a retrospective study of all identified maternal deaths that occurred in the United States from 1979 through 1986, and an ongoing prospective investigation of all pregnancy-associated deaths identified through the individual state systems and other sources of reporting, starting with maternal deaths that occurred in 1987. This paper presents new findings from the retrospective study.

We classified a woman's death as maternal if it occurred during pregnancy or within 1 year after pregnancy and resulted from: 1) complications of the pregnancy itself, 2) a chain of events that was initiated by the pregnancy, or 3) the aggravation of an unrelated condition by the physiologic or pharmacologic effects of the pregnancy. A woman's death was considered to be a potential maternal death if a check box for pregnancy was marked on the death certificate, if the death certificate otherwise indicated that the woman was pregnant at the time of death, or if the woman's death certificate was linked to a birth certificate or a fetal death record within 1 year after the pregnancy. We reviewed each death in detail to determine whether it was a maternal death.

To classify deaths, we used a new system designed in collaboration with members of the Maternal Mortality Special Interest Group of ACOG. This system differentiates between the immediate and underlying causes of death as stated on the death certificate, associated obstetrical conditions or complications, and the outcome of pregnancy. The classification scheme allows better analysis of the multiple factors that led to death and focuses on the causes of death for each outcome of pregnancy.

With the assistance of all state vital statistics offices, we created a database of all identifiable maternal deaths for 1979-1986 linked with corresponding live birth or fetal death records. Having a linked outcome certificate for the majority of women whose pregnancy outcomes were a live birth or a stillbirth provided data not available on the death certificate alone. This additional information enabled us to analyze the risk of maternal death by educational level and adequacy of prenatal care. A total of 2,726 pregnancy-associated deaths were reported to CDC for 1979-1986. Our review of all available records determined that 2,644 were maternal deaths. Most of the deaths were associated with a live birth (51.6%), an ectopic pregnancy (13.0%), or a stillbirth (9.9%).

The overall maternal mortality ratio for the 8-year study period was 9.1 deaths per 100,000 live births (Table 1); the ratio dropped steadily, from 10.9 in 1979 to 7.4 in 1986--a 32% decrease. Nonetheless, even the 1986 figure was almost 1.5 times higher than the goal for the 1990 health objectives for the nation.

TABLE 1. Maternal deaths and maternal mortality ratios,* by year, United States,+ 1979-1986

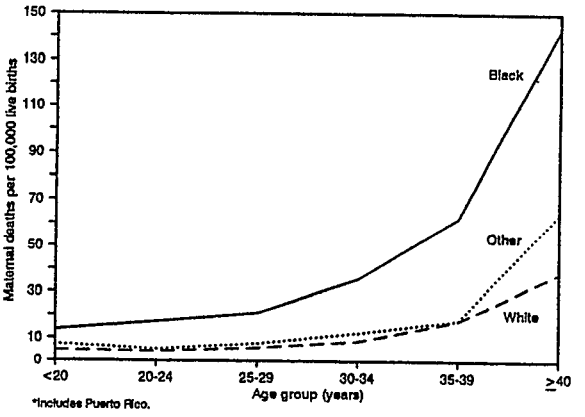
Year	Maternal deaths	Maternal mortality ratio
1979	380	10.9
1980	379	10.5
1981	346	9.5
1982	337	9.2
1983	313	8.6
1984	304	8.3
1985	307	8.2
1986	278	7.4
1979-1986	2,644	9.1

*Maternal deaths per 100,000 live births.
+Including Puerto Rico.

Overall, women who were 30 years of age and older had a higher risk of maternal death than younger women (Figure 1). Women who were 35-39 years old had almost four times the risk of dying that women aged 20-24 years had; this disparity was almost nine-fold for women who were 40 years and older. In fact, the ratio for women aged 40 years and over was 11 times that of the 1990 objective.

Race was also strongly associated with maternal mortality. Black women were three times more likely than white women to die from maternal causes. The maternal mortality ratio for black women (22.0 per 100,000 live births) was over four times higher than the 1990 objective.

Figure 1. Maternal mortality ratios, by age group and race, United States,* 1979-1986



Age-specific mortality ratios were also much higher for black women than for white women. Women of races other than black or white had slightly higher age-specific maternal mortality ratios than those for whites, although the disparity became more pronounced among women aged 40 years and older.

Unmarried women had almost a three times higher risk of maternal death than married women. Unmarried white women had an age-adjusted ratio 2.7 times that for married white women (15.6 versus 5.8), whereas unmarried black women had an age-adjusted ratio only 1.2 times that for married black women (24.7 versus 20.5).

Women residing in the Northeast region had the highest risk of death, and women residing in the North Central region had the lowest risk. A previous study found that for 1986, women residing in the North Central region of the country had the highest level of prenatal care.[5] These researchers also observed that during the period of 1984-1986, the proportion of women receiving delayed or late prenatal care increased more in the Northeast than in any other region.

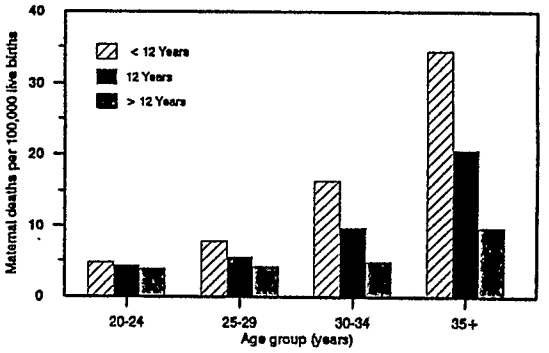
TABLE 2. Maternal-mortality ratios* and risk ratios, by region of residence, United States,+ 1979-1986.

Geographic region of residence	Maternal deaths	Maternal mortality ratio	Risk ratio	95% Confidence limits
Northeast	538	10.0	1.4	(1.21, 1.55)
North central	538	7.3	referent	
South	980	9.8	1.3	(1.20, 1.48)
West	530	8.3	1.1	(1.00, 1.27)
All regions	2,586	9.1		

*Maternal deaths per 100,000 live births.
+Excludes Puerto Rico.

The risk of maternal death by years of education was determined only for women whose pregnancy outcomes were a live birth or a stillbirth (Figure 2). We further restricted our analysis of education to women aged 20 years and older, most of whom would have at least had the opportunity to graduate from high school. The risk of maternal death increased with decreasing levels of education. Overall, women who had not completed high school had the highest maternal death ratios. For all age groups, women who had completed more than 12 years of education had the lowest risk of dying. Compared with college-educated women, women with less than 12 years of education had a much more pronounced risk among those 35 years and older (RR=3.5; 95% CL 2.42, 5.15) than in women aged 20-24 years (RR=1.2, 95% CL 0.82, 1.53). In fact, higher levels of education seemed to dampen the effect of age on the risk of maternal death.

Figure 2. Age-specific maternal mortality ratios,* by education, for women having live births or stillbirths, United States,+ 1979-1986

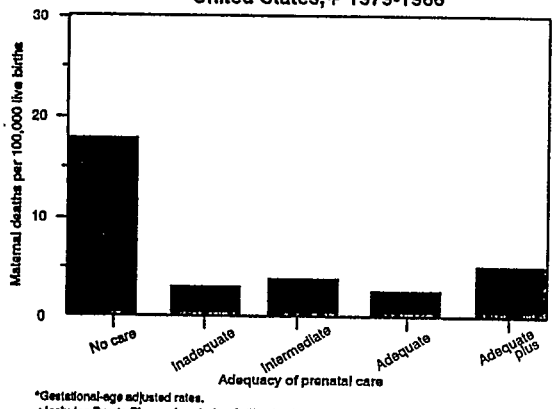


*Maternal deaths per 100,000 live births for women aged 20 years and older.
+Includes Puerto Rico and excludes California, Connecticut, Minnesota, Texas, and Washington.

To assess prenatal care, we used the adequacy of prenatal care use (APCU) index, developed by Kotelchuck, for women who delivered a live birth. This index measures adequacy of prenatal care by the timing of the first prenatal visit and by the appropriateness of the number of visits (based on gestation at the first prenatal visit and delivery).[6] The APCU index defines four levels of prenatal care adequacy. We added a level for women with no prenatal care.

Women who had received any amount of prenatal care had a lower risk of dying than women who had received no care (Figure 3). Women who had received "inadequate" prenatal care had a slightly higher risk of dying than women with "adequate" care. Women whose care was determined to be have been "adequate plus" had a 1.7 times risk of dying as women with "adequate" care. The women who had received more care, however, were likely to have had complicated medical conditions that required these additional visits. Such conditions would increase these women's likelihood of having poor pregnancy outcomes, including maternal death.

Figure 3. Adjusted* maternal mortality rates, by levels prenatal care adequacy, for women having live births, United States,+ 1979-1986



*Gestational-age adjusted rates.
+Includes Puerto Rico and excludes California, Connecticut, Minnesota, Oklahoma, New Mexico, Rhode Island.

Notably, women who had received no prenatal care had a crude risk of maternal death 6.5 times (95% CL 5.17, 8.24) that of women with "adequate" care. When adjusted for gestational age, the risk from having received no care dropped somewhat, to 5.7. Overall, 1.9% of women delivering a live birth in 1986 had had no prenatal care.[7] In contrast, 8.3% of women who died following a live birth during the study period had not received prenatal care. More information is needed to determine whether the absence of prenatal care itself or the social and behavioral factors associated with a lack of prenatal care were responsible for the increased risk of maternal death.

This study's new system of classifying maternal deaths specifically allowed us to compare causes of death by pregnancy outcome. The leading causes of death differed by pregnancy outcome. For women whose pregnancy ended in a live birth, the leading causes of death were pulmonary embolism (primarily, thrombotic embolism), pregnancy-induced hypertension complications (primarily, central nervous system complications related to eclampsia and preeclampsia), hemorrhage (primarily, postpartum uterine bleeding), and infection.

For women whose pregnancy ended in a stillbirth, the leading causes of death were hemorrhage (largely from abruptio placentae), pregnancy-induced hypertension complications, and pulmonary embolism (primarily, amniotic fluid embolism). For women whose pregnancies ended in a spontaneous or induced abortion, the leading causes of death were hemorrhage from uterine bleeding, generalized infection, and thrombotic pulmonary embolism. For women whose pregnancy ended in an ectopic pregnancy, almost 90% of deaths were from hemorrhage that resulted from rupture of the ectopic site.

To ascertain most deaths in this study, we used surveillance based on routine vital statistics. Reports using routine vital statistics of maternal deaths (based on death certificate information alone) have three limitations. First, vital records are not designed to investigate and understand the risk factors associated with maternal deaths. Second, reports based only on vital statistics do not provide enough detail to assess, for prevention purposes, the pathophysiology and circumstances leading to maternal death or the determination of associated risk factors. Third, studies based only on vital statistics understate maternal mortality ratios. Other studies have shown that maternal deaths not identified by vital statistics range from 18% (New York City),[8] to 27% (Georgia),[9] to 73% (Puerto Rico).[10]

Finally, reports based only on death certificates are often categorized in a way that does not give specific information on all causes of maternal death; recent national vital statistics reports have attributed over 40% of all maternal deaths to "other" causes. In fact, pulmonary embolism, which is now the leading cause of maternal death, is not listed separately as a cause of maternal death in routine vital statistics reports.[2]

Even though the availability of linked birth and fetal death records improved the quality and quantity of information available for us to assign a cause for each death, the absence of detailed clinical information limited our ability to assess risk factors and assign specific causes to some of the deaths. Also, because we ascertained most cases by routine vital statistics, the ratios likely underestimate the actual number of maternal deaths occurring during the study period.

Despite the decreasing trend in maternal mortality over this 8 year period, the 1990 objective has not likely been achieved for all women. The gap between white women and women of other races continues. To meet the Healthy People 2000 objective of reducing maternal mortality for all groups, comprehensive data collection and monitoring systems must be in place, and attention must be paid to the population groups at highest risk for maternal death--primarily, black women. Enhanced surveillance of maternal deaths and collection of detailed information from medical records, autopsy reports, reports from maternal mortality review committees, and from other sources will help clarify the magnitude, risk factors, characteristics, and causes of maternal deaths. Comprehensive data must be gathered and used to assess risk factors and then disseminated to policy makers and clinicians to develop strategies to reduce these deaths.

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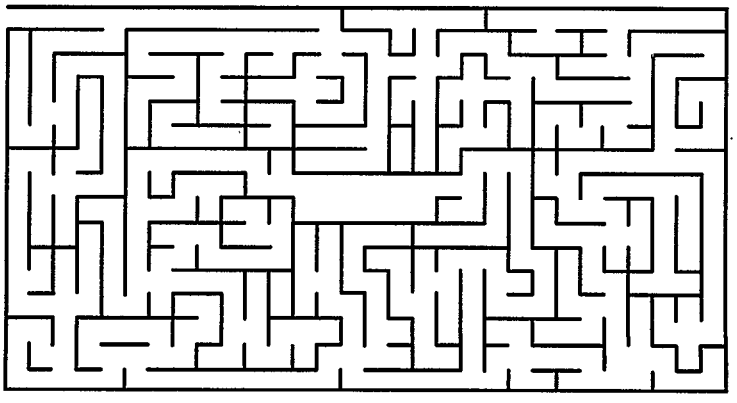
Session L

Poverty, Uninsured, and Homeless



POVERTY AND HEALTH: A NATIONAL STUDY OF THE DETERMINANTS OF EXCESS MORTALITY*

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James M. Lepkowski

Socioeconomic status (SES) is a strong and consistent predictor of variations in morbidity and mortality. Persons of high social status live longer and enjoy better health than their less favored counterparts (1-4). Especially impressive is the persistence of SES differences in health status over time. Recent reviews indicate that socioeconomic differences in health status exists throughout Western Europe despite the ready availability of medical care, increased economic development, and marked improvements in the standard of living during this century (4-8). Despite the consistency with which socioeconomic factors predict changes in health status, the reasons underlying this relationship are yet to be clearly identified. There is growing recognition that social status variations in health reflect the location of social groups in a stratified social system and are therefore linked to the particular conditions of life under which these groups live (4). Accordingly, identifying the determinants of SES differences in health status will require the identification of the "general features of lower class living environments that compromise bodily defense" (3).

A broad range of social and behavioral factors have been nominated as potential linkages between social stratification and health status (4,9). These psychosocial factors such as marital patterns and health behaviors have also emerged as central determinants of health (10). The United States Surgeon General's report, for example, indicates that 50 percent of U.S. mortality is due to unhealthy behavior and lifestyle. In contrast, 20 percent is attributable to environmental factors, 20 percent to genetic factors and 10 percent to inadequate medical care (11). A growing body of evidence also suggests that these health enhancing psychosocial resources are all positively related to socioeconomic position (4,12).

Few attempts have been made to empirically verify the extent to which psychosocial factors can account for the association between SES and health status, and the available evidence is equivocal. House et al. (13) recently reported that adjustment for psychosocial factors completely accounts for the association between low socioeconomic status and self reported health. Rose and Marmot (14) found that adjustment for cholesterol, smoking, blood pressure, body mass index, blood glucose, physical activity, and height accounted for more than half of the increased risk of coronary heart disease mortality for manual and low-skilled white collar workers. On the other hand, a study in eastern Finland found that a significant association between heart disease mortality and low levels of education and income persisted after adjustment for age, cholesterol, smoking and blood pressure (15). Similarly, analyses of the Alameda County Study found that the significant association between poverty area residence and mortality remained virtually unchanged after adjustment for baseline health status, race, income, employment status, access to medical care, health insurance coverage, smoking, alcohol consumption, physical activity, body mass index, sleep patterns, social isolation, marital status, depression, and personal uncertainty (16). This study concluded that SES differences in mortality are not due to these social and behavioral risk factors.

The SES measure in the Alameda County Study was a dichotomous indicator of residence in poverty areas versus residence in nonpoverty areas. Race was more strongly related to poverty area residence than any other demographic, socioeconomic, or behavioral characteristic. Sixty-seven percent of poverty area residents were black compared to thirteen percent of nonpoverty area residents. Since the degree of residential segregation by race is still very high in most major metropolitan areas (17), it is likely that there is considerable variation in socioeconomic status, especially among blacks, within federally designated poverty areas. Thus, although the findings of the Alameda County Study clearly underscore that place of residence can be a potent determinant of adverse changes in health status, given the strong relationship between behavioral risk factors and individual level indicators of SES in Alameda County (10), these risk factors are likely to explain more of the socioeconomic variation in health outcomes when SES is measured at the individual as opposed to the ecological level.

More generally, studies that have assessed the role of psychosocial factors in explaining SES differences in mortality have varied in the behavioral risk factors assessed and have not uniformly considered a broad range of factors. The NHANESI Epidemiologic Followup Study provides a unique opportunity to study the determinants of socioeconomic differences in mortality in a large national probability sample. Specifically, we address the following research questions: 1) how are health behaviors including dietary frequency, marital status, and health care utilization linked to economic status and mortality, and 2) to what extent can these risk factors, considered singly and in combination, account for SES differences in mortality.

METHODS

Study Population. The data for our analyses come from the First National Health and Nutrition Examination Survey (NHANESI) Epidemiologic Followup Study (NHEFS). NHANESI is a multi-stage, stratified, national probability sample of the noninstitutionalized civilian population (18,19). The study was conducted between 1971 and 1974 and was augmented by an additional national sample during 1974 and 1975 that increased the size of certain subpopulations. The total NHANESI sample is 23,808 persons, 1 to 74 years of age. NHANESI is composed of six distinct subsamples of the U.S. population and not all participants received the same questionnaires or examination components.

The NHEFS population comprises all of the 14,407 NHANESI participants who were 25 to 74 years of age when they were first interviewed and medically examined between 1971 and 1975 (20,21). Data collection in NHEFS took place between 1982 and 1984 and included tracing the vital status of each NHANESI subject. Ninety-three percent of the original NHANESI cohort were successfully traced. The length of followup ranged from 5 to 12 years, with an average of 9.5 years.

Measures. Mortality from all causes is the central dependent variable in all analyses. Our measure of SES is the federal definition of poverty originally developed at the Social Security Administration in 1964 and revised by Interagency Committees in 1969 and 1980 (22). The poverty thresholds are updated every year to reflect changes in the consumer price index. We classified all respondents into one of four categories: 1) poor (0-100% of the poverty level), 2) near poverty (101-150% above

Table 1

THE ASSOCIATION BETWEEN RISK FACTORS, CONSIDERED SINGLY AND IN COMBINATION, AND MORTALITY, FOR MALES AND FEMALES[1]

Risk Factors	Males		Females	
	Bivariate	Adjusted	Bivariate	Adjusted
Marital Status				
1. Married	-.79***	-.34*	-.72***	.06
Health Behavior				
2. Exercise	-.49***	-.31***	-.37***	-.18***
3. Alcohol				
a. Moderate Drinker	-.45***	-.08	-.60***	.07
b. None/Heavy (omitted)				
4. Weight				
a. Average	-.39***	-.32**	-.33***	-.43***
b. Over/Under (omitted)				
5. Smoking				
a. Non-Smoker	-.27**	-.74***	.24	-.38**
b. Smoker (omitted)				
Diet Frequency				
6. Fish				
a. Some	-.92***	-.57***	-.35*	.12
b. Never (Omitted)				
7. Cheese				
a. Once/day or more	.11	.43**	-.40**	-.42*
b. 6/weekly or less (omitted)				
8. Fruits/Vegetables				
a. Once/day or more	.69***	.11	-.28+	-.04
b. 6/weekly or less (omitted)				
9. Desserts/sweets				
a. Once/week or more	-.60***	.07	-.36***	-.06
b. L/T once/week (omitted)				
10. Candy				
a. Some	-.60***	.11	-.45***	-.14
b. Never (omitted)				
11. Snacks				
a. Some	1.25***	-.41***	-.92***	-.18
b. Never (omitted)				
Health Status				
12. Cholesterol	.00***	.00	.01***	-.00
13. Systolic	.03***	.01***	.03***	.01***
14. Diabetes (1=yes)	1.59***	.69***	1.45***	.52**
Medical Care				
15. Insurance (1=None)	.61**	.26	.56*	.52
16. Last checkup				
a. Never	.60**	.11	.69***	-.21
b. Last year	.29	.38	-.00	.33
c. Over 1 year (omitted)				
17. Place of Care				
a. M.D. office	-.13	.12	-.67***	-.44
b. Other (omitted)				

*=p<.05; **=p<.01; ***=p<.001

[1]The adjusted model includes all covariates listed as well as age, race and poverty status.

poverty), 3) above poverty (151%-200% above poverty), and 4) well above poverty (201% or more above poverty).

Physical exercise, alcohol consumption, weight status, smoking, and nutrition are the indicators of health behavior utilized. The two item physical exercise index estimates how active respondents are in their usual daily activities and in their recreational pursuits. Alcohol consumption, measured in ounces of ethanol consumed per day is, divided into three categories: 1) non-users, less than .01 on the ethanol scale, b) moderate-users, between .01 and .99, and c) heavy users, a score over 1.0 (23). Moderate-users are compared to other users. The body mass index (BMI), weight in kilograms divided by the square of height in meters, contrasts persons with moderate weight to all others. The top quartile of BMI is defined as overweight, the middle two quartiles as moderate weight, and the bottom quartile as underweight (24). Smoking data was initially collected only for a subset of NHANESI respondents (N=6,913). Smoking status at baseline was imputed from the smoking history obtained at followup for NHANESI respondents with missing data (25). Non-smokers are contrasted with current smokers. Six nutritional variables, (the frequency of consuming fish, cheese, fruits and vegetables, desserts and sweets, candy, and snacks), which showed significant relationships to mortality in initial analyses are utilized. We followed the strategy suggested by Murphy et al. (24) of focusing on those individuals at the extremes of the distribution of

Table 2

THE DISTRIBUTION OF RISK FACTORS BY POVERTY, NHEFS
MEANS AND PROPORTIONS(P)

Risk Factors	Poverty Status Poor	100-150%	151-200%	201%+
Marital Status				
1. Married	.52+	.69*	.81*+	.85*+
Health Behavior				
2. Exercise	3.81+	3.95*	4.13*+	4.20*+
3. Alcohol				
a. Heavy Drinker (P)	.08	.09	.07	.11*+
b. Moderate Drinker (P)	.35+	.43*	.48*+	.59*+
b. Non-Drinker (P)	.58+	.48*	.45*	.30*+
4. Weight				
a. Average (P)	.43	.45	.53*+	.52*+
5. Smoking				
a. Non-Smoker (P)	.69	.67	.65	.69
Diet Frequency (P)				
6. Fish	.85+	.89*	.93*+	.94*+
a. Some				
7. Cheese				
a. Once/day or more	.08+	.11*	.12*	.16*+
8. Fruits/Vegetables				
a. Once/day or more	.76+	.85*	.89*+	.95*+
9. Desserts/sweets				
a. Once/week or more	.73+	.78*	.85*+	.83*+
10. Candy				
a. Some	.70	.73	.79*+	.79*+
11. Snacks				
a. Some	.65	.66	.71*+	.77*+
Health Status				
12. Cholesterol	219+	224*	218+	220+
13. Systolic	140+	137*	132*+	130*+
14. Diabetes (1=yes)	.06	.06	.03*+	.03*+
Medical Care (P)				
15. Insurance (1=None)	.29+	.16*	.11*+	.06*+
16. Last checkup				
a. Never	.32+	.26*	.17*+	.13*+
b. Last year	.25	.25	.28	.32*+
c. Over 1 year	.43+	.50*	.55*	.56*+
17. Place of Care				
a. M.D. office	.39+	.48*	.53*	.61*+

*=significantly different from below poverty (p<.05)
+=significantly different from 100-150% of poverty (p<.05)

dietary intake patterns.

Age in years at first interview and race (1=black, else=0) are the sociodemographic control variables employed in the analyses. Marital status (married=1, unmarried=0) is the measure of social integration employed. Three measures of initial health status are available for the entire sample: 1) serum cholesterol (mg/100ml); 2) systolic blood pressure; and 3) the respondent's report of a physician's diagnosis of diabetes (1=yes, 0=no). Two additional measures of initial health status, forced expiratory volume in one second (FEV_1) and perceived health, are available in the smaller subsample.

Three indicators of medical care are available for respondents in the 20 percent subsample of NHANESI. Medical insurance is a dichotomous indicator of the presence of some versus no health insurance. Last checkup is a measure of the recency of contact with the health care system for non-emergency care. It has three categories: 1) never had a checkup, 2) had a checkup in the last year, and 3) had a checkup over one year ago. Place of care contrasts receiving care in a private physician's office (M.D.'s office) to the receipt of care elsewhere.

Statistical analysis. Simple descriptive analyses are used to present the distribution of risk factors by poverty. However, this report relies primarily on the multiple logistic regression analyses using maximum likelihood estimation procedures for assessing the magnitude and statistical significance of the relationships among poverty, risk factors and mortality. All analyses are weighted for differential sampling probability and to make analyses generalizable to the population of the United States.

Multiple logistic models for the association between SES and mortality were estimated under five conditions. In the first model, a continuous age variable and a dummy variable for race are included along with poverty. To this base model each class of risk factors is added one at a time while a final model includes the covariates from all previous models. Thus, the second model adds marital status, the third model considers the health behavior variables, the fourth, the measures of initial health status, and the final equation considers the combined effect of all of these variables. When the smaller subsample is utilized, an additional model that includes the medical care variables is added. The primary interest in models 2-4 is in assessing change in the logistic coefficients for poverty between the model under consideration and the first one. Reductions in the size of the coefficients for poverty (or the odds ratios calculated from these), indicates that the variables in that particular model are partly responsible for the observed SES differentials in mortality.

RESULTS

Table 1 shows the logistic regression coefficients for the association between the risk factors and mortality for males and females. Two models are presented. The first shows the unadjusted bivariate relationship between each risk factor and mortality. The second model has all

Table 3

ODDS RATIOS FOR THE ASSOCIATION BETWEEN POVERTY AND MORTALITY NHEFS, MALES[1]

	Age & Race[a]	Adjusted for Marital Status	Health Behavior	Health Status	All Vars.
ALL MALES					
Poverty					
a. Poor	2.32***	2.08***	1.44*	2.24***	1.43*
b. 100-150% above	2.39***	2.27***	1.76***	2.31***	1.74***
c. 151-200% above	1.18	1.18	1.03	1.18	1.04
d. 201% + (omitted)	1.00	1.00	1.00	1.00	1.00
			N=4,133		
MALES 25-44					
Poverty					
a. Poor	6.03***	5.65***	4.55***	5.97***	4.76***
b. 100-150% above	3.28**	3.16**	1.77	3.23**	1.99
c. 151-200% above	1.44	1.43	.68	1.50	.77
d. 201% + (omitted)	1.00	1.00	1.00	1.00	1.00
			N=1,375		
MALES 45-64					
Poverty					
a. Poor	2.18***	1.85**	1.24	2.09***	1.15
b. 100-150% above	3.20***	2.95***	2.29***	3.01***	2.13***
c. 151-200% above	1.04	1.06	.95	1.03	.95
d. 201% + (omitted)	1.00	1.00	1.00	1.00	1.00
			N=1,256		
MALES 65+					
Poverty					
a. Poor	1.78*	1.65*	1.36	1.78*	1.30
b. 100-150% above	1.44	1.42	1.21	1.44	1.20
c. 151-200% above	1.21	1.21	1.05	1.23	1.06
d. 201% + (omitted)	1.00	1.00	1.00	1.00	1.00
			N=1,502		

*=p<.05; **=p<.01; ***=p<.001
[a]Age and race are included in all subsequent models
[1]From logistic regression analysis

of the other risk factors as well as age, race, and poverty status. There are few surprises in Table 1. Marital status is inversely related to mortality, but this association remains significant only for males when adjusted for all the other covariates. Exercise, alcohol consumption, weight status, and cigarette smoking display the expected associations with mortality, but the inverse association between moderate alcohol consumption and mortality does not remain significant for either sex when adjusted for the other risk factors. Most of the significant bivariate associations between dietary frequency and mortality do not survive controls for the other risk factors. However, the consumption of fish remains significantly inversely related to mortality for men; cheese consumption is positively related to mortality for men but inversely related for women; and men who consume snacks have a lower mortality risk than those who never snack between meals. The health status and medical care measures also show the expected patterns of association with mortality. It is worth noting, though, that none of the medical care measures remain significant after adjusting for the other covariates.

Table 2 shows the distribution of the risk factors by poverty status. Economic status is positively related to being married, getting regular exercise, consuming alcohol, maintaining normal weight, eating fish, cheese, fruits and vegetables, desserts, candy and snacks, having health insurance, getting regular checkups, and receiving health care in a physician's office. This positive association between economic well-being and the consumption of desserts, sweets and candy probably accounts in large part for the inverse association noted in Table 1 between these variables and mortality. The general pattern in Table 2, though, is for the risk factors known to be related to adverse changes in health status to be more prevalent in the poor and the near-poor groups.

Table 3 presents odds ratios for the association between poverty and mortality for males. The first panel of Table 3 shows the results for all males, while the subsequent panels present the results for males divided into three subgroups: 25 to 44 years of age, 45 to 64 years of age, and over 65 years of age. The first column of the top panel in Table 3 shows that men who fall beneath the federal poverty threshold and men who are in the near poverty group (100 to 150 percent above poverty), are 2.3 and 2.4 times more likely, respectively, to have died in the followup period compared to men who were at more than twice the federal poverty limit. Importantly, men who are between one and one-half and twice the poverty level do not have a higher mortality risk than those who are well above the poverty level.

Adjustment for each class of risk factors produces some reduction in the association between poverty and

Table 4

ODDS RATIOS FOR THE ASSOCIATION BETWEEN POVERTY AND MORTALITY, NHEFS, NUTRITION AND DETAILED HEALTH EXAMINATION ONLY MALES AND FEMALES[1]

	MALES					
	ADJUSTED FOR					
	Age & Race[a]	Marital Status	Health Behavior	Health Status	Medical Care	All Vars.
Poverty						
a. Poor	1.94*	1.64	1.20	1.77*	1.63	0.95
b. 100-150%	1.23	1.13	0.99	1.23	1.14	0.92
c. 151-200%	1.05	1.05	1.01	0.99	1.04	0.96
d. 201%+ (omitted)	1.00	1.00	1.00	1.00	1.00	1.00
	N = 1660					
	FEMALES					
	ADJUSTED FOR					
	Age & Race[a]	Marital Status	Health Behavior	Health Status	Medical Care	All Vars.
Poverty						
a. Poor	1.69*	1.70*	1.57	1.53	1.45	1.39
b. 100-150%	1.09	1.10	1.07	1.03	0.96	0.94
c. 151-200%	1.29	1.29	1.38	1.25	1.15	1.28
d. 201%+ (omitted)	1.00	1.00	1.00	1.00	1.00	1.00
	N = 1844					

*=p<.05
[a]Age and race are included in all subsequent models
[1]From logistic regression analysis.

mortality with health behavior making the largest contribution. The odds ratios for the poor and near-poor groups are reduced from 2.3 and 2.4 adjusted for age and race to 1.4 and 1.8, respectively, when adjusted for the health behavior variables. It is also worth noting that the variables considered produced larger reductions in the coefficient for the lowest poverty category than for the next highest one. However, even after adjustment for all of the risk factors, the poor and near-poor groups are still 1.4 and 1.7 times more likely to have died in the followup period than the nonpoor.

When the results are considered by age, we note that the strongest association between poverty and mortality is among the 25-44 age group with the association becoming progressively weaker with increasing age. However, the pattern observed for the total population persists in the age groups, with health behavior playing the largest role in reducing the association between poverty and mortality and with significant relationships remaining between poverty and mortality (except in the oldest group where the association is weakest) even after adjustment for all risk factors.

Analyses, similar to those in Table 3, assessed the relationship between poverty and mortality for females. Surprisingly, there is no significant association between poverty and mortality for females in these data. The pattern of odds ratios are similar to those observed for males in that the largest odds ratios are found for women in the 25-44 age group. But even here, none of these associations achieve statistical significance.

We also considered the role of medical care in accounting for the association between poverty and mortality in the Nutrition and Detailed Health Examination component of NHANESI. This subsample of NHANESI respondents is a national probability sample of 3,854 respondents. Table 4 presents the results of these analyses. Models are presented similar to those in Table 3, except that there is an additional model that explicitly considers the role of the medical care utilization variables. Table 4 reveals that the association between poverty and mortality is slightly weaker for males and slightly stronger for females than that reported earlier. For men, marital status, health behavior and medical care reduce the relationship between poverty and mortality to nonsignificance, while for females a similar result is achieved when this association is adjusted for health behavior, health status and medical care. The health behavior variables produce a larger reduction in the odds ratios for poverty than the medical care variables for males but not for females.

In sum, our analyses underscore the continuing significance of economic status as a determinant of mortality. Persons in or near poverty experience higher death rates than the nonpoor. This relationship is stronger for men than for women, largest in the 25-44 age group, and weakest for the over 65 age group. The risk factors considered, marital status, health behavior, health status and medical care all vary by economic status and play a role in accounting for some of the excess mortality within the poverty population.

DISCUSSION

Our analyses document that the risk factors considered are differentially distributed by poverty status. Research is needed that would go beyond the mere demonstration of associations to elucidate the specific intervening mechanisms that link socioeconomic status to these risk factors. For example, we noted that persons in poverty were less likely to be married than the nonpoor. We need to understand the ways in which both the propensity to marry and rates of marital disruption are linked to larger social processes. For example, Bishop (26) indicates that unemployment, declines in income, and high job turnover are all associated with increased rates of marital dissolution; the number of female headed households decline when males' earnings rise and rise when male unemployment increases. In other words, to understand poverty status variations in the rates of marriage we must address the larger social and political forces that affect employment opportunities for males (and females) and the consequences that these have on marital patterns.

It is important to distinguish basic causes from superficial or surface causes (27). Basic causes are those factors that are responsible for generating a particular health outcome. Changes in these forces produce change in the outcome. In contrast, surface causes are related to the outcome but changes in these factors do not produce change in the outcome. It is likely that our system of social stratification is the fundamental cause for the observed poverty differences in health (4). The risk factors considered are the superficial causes, the current intervening mechanisms. However, as long as the basic causes remain operative, the modification of surface causes are likely to give rise to new intervening mechanisms to maintain the same outcome.

It is doubtful that the complete elimination of inequality is politically feasible in our society. Our analyses suggest though, that it may not be necessary to absolutely eliminate inequality to reduce the excess levels of ill health in low SES groups. In these data, persons whose income was at least one and one-half, but not more than twice, the poverty level did not have elevated rates of death. Thus, societal changes that move deprived populations above some minimal threshold of economic well-being, may produce substantial improvements in the health status of low socioeconomic groups, even though some inequality persists. More generally, efforts to improve the health and risk factor profile of the poor must include attempts to improve their socioeconomic conditions and life chances.

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TRENDS IN HEALTH AND HEALTH CARE AMONG BLACKS AND HISPANICS IN NEW YORK CITY DURING THE 1980S

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INTRODUCTION

The decade of the 1980s was marked by major changes in the organization, regulation and financing of medical services with potential effects on health and health care among most populations groups. The changes include the introduction of hospital payment through Diagnostic Related Groups, modifications in Federally supported health programs including Medicaid and categorical program support, and, of course, increases in health care costs considerably in excess of other cost increases. Because many of the changes were in government supported programs there is special concern that their impact could be greater among low income and minority groups who are most dependent on them.

At the beginning of the decade in New York City between 60 and 70 percent of the Black and Hispanic population had incomes which placed them at or near the poverty level, that with incomes below 200 percent of poverty. This contrasted with about one third of New York City's white population with income at these levels. This report examines changes in health and health care among New Yorkers during the period from 1979 through 1989, focusing on changes among that city's Black and Hispanic population through data from the National Health Interview Survey.

USING NHIS DATA FOR NEW YORK CITY

Evidence of changing patterns in the delivery of health services have already been documented from data sources describing hospital and nursing home utilization, while evidence of increased costs in medical care have come from Medicare, Medicaid, and private insurance sources. The overall impact of events over time are best documented, however, through population-based data sources which provide information on both users and non-users of health services. Moreover, service-based data are severely limited in information on patient demographic characteristics and measures of health status. For these measures the value of the National Health Interview Survey is almost unmatched. This is particularly true in those urban areas which are Primary Sampling Units of the NHIS permitting population estimates to be made from the sample data.

There are important advantages to limiting an analysis of change in health and health care to a single political entity, in this case the City of New York. While changes in Federal laws and regulations may have broad national impact, many of the changes in health financing and regulations during the 1980s were locally initiated or were regional responses to national changes. Confining the analysis to one area eliminates differences in local responses and strengthens our ability to observe events and their likely consequences. Fortunately, there is the added advantage for New York City in that it yields sample sizes sufficiently large for detailed analysis.

The NHIS sample in New York City includes about 3,000 persons annually. In order to enhance the sample size and permit detailed analysis of population subgroups several years of data are combined. Eleven years of data for the years 1979 through 1989 are combined in this report into the following groupings: 1979 through 1981; 1982 through 1984; 1985 and 1986; and 1987 through 1989.

This data analysis is limited to information for persons age one through 64 years of age. Persons 65 years of age and older have been excluded here in part because nearly all have Medicare or Medicare/Medicaid health coverage for which there has been little change in benefits over the decade. Moreover, comparisons among ethnic groups may be confounded by the fact that in 1989 about 70 percent of those 65 years and older in New York City are white. Children under one year of age are also excluded from this analysis because the high utilization of health services by infants could obscure other trends of interest in this report.

Even with the exclusion of persons 65 years of age and older significant age differences among white, Black, and Hispanic New Yorkers persist. During the period 1987-89, for example, 16 percent of the white population and about 32 percent of Blacks and Hispanics were under 18 years of age. The data described here are not age-adjusted, permitting trend analysis of population sub-groups based on their actual age distributions.

DEFINING ETHNIC GROUPS AND LEVELS OF POVERTY

Ethnic group classification into white, Black, and Hispanic follows the method used by the National Center for Health Statistics. The initial classification is of persons who self-identify as being of Hispanic origin or ancestry, and the remaining sample is classified into white and Black according to information obtained during the interview. Others not included in this analysis are largely Asian, about three percent in 1979 and 7 percent in 1991.

Poverty status, clearly related to ethnicity is based on information about family income and family size. In most of the eleven year study period this information was available for about 87 percent of the

sample. Federal poverty levels are used to establish four levels of poverty: Poor persons with family incomes up to 100 percent of the poverty level; the near-poor with family incomes from 101 to 200 percent of poverty; persons with family income between 201 and 300 percent of poverty, and those in families with incomes more than 300 percent above poverty.

During the period from 1979 through 1981, 31 percent of New Yorkers were at or below the poverty level. During 1987-89 there was a slight decline to 28 percent. In the later period eleven percent of the white population were at or below poverty, compared with 35 percent of the Blacks and 51 percent of Hispanics.

In an earlier analysis of NHIS data for the years 1982 through 1984 conducted by the Medical and Health Research Association and the United Hospital Fund significant variations in health status and health utilization were observed according to ethnicity and poverty classifications. This analysis examines the whether the health status gap between economically and socially disadvantaged New Yorkers and other New Yorkers narrowed or widened, and whether access to care among these groups has changed either absolutely or relative to one another?

In the first part of this report information is provided comparing whites, Blacks and Hispanics over the decade. The relationship between poverty and ethnicity is further explored through an examination of changes among ethnic groups at the poor and near-poor levels.

It should be noted that data for some items are not presented for the earliest period from 1979-81 because of significant changes in question wording instituted in 1982.

TRENDS IN HEALTH STATUS DURING THE 1980S

During 1982-84 eight percent of the whites, 14 percent of Blacks and 19 percent of Hispanics described their health as either "fair" or "poor". Although there was a slight decline among all groups in the rates of those describing their health as "fair" or "poor" among none of the ethnic groups was the decline significant (Table 1). At the end of the decade there was little narrowing of the reported health status gap. Blacks and Hispanics remained significantly more likely than whites to report their health as "fair" or "poor."

In contrast there was some narrowing in reports of bed days due to illness. Differences in 1979-81 among whites and Blacks on the one hand and Hispanics on the other almost disappeared in the later years (Table 2). Measures of differences in reduced activity due to chronic disease showed inconsistent patterns among ethnic groups over the years with no clearly discernable narrowing among the three groups (Table 3).

TRENDS IN THE USE OF HEALTH SERVICES

NHIS respondents are asked to estimate the number of medical visits during the year preceding the interview. During 1979-81 whites reported an average of 4.0 visits annually compared with 4.5 among Blacks and 5.1 among Hispanics (Table 4). Over the decade there was little change in average annual visits among whites - among Blacks and Hispanics, however, there were declines of nearly 20 percent to 3.7 and 4.1 visits respectively. At decades' end average utilization was about the same among all three groups.

There were increases among all three ethnic groups in the rates of those who did not receive any medical care during the previous year: whites from 25 to 30 percent; Blacks from 21 to 28 percent; and Hispanics from 22 to 29 percent (Table 5). There was little difference among them at the beginning and again at the end of the decade, but there was reduced medical contact among all.

Respondents who received an outpatient medical service during the two weeks preceding the interview were asked about the source of that care - outside the hospital in a doctor's office or in a clinic; inside the hospital in a clinic, OPD, Emergency Room or doctor's office. Information is presented here for services received in a doctor's office outside a hospital setting. There were different patterns of change among each of the three ethnic groups between 1982-84 and 1987-89. The proportion of whites receiving care in a private doctor's office declined from 76 to 71 percent; among Blacks the rate remained the same at about 44 percent; and among Hispanics there was an increase from 34 to 46 percent(Table 6).

Inpatient Care - For all three groups of New Yorkers living at home during the 1980s there were declines in the proportion who had at least one hospital episode during the previous year, albeit these were small declines from about six or seven percent to four to six percent(Table 7). Declines in hospital days per thousand were more dramatic. During the period from 1982-84 to 1987-89, hospital days per thousand persons declined among whites by about a third and among Blacks and Hispanics by 39 percent and 43 percent respectively(Table 8). Hospital utilization among Blacks and Hispanics was higher than among whites during the earlier and later periods, although there was some decline in the differences.

ETHNIC DIFFERENCES AMONG THE POOR AND NEAR POOR

The analysis which follows examines ethnic

differences among two categories of poor, those in poverty using the Federal definition, and the near poor with family incomes at 101 to 200 percent above poverty. An important distinction between these two groups of poor people lies in their eligibility for medical payments through Medicaid. Throughout the 1980s about 80 percent of those at the poverty level have been eligible for Medicaid. In contrast only about 20 percent of the near-poor have been Medicaid eligible. Indeed, those classified as near-poor are known to be least likely to have any health insurance.

Throughout most of the decade, among all three ethnic groups the poor and near poor were two to three times as likely than others to report their health as "fair" or "poor". During the period from 1982-84 Hispanics in both low income categories were more likely than either whites or Blacks to report poorer health. By 1987-89 differences among the groups had diminished. Among the poverty group, for example, the proportion of whites reporting their health as "fair" or "poor" increased from 16 to 20 percent, and among Hispanics there was a slight decline(Table 9). The net effect, however, was a difference between the groups of 10 percent during 1982-84 and in 1987-89 the difference had diminished to four percentage points.

In their use of outpatient medical services, among both the "poor" and "near poor" there was a pattern of increase in utilization among whites with accompanying declines among Blacks and Hispanics(Table 10). During 1979-81 whites received an average of 6.0 services per year, Blacks 6.4. In 1987-89 whites received 6.6 vs 5.2 among Blacks. Among all three ethnic groups in poverty there were significant increases among those in poverty in the proportion of those who had not seen a physician during the previous year (Table 11).Among those in poverty, throughout the decade whites were more likely not to have received outpatient medical attention during the previous year.

Over the decade there was a decline among poorer whites in the use of private physician's offices and increases in hospital-based care (Table 12). Among whites at the poverty level between 1982-84 and 1987-89 the proportion of services in a physician's office declined from 52 to 43 percent; among near-poor whites the decline was from 72 to 57 percent. There was little change among poorer Blacks over this period, while the use of private physicians among Hispanics in poverty increased from 28 to 41 percent. By decades end among those in poverty there was little difference in the proportion using private physicians in their most recent medical visit.

Data on inpatient utilization should be treated with caution because of the relatively small number of persons age one through 64 years living at home who receive inpatient care. In a number of cases only 10 to 20 persons in the sample categories were hospitalized during the previous year. Trends in utilization, however, may be illustrative of what is being seen generally and are presented here for heuristic purposes.

In general the pattern of change indicates increased use of hospital services by poor whites accompanied by declines among Blacks and Hispanics (Table 13). During 1982-84 hospital utilization among Blacks and Hispanics considerably exceeded that of whites. By decade's end the rate of in-hospital utilization by whites was greater than among both the other groups.

DISCUSSION

Following trends in health and health care among Blacks and Hispanics in New York City during the 1980s reveals a pattern of decline in the average number of outpatient services received, in the percent of persons receiving medical care during the preceding year, and in the rate of hospital bed days. Early in the decade Blacks and Hispanics tended to receive more health services that whites, and this is the gap which has narrowed. The change that has come about appears to be a result of more precipitous declines in utilization among minorities. There was little change over the decade among whites in the average number of annual health services even while utilization declined among minorities. During 1982-84 minority inpatient services exceeded those of whites by about 60 percent; in 1987-89 this differences had been reduced to about 40 percent.

Blacks and Hispanics are particularly affected by changes in publicly supported programs - they are three and four times as likely as whites to have incomes placing them at the poverty level, and more likely to be eligible for Medicaid or to receive care through hospital-based medical services. Among those at the poverty level, there were declines among Blacks and Hispanics of about 15 percent in the average number of health services and by more than 30 percent in inpatient services. Poverty-level whites experienced increases in both.

It should be noted that during the 1980s declines in the use of health services were experienced by middle income as well as lower income persons. It is also true that, throughout the decade, utilization remained generally higher for those at the poverty level than for others. Nevertheless, declines in the use of health services were not uniform and were more likely to be experienced by persons in minority groups.

We do not at present have a ready explanation for some of the differing patterns among ethnic

groups observed in this study. There have been neither improvements nor worsening in self-reports of health status among Blacks and Hispanics.A preliminary review of Medicaid enrollment and expenditures in New York City reveals no major changes in either Medicaid eligibility nor in public funding for health services. While the role of DRGs in reducing hospital utilization is apparent, we lack an explanation for the differential effects among population groups.

Reviews and discussions with health policy makers in New York City are currently under way exploring some possible explanations of these study findings. It may be, for example that publicly funded health expenditures have been shifting toward institutionalized populations, or groups not normally reached in population surveys. This would include those in nursing homes and the homeless, for example. We may also be observing the impact of recently reorganized hospital outpatient settings on the use of these services by both low and middle-income populations with concurrent change in utilization patterns. Or, other long-term trends may be underway in areas not yet tapped.

There is important potential in the use of the National Health Interview Survey in understanding current and changing patterns of health care, particularly in urban areas. It would be of considerable value if other communities were to employ these data to explore issues of common interest and compare findings.

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TABLE 1

PERCENT REPORTING HEALTH STATUS AS "FAIR" OR "POOR" BY ETHNIC GROUP: New York City, 1982-89.

Ethnic Group	TIME PERIOD 1979-81 %	1982-84 %	1985-86 %	1987-89 %
White	NA	8	8	7
Black	NA	14	13	12
Hispanic	NA	19	15	16

TABLE 2

PERCENT REPORTING ONE OR MORE BED DAYS IN PAST TWO WEEKS BY ETHNIC GROUP: New York City, 1979-89.

Ethnic Group	TIME PERIOD 1979-81 %	1982-84 %	1985-86 %	1987-89 %
White	7	5	5	5
Black	8	7	6	5
Hispanic	12	9	7	6

TABLE 3

PERCENT UNABLE TO PERFORM MAJOR ACTIVITY OR LIMITED ACTIVITIES DUE TO HEALTH BY ETHNIC GROUP: New York City, 1979-89.

Ethnic Group	TIME PERIOD 1979-81 %	1982-84 %	1985-86 %	1987-89 %
White	29	28	33	31
Black	36	36	32	42
Hispanic	32	45	32	35

TABLE 4

AVERAGE ANNUAL MEDICAL SERVICES PER PERSON IN PAST YEAR BY ETHNIC GROUP: NEW YORK CITY, 1979-89.

Ethnic Group	TIME PERIOD 1979-81 %	1982-84 %	1985-86 %	1987-89 %
White	4.0	4.2	3.9	4.1
Black	4.5	4.1	3.6	3.7
Hispanic	5.1	4.9	4.5	4.1

TABLE 5

PERCENT WITH NO MEDICAL SERVICE IN PAST YEAR BY ETHNIC GROUP: NEW YORK CITY, 1979-89.

Ethnic Group	TIME PERIOD 1979-81 %	1982-84 %	1985-86 %	1987-89 %
White	25	26	27	30
Black	21	21	27	28
Hispanic	22	24	23	29

TABLE 6

PERCENT WITH MOST RECENT OUTPATIENT CARE IN A PRIVATE DOCTOR'S OFFICE BY ETHNIC GROUP: New York City, 1979-1989.

Ethnic Group	TIME PERIOD 1979-81 %	1982-84 %	1985-86 %	1987-89 %
White	78	76	69	71
Black	54	43	32	44
Hispanic	57	34	47	46

TABLE 7

PERCENT WITH ONE OR MORE HOSPITAL EPISODES IN PAST YEAR BY ETHNIC GROUP: NEW YORK CITY, 1982-89.

Ethnic Group	TIME PERIOD 1979-81 %	1982-84 %	1985-86 %	1987-89 %
White	NA	6	5	4
Black	NA	6	5	6
Hispanic	NA	7	6	5

TABLE 8

HOSPITAL DAYS PER THOUSAND PERSONS PER YEAR
BY ETHNIC GROUP: NEW YORK CITY, 1982-89.

TIME PERIOD

Ethnic Group	1979-81 %	1982-84 %	1985-86 %	1987-89 %
White	NA	612	467	403
Black	NA	888	676	541
Hispanic	NA	977	491	553

TABLE 9

PERCENT REPORTING HEALTH STATUS AS "FAIR" OR "POOR"
BY ETHNIC GROUP: New York City, 1982-89.

POOR AND NEAR POOR

TIME PERIOD

Ethnic Group	1979-81 %	1982-84 %	1985-86 %	1987-89 %
At or below poverty				
White	NA	16	12	20
Black	NA	20	16	19
Hispanic	NA	26	25	24
101 to 201 % poverty				
White	NA	11	15	13
Black	NA	13	12	16
Hispanic	NA	18	16	17

TABLE 10

AVERAGE ANNUAL MEDICAL SERVICES PER PERSON IN PAST YEAR
BY ETHNIC GROUP: NEW YORK CITY, 1979-89.

POOR AND NEAR POOR

TIME PERIOD

Ethnic Group	1979-81 %	1982-84 %	1985-86 %	1987-89 %
At or below poverty				
White	6.0	4.2	3.5	6.6
Black	6.5	5.1	6.2	5.2
Hispanic	6.2	6.0	6.2	5.6
101 to 201 % poverty				
White	3.3	4.3	4.1	4.6
Black	4.0	3.7	2.6	3.4
Hispanic	4.3	4.3	4.0	3.4

TABLE 11

PERCENT WITH NO MEDICAL SERVICE IN PAST YEAR
BY ETHNIC GROUP: NEW YORK CITY, 1979-89.

POOR AND NEAR POOR

TIME PERIOD

Ethnic Group	1979-81 %	1982-84 %	1985-86 %	1987-89 %
At or below poverty				
White	25	28	26	32
Black	16	16	19	23
Hispanic	16	16	15	26
101 to 201 % poverty				
White	29	31	34	32
Black	27	24	24	30
Hispanic	30	30	23	32

TABLE 12

PERCENT WITH MOST RECENT OUTPATIENT CARE IN A PRIVATE
PHYSICIAN'S OFFICE: NEW YORK CITY, 1982-89.
POOR AND NEAR POOR

TIME PERIOD

Ethnic Group	1979-81 %	1982-84 %	1985-86 %	1987-89 %
At or below poverty				
White	NA	52	46	43
Black	NA	37	24	41
Hispanic	NA	28	48	41
101 to 201 % poverty				
White	NA	72	39	57
Black	NA	37	38	35
Hispanic	NA	38	46	43

TABLE 13

HOSPITAL DAYS PER THOUSAND PERSONS PER YEAR
BY ETHNIC GROUP: NEW YORK CITY, 1979-89.*

POOR AND NEAR POOR

TIME PERIOD

Ethnic Group	1979-81 %	1982-84 %	1985-86 %	1987-89 %
At or below poverty				
White	NA	671	447	959
Black	NA	1026	1251	696
Hispanic	NA	1167	704	798
101 to 201 % poverty				
White	NA	605	497	692
Black	NA	721	825	545
Hispanic	NA	1212	454	549

PERSONS DISABLED AND UNINSURED IN THE UNITED STATES

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This paper addresses health insurance coverage of persons with disabilities and utilization of physician and hospital care as a function of health insurance coverage status. A principal motivation of this study is that while it is known that utilization of health care is diminished for the uninsured (Davis & Rowland, 1983), the effect of uninsurance on persons with disabilities has not been measured.

The most recent estimates of available are that 34 to 37 million persons in the United States are without insurance. The former estimate is from the 1989 National Health Interview Survey (Ries, 1991) and the latter from the 1987 National Medical Care Expenditure Survey (Short, Monheit, & Beauregard, 1989).

The uninsured are persons who cannot obtain affordable private health insurance plans and are ineligible for or fail to avail themselves of public programs. Groups with greater risks of being uninsured include young adults, racial and ethnic minorities, unmarried persons, persons in poverty, persons with low educational attainment, unemployed persons, those who work for low wages, work part-time or in seasonal or temporary jobs, or who are self-employed.

Despite the fact that most persons obtain insurance through employment, the majority of the uninsured are employed or dependents of workers. This fact has led to serious consideration of options to reduce the prevalence of uninsurance by targetting employers. Though employment is a variable that affords a major policy option, different approaches are required to reduce uninsurance of single nonworkers and individuals in families without a working adult. From NMES, about 14 percent of all persons under age 65 are in families without a working adult and 29% are without insurance. Persons with disabilities are less likely than persons without disabilities to be working, but may be dependents of workers.

The insurance status of persons with disabilities has not been studied in much depth. Persons with disabilities are among the highest utilizers of health care and long-term care, are at high risk of mortality, and are in greatest need of health care coverage. Therefore, it is worthwhile to examine their health insurance coverage status and the impact of insurance coverage on utilization of health care.

Data and methods

The data are from the 1989 Health Insurance Supplement to the National Health Interview Survey (NHIS). The 1989 NHIS sampled 116,929 persons, but 3,289 were found not to have participated in the Health Insurance Supplement. Examination revealed no major differences in the characteristics of those who failed to respond from those who did, and the data were re-weighted for the 64 age-sex-race cells post-stratified to match the 1989 noninstitutional population totals (Adams & Benson, 1990). Because of the high enrollment of the elderly in Medicare, the analysis was restricted to persons under age 65.

The NHIS is a highly stratified multi-stage complex sample and standard errors of estimates were calculated by Taylor series linearization using stratum and PSU variables.

Disability is defined for children as those who are unable to attend school, are limited in the amount or kind of school work they can do, or are limited in activities other than school. A further distinction is made for children with activity limitation concerning whether the child needs assistance in self-care activities (ADLs). An adult with a disability is one who cannot work or do housework, is limited in the amount or kind of work or housework, or is limited in other activities. A further distinction is made for an adult with activity limitation concerning whether the adult needs assistance in self-care activities (ADLs) or routine care activities (IADLs).

Health insurance categories include private insurance plans, Medicare, Medicaid and other public assistance, and military. Individuals having none of these forms of coverage are considered uninsured.

Results

In 1989, 35.3 million nonelderly persons were without health insurance in the United States (Table 1). About 4.1 million persons with activity limitation were uninsured, or 11.5% of all uninsured persons.

Among persons under age 65, 17.5% of persons with activity limitation were uninsured, not significantly different from the 16.3% of persons without activity limitation. Among children, those with activity limitation are as likely as those without limitation to be uninsured (about 15.8%). Persons with activity limitation are much more likely to be covered by public insurance than persons without activity limitation. Private plans and public programs together result in a level of health coverage for persons with activity limitation at roughly the average level for nonlimited persons.

Adults with activity limitation generally receive less care if they are uninsured compared to similarly limited adults with insurance. Among persons unable to perform their major activity, those with insurance have 20.9 annual physician visits, significantly higher than the 15.6 annual physician contacts of those without insurance (Table 2). This difference appears to be due to a high rate of contacts among those with private insurance. Among persons limited in activities other than their major activity, those with insurance have 8.9 annual physician visits, significantly higher than the 4.0 annual physician contacts of those without insurance. No significant difference was observed among persons limited in the amount or kind of major activity between those with and without insurance, but those with Medicaid coverage had a significantly higher rate of contacts than those with no coverage. A similar pattern was observed for limitation in work activity. Among persons limited in basic life activities, an indicator of more severe disability, no significant differences were observed by insurance status.

Rates of hospital discharges per 100 persons and average length of stay per hospital discharge are shown in Table 3. Generally, persons with insurance have significantly higher rates of hospital discharges than those without insurance, regardless of disability status. For example, among persons unable to perform their major activity, those with insurance have 56.7 annual hospital discharges, significantly higher than the 35.7 annual discharges of those without insurance. Rates of hospital discharges are significantly higher for the insured than the uninsured regardless of type of insurance coverage. Few differences in average length of stay per discharge were observed.

Discussion

Persons with activity limitation are as likely as persons without limitation to be uninsured (17.5% and 16.3%, respectively). This translates, however to almost 4.1 million persons in the United States who are limited in activity and are uninsured, about 11.5% of all persons without insurance. Persons with disabilities have higher levels of health care utilization than persons without disabilities, and this increases with greater severity of the disability. The availability of insurance appears to increase the level of access of persons with limitation to health care services. Among persons with activity limitation, those with insurance have significantly higher annual physician contacts and significantly higher rates of hospitalization than those without insurance. On average, among persons unable to work, those who are uninsured have 40% fewer hospital discharges and 30% fewer physician contacts.

It is possible that the higher level of health care utilization of persons with disabilities who are insured reflect more severe levels of disability and poorer health status that are left unmeasured. Multivariate analysis controlling for categorical disabling conditions, perceived health, and annual restricted activity days is underway to investigate this further.

Policy options to reduce uninsurance should ensure that persons with disabilities are covered, as they are in greatest need of coverage and appear to experience lower access to health care services if they are not covered.

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Table 1. Health Insurance Coverage by Disability Status for Children and Adults: United States, 1989

Disability Status and Age Group	Population in 1,000's	Number of Persons in 1,000's with Private Coverage	Public Coverage	No Insurance Coverage	Percent with Private Coverage	Public Coverage	No Insurance Coverage
All Ages (0-64)							
Total	214,313	161,545	16,348	35,304	75.4	7.6	16.5
With Activity Limitation	23,197	14,533	5,326	4,063	62.7	23.0	17.5
Without Activity Limitation	191,116	147,012	11,022	31,241	76.9	5.8	16.3
Children (0-17)							
Total	64,005	45,572	7,681	10,113	71.2	12.0	15.8
With Activity Limitation	3,437	2,107	840	546	61.3	24.4	15.9
Without Activity Limitation	60,567	43,487	6,844	9,570	71.8	11.3	15.8
Adults (18-64)							
Total	150,309	116,039	8,718	25,102	77.2	5.8	16.7
With Activity Limitation	19,760	12,426	4,486	3,517	62.9	22.7	17.8
Without Activity Limitation	130,549	103,525	4,178	21,671	79.3	3.2	16.6

Table 2. Average Number of Physician Visits in Past 12 Months by Source of Coverage and Disability Status, Persons Aged 18-64: United States, 1989

	Population in 1,000s	Sample Size N	Age Mean	Type of Health Insurance Coverage: All Persons	Any Private	Private Only	Any Public	Public Only	Medicare	Medicaid	Military	All Insured	All Not Insured
				Number of Physician Visits									
Total	150,309	68,211	37.9	5.2	5.2 ‡	5.0 ‡	10.0 ‡	10.0 ‡	13.6 ‡	11.0 ‡	7.5 ‡	5.5 ‡	3.4
Major Activity													
Unable to perform major activity	6,772	3,226	47.1	20.0	24.1 ‡	25.7 ‡	17.7	16.7	16.7	19.3	17.5	20.9 §	15.6
Limited in amt/kind of major activity	7,498	3,465	43.7	10.9	10.8	10.6	13.2 §	13.7 §	13.6	15.3 §	10.3	11.2	9.8
Limited in other activity	5,490	2,540	43.4	8.1	8.6 ‡	8.6 ‡	10.6 ‡	10.9 ‡	8.1 §	11.9 ‡	8.6 §	8.9 ‡	4.0
Not limited in activity	130,549	58,980	36.9	3.9	4.2 ‡	4.2 ‡	5.8 ‡	6.0 ‡	6.0 ‡	6.2 ‡	5.4 ‡	4.3 ‡	2.3
Work Activity													
Unable to work	7,980	3,818	47.8	19.2	22.4 ‡	23.6 ‡	17.5	16.9	16.3	19.3	16.9	20.0 §	15.2
Limited in amt/kind of work	6,776	3,106	42.6	9.9	10.4	10.4	9.1	8.2	7.1 *	9.5	9.9	10.2	8.3
Limited in other activities	5,004	2,307	43.0	8.4	8.6 ‡	8.4 ‡	12.3 ‡	12.6 ‡	15.6 * §	13.5 ‡	9.0	9.0 ‡	5.0
Not limited in work or other activities	130,549	58,980	36.9	3.9	4.2 ‡	4.2 ‡	5.8 ‡	6.0 ‡	6.0 ‡	6.2 ‡	5.4 ‡	4.3 ‡	2.3
Basic Life Activities													
Needs assistance in self care	780	370	47.0	28.9	28.4	41.1	25.7	30.7	20.2	32.1	20.2 *	29.2	26.5 *
Needs assistance in routine activities	2,210	1,067	46.5	23.3	27.3	27.5	18.8	15.8	19.7	19.5	21.2 *	22.3	29.8
Not limited in basic life activities	147,320	66,774	37.7	4.8	4.9 ‡	4.8 ‡	8.3 ‡	8.5 ‡	10.9 ‡	8.9 ‡	6.9 ‡	5.1 ‡	3.0

Table 3. Hospital Discharges Per 100 Persons and Average Length of Stay Per Discharge In Past 12 Months by Source of Coverage and Disability Status, Persons Aged 18-64: United States, 1989

	All Persons		Type of Health Insurance Coverage: Any Private		Private Only		Any Public		Public Only		Medicare		Medicaid		All Insured		All Not Insured	
	HD	ALOS	HD	ALOS	HD	ALOS	HD	ALOS	HD	ALOS	HD	ALOS	HD	ALOS	HD	ALOS	HD	ALOS
Total	8.8	6.1	8.2 ‡	5.7	7.6 §	5.3 §	24.8 ‡	8.1	24.4 ‡	7.7	39.4 ‡	9.2 §	26.6 ‡	8.7	9.3 ‡	6.1	6.4	6.8
Major Activity																		
Unable to perform major activity	53.1	9.1	61.7 ‡	9.1	61.7 ‡	8.3	53.1 ‡	9.7	49.7 §	9.0	52.1 ‡	10.1	56.3 ‡	10.5	56.7 ‡	9.1	35.7	9.3
Limited in amt/kind of major activity	24.4	6.2	25.6 ‡	6.1	24.8 ‡	5.8	33.0 ‡	8.1	32.6 ‡	7.9	33.5 §	5.9	35.0 ‡	9.8 §	26.4 ‡	6.4	16.2	5.1
Limited in other activity	13.8	5.2	14.4 ‡	4.9	13.9 ‡	4.9	23.5 ‡	6.1	23.5 ‡	6.7	38.2 ‡	7.4	19.9 ‡	5.2	15.5 ‡	5.2	5.0	5.0 *
Not limited in activity	5.4	4.7	5.4 ‡	4.4 §	5.4 §	4.5 §	10.4 ‡	4.9	11.1 ‡	5.1	5.8 *	3.3 *§	12.1 ‡	5.1	5.7 ‡	4.5 §	4.2	6.1
Work Activity																		
Unable to work	49.2	8.7	56.9 ‡	8.8	55.1 ‡	7.8	51.2 ‡	9.2	47.1 ‡	8.3	50.8 ‡	9.5	52.9 ‡	9.9	52.9 ‡	8.6	31.7	9.4
Limited in amt/kind of work	20.7	6.0	22.8 §	5.8	22.7 §	5.9	18.7	7.9	15.6	10.3 *	13.3 *	5.2 *	15.0	11.4 *	22.0 §	6.1	15.7	4.9
Limited in other activities	17.0	6.7	16.7 ‡	5.9	16.4 ‡	6.0	34.3 ‡	9.4 §	39.7 ‡	10.5 §	53.7 *‡	9.8 §	36.1 ‡	9.9 *	19.0 ‡	6.9 §	6.6 *	3.8
Not limited in work or other activities	5.4	4.7	5.4 ‡	4.4 §	5.4 §	4.5 §	10.4 ‡	4.9	11.1 ‡	5.1	5.8 *	3.3 *§	12.1 ‡	5.1	5.7 ‡	4.5 §	4.2	6.1
Basic Life Activities																		
Needs assistance in self care	82.2	13.6	75.5	14.8	100.3	17.9 *	73.2	13.2	84.7	14.4	63.4	14.8	85.8	14.9	79.5	14.5 §	101.8	8.5
Needs assistance in routine activities	50.9	8.8	58.0	8.6	56.9 §	8.2	51.4	8.5	47.8	8.1	49.4	9.7	51.9	8.1	53.6 §	8.5	34.0	12.0 *
Not limited in basic life activities	7.8	5.5	7.5	5.2	7.1 ‡	4.9 §	19.7 ‡	7.1	19.2 ‡	6.3	33.1 ‡	7.5	20.6 ‡	7.6	8.3 ‡	5.4	5.7	6.3

*Estimate has low statistical reliability (relative standard error > 30%).
†Estimate is exactly 0 or standard error is indeterminate.
‡Significantly different from uninsured p<.01.
§Significantly different from uninsured p<.05.

THE RELATIONSHIP BETWEEN FAMILY HOMELESSNESS, INSURANCE COVERAGE, HEALTH STATUS, AND HEALTH CARE-SEEKING BEHAVIOR

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INTRODUCTION

The health care needs of homeless families and the barriers to care which this population experiences should be of greater concern now more than ever, because this special population is less likely to meet the Surgeon General's goal of increasing the proportion of persons nationally who have a specific source of ongoing primary care. The purpose of this paper is to examine homeless families and domiciled low-income families in order to determine whether there are any differences in health status, access to care, and health care utilization between these two groups which might impact on the type and quality of health care these families receive.

Recent research suggests that homeless children and adults living in families are more likely to be in poor health than low-income domiciled families, and that their health problems are largely preventable. Homeless parents, who are most often young, single, minority women (Weinreb and Bassuk, 1990), suffer from health problems at higher rates than the general U.S. population (Wright and Weber, 1987). In addition, an estimated 16 to 20% of homeless women are pregnant and at high risk for poor nutrition, inadequate or no prenatal care, and relatively high low birth weight and infant mortality rates (Chavkin et al., 1987). In addition, the number of homeless mothers who abuse chemical substances such as "crack" cocaine is unknown; however, anecdotal evidence suggests that this problem has become extremely widespread in this population during recent years, as it has in the general population (Weinreb and Bassuk, 1990). Since most of the data on substance abuse are self-reported, the prevalence of substance abuse is likely to be underreported.

The children of these families are also vulnerable to poor health by virtue of their homelessness, in addition to other factors common to low-income children. Homeless children experience many of the health problems found among urban domiciled low-income children, but to a greater degree (Wright and Weber, 1987) including lead poisoning (Alperstein et al., 1988), iron deficiency anemia (Acker et al., 1987), obesity (Wood et al., 1990b; Miller and Lin, 1988), dental problems (Miller and Lin, 1988), and delayed immunizations (Miller and Lin, 1988; Alperstein et al., 1988; Acker et al., 1987).

In addition to the conditions described above, homeless children are highly vulnerable to communicable diseases (Wood et al., 1990b), developmental problems, poor school attendance (Bassuk et al. 1986; Wood et al., 1990b) and injuries and emotional problems due to child abuse and neglect (Wood et al., 1990a; Alperstein et al., 1988).

The poorer health status of homeless families is often exacerbated by the increased economic barriers to health care which they experience due to their homelessness, such as lack of insurance coverage. Economic characteristics, particularly insurance status, play a critical role in access to ambulatory care services (Link et al., 1980). Homeless families are more likely to lack health insurance coverage and a regular health care provider, or suffer from gaps in insurance coverage, than the general population (Miller and Lin, 1988; Wood et al., 1990a). Those who report having a regular source of care may utilize hospital emergency rooms or outpatient clinics for well-child care, decreasing the chance that they will receive comprehensive and continuous care (Miller and Lin, 1988; Weinreb and Bassuk, 1990).

Unfortunately, much of the research on the health of homeless persons is plagued by methodological problems (Winkleby, 1990; Wood et al., 1990b; Gelberg and Linn, 1989). The utility of the information collected is often diminished by the use of research instruments which fail to take the unique characteristics of homeless persons, such as residential mobility, into account. For example, in Pennsylvania, Department of Public Welfare regulations require a re-determination of Medicaid benefits every six months or less. A client who does not reply to the redetermination notice in a timely fashion loses his or her eligibility status.

The health care needs of homeless families are obviously substantial. The next step is to pinpoint barriers to comprehensive care so that these barriers may be addressed by informed policy-makers. This paper compares the health status, access to care, and health care utilization of a group of homeless families to a group of similar domiciled low-income families in order to examine whether homeless families differ in these characteristics, and if so, whether these differences affect the type and quality of health care they receive.

METHODOLOGY

The 73 homeless families included in this study were residents of Philadelphia family shelters who voluntarily enrolled in a comprehensive case management program for homeless families funded by the United Way of Southeastern Pennsylvania. Additional data were also collected in a general survey of the Philadelphia population, from which 73 domiciled families matched for age, race or ethnicity, gender, and income level were selected.[1] Income levels of the two groups were not exactly comparable; homeless families were between 70 and 80% or less of the Federal Poverty Level and domiciled low income families were at 100% or less of the Federal Poverty Level.

RESULTS

Socio-economic and demographic characteristics

The socio-economic and demographic characteristics of the homeless families in the study were similar to those reported in a recent study of the homeless in Philadelphia shelters (Goldstein et al., 1989). The overwhelming majority of the homeless families were headed by single, minority (African-American or Latina) women with two or three pre-school aged children, as shown on Table 1. Minorities, particularly blacks, were overrepresented in the study population (63.0%) in comparison to their representation in the Philadelphia population (38.0%)(U.S. Bureau of the Census, 1990). In the case of Latinos (12.3% in the sample vs. 3.8% in the population) the overrepresentation was due, in part, to deliberate over-sampling. On the other hand, there were no Asians in the study population, mirroring the small numbers of Asians in Philadelphia shelters relative to their representation in the general city population (1.0%).

The average age of parents was 28. There was only one single male parent. Nearly one-half (49.3%) of the parents had never been married. Although three-quarters of the participants (74.4%) were high school graduates, only 16.7% were employed full- or part-time at the time of intake. The primary source of income at intake for most families was public assistance (79%).

In contrast to homeless families, domiciled low-income families were significantly more likely to derive their income from employment (79.4% vs. 16.7%) and to be single (67.1% vs. 49.3%), but significantly less likely to be high school graduates (69.8% vs. 74.4%).

As shown on Table 2, the homeless families were very mobile: one-half (50.0%) had moved three or more times in the past twelve months, and 47.7% had moved five or more times in the past five years.

TABLE 1 Characteristics of Homeless and Low-Income Domiciled Families

	Low-income Families (N = 73)	Homeless Families (N = 73)
	%	%
Characteristics		
Age		
18-21	6.8	6.9
22-25	24.7	24.6
26-29	21.9	21.9
30-33	34.3	34.2
≥ 34	12.3	12.2
Gender		
Female	97.2	97.2
Race/ethnicity		
White	23.3	23.3
Black	63.0	63.0
Hispanic	12.3	12.3
Asian	0.0	0.0
Other	1.4	1.4
Number of children		
≤ 2*	50.0	57.5
≥ 3	50.0	41.1
% Employed*	16.7	79.4
Benefits		
AFDC*	79.0	12.5
WIC	47.7	34.2
Food Stamps*	90.0	56.2
Marital status		
Married	11.0	17.8
Never married*	49.3	67.1
Divorced	11.0	4.1
Separated*	26.0	6.8
Widowed	0.0	2.7
Other	2.7	1.4
Education		
Some H.S.	35.6	30.1
H.S. Grad/GED	42.5	54.8
Some college*	20.5	8.2
College grad	1.4	6.8

Health status and utilization of care

Both homeless and domiciled low-income families reported high levels of poor health status. As shown on Table 3, more than one-fourth (27.2%) of homeless adults reported that their health status was fair or poor, compared to 20.5% for domiciled adults. In contrast to the self-reported health status of the adults, homeless parents were less likely to report that their children were in fair or poor health (8.9%) than parents in low-income domiciled families (12.7%).

TABLE 2 Residential Mobility of Homeless Families

	Homeless Families (N = 73)
	%
Number of moves in past 12 mos.	
1-2	50.0
3-4	33.2
5 or more	16.7
Number of moves in past 5 years	
1-2	16.4
3-4	35.8
5 or more	47.7

TABLE 3 Health Status of Homeless and Low-income Domiciled Families

	Homeless Families (N = 73)	Low-income Families (N = 73)
	%	%
% of adults reporting fair or poor health	27.2	20.5
% of children for whom fair or poor health was reported	8.9	12.7

Access to care

Table 4 presents information on several measures of access to health care among homeless and domiciled families. As one might expect, the homeless families were significantly more likely to be insured through Medicaid (75.0%) than the domiciled families (48.0%). Although homeless families were as likely as domiciled families to lack health insurance coverage (18.6% vs. 19.2%), they were more likely to report that their insurance coverage had decreased in the previous year (15.3% vs. 5.7%).

Among those families with a regular source of care, homeless families were more likely to use federally-funded clinics (18.1%) and hospital emergency rooms (6.9%) than domiciled families (13.6% and 1.7%, respectively), but less likely to utilize City Health Centers (6.9% vs. 8.5%).

In terms of regular source of care, homeless families were more likely to lack a regular source of care (26.4%) than domiciled low-income families (19.2%). Among those without a regular source of care, homeless families were two to three times more likely to report living in a new location (15.0%) or cost (20.0%) as factors in not having a regular source of care than domiciled families (7.7% and 7.7%, respectively). Domiciled families were also nearly twice as likely (46.2%) to state that they did not need a regular source of care as homeless families (25.0%).

For homeless families, frequent residential mobility may impuit their health insurance coverage. For example, as shown on Table 5, homeless families who moved five or more times (21.9%) over the past five years were more likely to lack health insurance coverage than homeless families who experienced less than five changes in residence (15.2%).

TABLE 4 Access to Health Care of Homeless and Low-income Domiciled Families

	Homeless Families (N = 73)	Low-income Families (N = 73)
	%	%
% with no health insurance coverage	18.6	19.2
% with medicaid coverage*	75.0	48.0
% reporting decreased insurance in prior year	15.3	5.7
% with no regular source of health care	26.4	19.2
Source of regular care		
Private physician	27.8	30.5
Co./union clinic	2.8	1.7
City Health Center	6.9	8.5
Neighborhood Clinic	18.1	13.6
Hospital outpatient	37.5	42.4
Emergency room	6.9	1.7
Other	0.0	1.7
Reason for no source of regular care		
Don't need it	25.0	46.2
Moved	15.0	7.7
Use specialists	0.0	7.7
No particular Dr.	15.0	15.4
Cost	20.0	7.7
Other	25.0	15.4

TABLE 5 Health Insurance Status of Homeless Families by Number of Moves in Past Five Years

	≤4 Moves (N=33)	>5 Moves (N=33)
	%	%
Insurance Coverage		
Yes	84.8	78.1
No	15.2	21.9

Health Care Utilization

Although a high percentage in both homeless and domiciled low-income groups reported being in fair or poor health, there were significant differences between homeless and domiciled adults in percent reporting a medical emergency and an overnight hospital stay in the previous year -- two indicators of poorer health status. As shown on Table 6, homeless adults were significantly more likely to report a medical emergency or overnight hospital stay in the previous year than domiciled adults (37.5% and 33.8% vs. 20.5% and 13.7%, respectively). In contrast to homeless adults, homeless children were only slightly more likely than domiciled children to have had a reported medical emergency (23.9% vs. 21.8%).

When we compare utilization of preventive health care for homeless and domiciled adults and children, the results show conflicting patterns. As shown on Table 7, homeless adults were significantly less likely to have had a dental examination (38.0% vs. 58.9%) and homeless females were less likely to have received birth control (34.3% vs. 41.4%) than domiciled adults. Domiciled adults, however, were less likely than homeless adults to report receipt of other types of preventive health care, such as blood pressure reading, and pap tests and breast examinations for females. In contrast to homeless adults, homeless children were less likely than domiciled children to have received vaccinations for measles/mumps/ rubella, diphtheria/pertussis/tetanus, and polio, or hearing, eye or dental examinations.

DISCUSSION

This study was an attempt to discover whether homeless families have unique health care problems and difficulties obtaining access to care which place them at higher risk for poor health than the general domiciled, low-income population.

The data show that the homeless and domiciled families in this study differed in several important health-related factors. A high percentage in both populations reported being in fair or poor health and not having health insurance coverage for themselves and their children relative to the general population. Although some studies (Wood et al., 1991a) have suggested that homeless parents underreport illness, it is also likely that, since the homeless families in this study varied in the length of time in shelter, they may have received the benefit of shelter-based health care services. In this study the homeless families may have lacked health insurance and a regular source of primary care because of the disruption caused by their frequent changes in residence, while the comparison group of domiciled families may have been members of the "working poor" whose employers do not provide insurance coverage.

TABLE 6 Health Care Utilization by Homeless and Low-income Domiciled Families

	Homeless Families (N = 73)	Low-income Families (N = 73)
% reporting a medical emergency in prior year		
Adult	37.5	20.5
Child	23.9	21.8
% reporting a hospital stay in prior year		
Adult	33.8	13.7

TABLE 7 Preventive Health Care Utilized by Homeless and Low-income Families

	Homeless Families (N = 72)	Low-income Families (N = 72)
	%	%
% Adults who have had:		
Blood pressure reading	81.7	72.6
Dental exam	38.0	58.9
Birth control	34.3	41.4
Pap test	63.8	57.1
Breast exam	66.7	64.3
% Children who have had:		
TB test	86.6	84.9
MMR vaccine	92.4	96.1
DPT vaccine	95.5	96.4
Polio medicine	94.1	96.4
Hearing test	66.1	83.8
Eye exam	67.7	78.8
Dental exam	57.6	73.0

Despite their similarity in health status and insurance coverage, the homeless families in this study were more likely than the domiciled families to lack a regular source of care, report an overnight hospital stay and medical emergencies, and less likely to receive some preventive services, especially child immunizations. The fact that they were less likely to have a regular source of primary care, and more likely to

report moving and cost as barriers to care, suggests that a unique gap in services exists for these homeless families.

The high mobility of the homeless population should be of great concern to health care providers, since it is an additional barrier to care for a population which is already at high risk for poor health. Unfortunately, researchers as well as policy-makers fail to take these differences between homeless families and domiciled low-income families into account. Most research studies and health care programs are designed for a residentially stable population. The Health Care for the Homeless Program, which offers health care and assistance in obtaining benefits in shelters and on the streets, is an exception to this general approach. Gaps in services for the homeless will continue to exist as long as mobility is a barrier to continuous insurance coverage and primary care. If we really want to improve access to health care for homeless families, we, as researchers and policy-makers, need to acknowledge health care-seeking behavior and barriers to care that are vastly different from the social situation in which domiciled families exist, so that the public health insurance system can be made more responsive to the people it serves.

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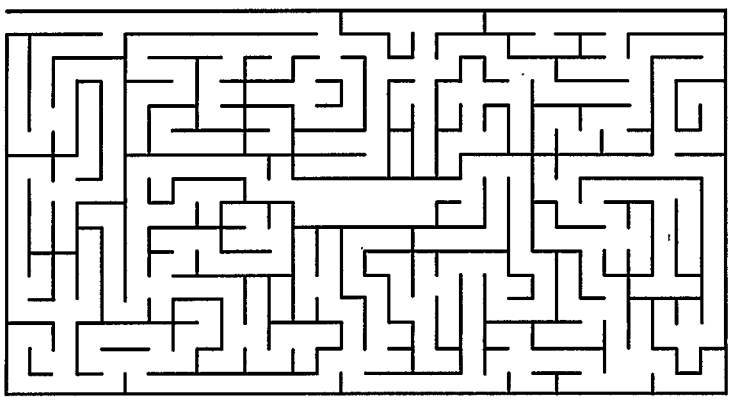
ENDNOTES

1. Philadelphia Health Management Corporation. Health Status and Health Care in Philadelphia. (Philadelphia, PA 1988).

* Significant at $p \leq .05$.

Session M

HIV/AIDS Assessment and Surveillance



AIDS SURVEILLANCE AND SURVIVAL STATUS: FINDINGS FROM A NEW JERSEY SURVEY

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As epidemiological and treatment patterns evolve in the AIDS epidemic, the monitoring of trends in survival with AIDS and the analysis of survival differences across subgroups of patients represent important public health data needs. Survival trends provide information on the overall impact of treatment patterns, while cross-group comparisons may be suggestive of differences in health care access or other variations of public health significance. Survival estimates provide the basis for translating incidence data from case reports into prevalence estimates; play a role in back-calculations to estimate seroprevalence; and are factored into estimates of lifetime cost per case. Surveillance information on vital status is used for health planning purposes in the form of statistics on the number of living cases who may need services, and changes in survival may imply changes in the size of the living population needing services which are not reflected in incidence trends.

Despite the importance of these issues, estimates of the distribution of survival times, trends in survival, and relative survival across patient subgroups vary considerably. There is no consensus, for example, on the extent of survival differences associated with race, gender, risk group, or region. For example, while Rothenberg et al (1987) found that non-whites had shorter survival, Friedland et al (1991) found no such effect and, indeed, found that among those diagnosed with pneumocystis carinii black race was associated with better survival. Given the need for survival information, it is important that the best be made of available data resources. AIDS registries constitute such a resource of obvious importance.

Registries, like New Jersey's, maintain information on vital status of reported cases. When surveillance staff learn of the death of an individual on the registry, the date of death is entered into the surveillance record. Thus, state AIDS registries and the CDC national registry into which they are merged are one of the sources for survival analyses. The CDC data set is a public use data set and has been used for survival analysis purposes (Piette et al, 1991). While the public use version of the data set is subjected to a degree of suppression of geographic information in order to ensure that there is no possibility of individuals being identified, data on geographical region are available as well as information on such variables as diagnosis date, presumed mode of transmission, diagnostic conditions used to establish caseness, race, age, and gender. Because of the great size of the data set, multivariate analyses of seemingly very high statistical precision can be performed.

However, a significant limitation of registry data is that some cases are lost to contact. The degree of completeness and accuracy of vital status information in registry data is uncertain. This is important because cases whose death has not been recorded in the registry are typically treated in survival analyses as having survived the period of observation, that is the period from diagnosis to the date at which a sample is drawn. A case misclassified as surviving can misattribute substantial survival experience to the subgroup to which it belongs. A particularly important concern is the possibility of differential misclassification across subpopulations, which will bias relative survival patterns. For example, if members of minority groups are more likely to be misclassified as survivors, their relative survival may be overestimated and any effects of differential access to medical care may not be captured. There is no simple solution to this problem because excluding cases whose vital status is unknown would introduce other biases. In order to evaluate the potential utility of registry data for survival monitoring purposes, it is important to find ways of assessing the completeness of the information they contain on vital status.

New Jersey has utilized vital status information in its AIDS registry to estimate the number and profile of living persons with AIDS. The department seeks to follow-up on the status of cases on the Registry at three-month intervals, though in the face of budget limitations such followup was not universal at the time of the study; liaison is also maintained with medical providers which may provide updates of a patient's status. In the course of a patient survey organized collaboratively by the Department of Health and Rutgers University, it was possible to independently ascertain information on the vital status of a sample of not-known-dead individuals on the registry and thus to explore the degree of misclassification of vital status in the registry data and its possible effect on survival estimates. While this was a broader study, in the present paper results of this investigation are discussed as they pertain to vital status.

The research from which these data are drawn was an effort to develop a statewide sample of persons with AIDS in New Jersey for a needs assessment survey. Many, perhaps most, studies of needs and health services utilization of persons with AIDS are based on clinic samples, and do not represent the full spectrum of health care sources or those patients not utilizing the health care system during a particular period, either because of lack of access to health care or absence of perceived need for care. The State had a strong interest in attempting to develop a more broadly based sample and proposed that a Registry based sample be utilized for a needs assessment. After extensive review and planning and human subjects approvals, such a survey was implemented. A Certificate of Confidentiality was granted by the U.S. Public Health Service which protected information gathered in the course of the study from any external demand for disclosure. A protocol was developed in which contact with the patient to invite participation in the survey was undertaken first by the health care provider if possible; by Surveillance staff if this were impossible; or if neither effort were successful, by direct contact by the research staff on the Rutgers survey team. The purpose of the study was to develop a profile of the socioeconomic circumstances and health care needs of persons with AIDS in the state, by interviewing a sample of persons with AIDS, for which they were paid. Indeed, though many cases in the original sample could not be located, the study population ultimately interviewed did not differ significantly from the total Registry population in terms of demographic characteristics. In the present report, however, we focus on vital status.

A sample of 475 cases of persons who had been reported with full-blown AIDS (as defined by the Centers for Disease Control) and who were not known to have subsequently died was randomly drawn in four waves between October 1988 and October 1989. Four subsamples rather than one large sample were drawn in order to provide a manageable flow of work to the study team and to try to limit the amount of time between sample drawing and attempted contact. For the first two waves, totalling 200 names, field location efforts were supplemented by searches of New Jersey death records. For the remaining 275 cases, death matches had been run on the total registry before the sample was drawn.

Table 1 shows the overall results of location and interviewing efforts. Of the 475 cases, 107 were interviewed, 35 refused, and 24 were too sick to be interviewed; these were generally individuals who were located because they were rehospitalized, often terminally. In forty-five cases, there was a notation in surveillance records that a reporting health care provider requested that surveillance staff not contact the patient; research staff did not contact these patients to invite study participation and their vital status was not determined. Seventy-two cases or 15% were not located and 16% died after the sampling date

but before they could be contacted. The data of particular interest concern the proportion determined to have died before the sample date. One hundred fifteen or 24% were determined to have died before the sampling date. Among cases whose vital status could be definitely established one way or the other, the proportion was 32%.

Matching with state death files was also implemented after the first two subsamples were completed, so that the second two subsamples had been pre-cleaned to the extent that matching with currently available death tapes permitted. Of those that had not been pre-matched and cases determined dead excluded, 30% were determined to have died before the sampling date; the figure was 20% for those that were pre-matched, suggesting that death tape matching does not eliminate the misclassification problem. The actual mis-classification rates may be even closer since more time was available for field location for the earlier, non-pre-matched samples, a process which was often time-consuming; thus the possibility of detecting mis-classification through field investigation was greater for the first two subsamples. Among those cases whose vital status could be definitely determined by field investigation one way or the other, 35% of the non-pre-matched samples and 29% of the pre-matched samples were determined to have died before sampling.

Of particular importance for the purpose of the present analysis was whether the proportion of not-known-dead cases who had actually died differed among major subgroups. Such differences would create systematic biases in survival analyses and cause overestimation of the groups more frequently lost to followup. Table 2 provides results by mode of transmission, ethnicity and gender. Seventeen percent of whites as compared with 28% of minorities had died before sampling. These differences were statistically significant by chi-square ($p=.028$).

Comparison of results by risk group indicates that 20% of gay men, 25% of IVDUs and 27% of others had predeceased the sample date. These differences did not attain statistical significance.

Not-known-dead cases in the Registry were classified as Registry data were classified as "lost to followup" or as "alive". These results are shown in Table 3. Of those classified as alive, 16% were determined to have predeceased the sample date. Of those classified as lost to followup, 45% were found to have died before the sampling date.

Study findings indicate that survival analyses which assume "not-known-dead" cases to be alive are likely to be significantly biased. They also suggest that such biases are likely to be non-homogeneous by ethnicity and may overestimate the relative survival of minority group persons with AIDS. Even with periodic matching to the most current available death tapes, apparent survival patterns may not represent reality. These results are likely to be characteristic of other state registries, since New Jersey's surveillance program is more oriented to an active surveillance approach than is true in a number of other states. It is likely that mis-classification of vital status is also a significant problem in the merged data from state registries which constitute the CDC national registry data set and that mis-classification cannot be assumed to be homogeneous across important subgroups of PWAs. These findings suggest the need for a great deal of caution in utilizing registry data for survival purposes.

Table 1

Outcome of Location Efforts

	n	%
Interview Completed	107	23
Refused	35	7
Too Sick	24	5
Can't Contact	45	9
Not Located	72	15
Died After Sample Date	77	16
Died Before Sample Date	115	24
TOTAL	475	100%

Table 2

Proportion of Original Sample Determined to be Deceased As of Sample Date (n=475)

	Number of Cases Deceased	Total Cases	Percentage Deceased
Mode of Transmission			
Homosexual/bisexual	24	118	20%
IVDU	72	286	25%
Other	19	71	27%
Race/Ethnicity[1]			
White Non-Hispanic	27	162	17%
Minority (Black, Hispanic, Asian)	88	313	28%
Gender			
Male	90	365	25%
Female	25	110	23%

[1] p = .028

Table 3

Outcome of Location Efforts,
By Registry Listing of Survival Status

	Total		Alive		Lost		Status Unknown	
	n	%	n	%	n	%	n	%
Location Outcome								
Alive at Sampling	243	51	207	61	25	21	11	58
Completed	107	23	99	29	6	5	2	11
Refused	35	7	32	9	3	3	-	-
Too sick	24	5	19	6	5	4	-	-
Died after sampling	77	16	57	17	11	9	9	47
Died Before Sampling	115	24	54	16	53	45	8	42
Vital Status Unknown	117	25	78	23	39	33	-	-
Can't contact	45	9	34	10	11	9	-	-
Can't locate	72	15	44	13	28	24	-	-
Total	475	99	339	100	117	100	19	100

[1] Percentages do not sum to 100% due to rounding.

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HIV SEROPREVALENCE SURVEY AMONG DELAWARE STATE HOSPITAL PATIENTS

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METHODOLOGY. The Delaware Department of Health and Social Services conducted an unlinked seroprevalence survey among Delaware State Hospital (DSH) patients from March 26, 1990 to October 18, 1990. Blinded aliquots of serum drawn for syphilis screening were tested for antibodies to HIV. Those tested included all newly admitted patients and long-term residents receiving annual evaluations. The study design ensured that individual test results were not linked to identifiable persons; therefore, the identities of the patients tested were unknown. The survey provides an estimate of HIV among DSH patients during the study period. Demographic data were collected to characterize those at highest risk for HIV by primary admitting diagnosis, race, age, gender and ZIP Code of home residence.

RESULTS. During the survey period, March 26 through October 18, 1990, 1,047 admissions or annual exams occurred. Of these, 115 (10.9%) were not included in the survey due to lack of a sera samples. Of the remaining 932 surveyed, 119 were patients readmitted after the survey began; six of the 119 readmitted patients were positive for HIV antibodies. Because limited demographic and clinical information was collected, it was not possible to match with certainty the data on the patients who had HIV antibodies in the "new" and "readmitted" groups. Therefore, the data from the 119 readmitted patients were eliminated from the analysis except where noted. The analysis focuses on the results from the remaining 813 individuals.

HIV antibodies were found in 2.6% ± 1.1% (21/813) of the sera samples tested. The prevalence of HIV antibodies was similar in women and men at 2.2% ± 1.6% (7/316) and 2.6% ± 1.4% (13/492) respectively. (Gender was not identified on five patients, one of which tested positive for HIV antibodies.) Although single individuals comprised only 55% (449/813) of those surveyed, they accounted for 95% (20/21) of all those with HIV. The one remaining person with HIV antibodies was divorced. Blacks had a higher prevalence of HIV than whites. The prevalence by race is as follows: Blacks--6.9% ± 3.2% (17/246), Hispanics--5% ± 9.6% (1/20), and Whites--0.65 ± 0.6% (3/523).

No clear association could be found between the total number of admissions and HIV antibody status. Patients readmitted after the beginning of the survey were more likely to have HIV than those admitted only once during the survey period--5.0% ± 3.9% (6/119) versus 2.6% ± 1.1% (21/813). HIV infection was not found to be present in long-term residents receiving annual evaluations (0/58).

For this study, the DSM-III-R codes were collapsed into nine diagnostic groups that would capture the primary admitting diagnoses of the majority of DSH patients. The categories are as follows: 1)Unknown/None; 2) Schizophrenia (not Schizoid); 3) Organic and Other Psychotic Disorders; 4) Mood Disorders; 5) Psychoactive Substance Abuse Disorder; 6) Anxiety/Somatoform/Dissociative Disorders; 7) Personality Disorder; 8) Adjustment Disorder; 9) Other (not included in the above groups). No clear association could be found between primary admitting diagnostic classification and HIV antibodies because some diagnostic category cell sizes were small and the confidence intervals were too wide to make any clear inferences. However, individuals with HIV antibodies were found in eight of the nine patient diagnostic categories. The one exception was the Anxiety/Somatoform/Dissociative Disorders category.

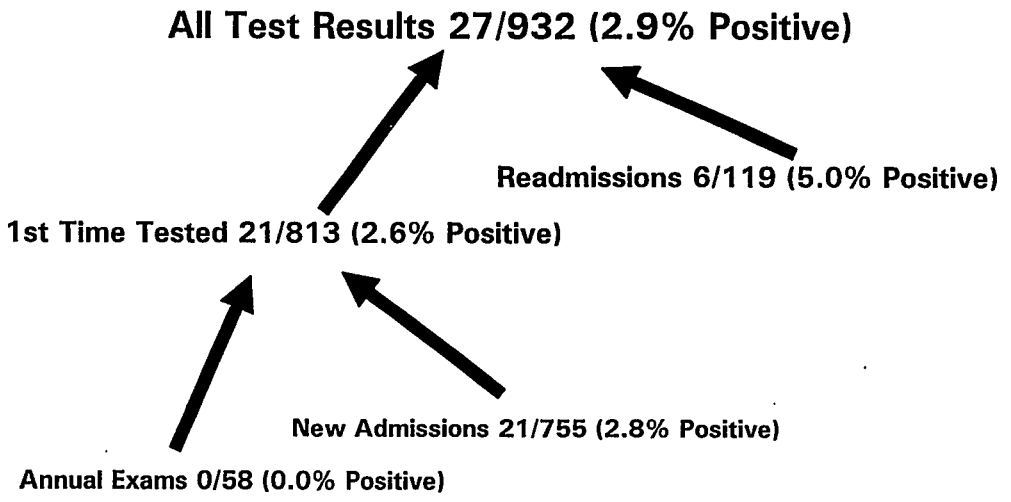
DISCUSSION. Caution should be used in interpreting these findings, as some of the cell sizes are small and the confidence intervals are quite large.

The higher HIV seroprevalence that was found among black and Hispanic individuals is consistent with other surveys occurring in Delaware and has been found in studies nationwide.

Psychoactive Substance Abuse Disorder was under-reported because only the primary admitting diagnostic category was collected. Patients with a primary admitting diagnosis of Psychoactive Substance Abuse are more likely to be referred to a drug treatment program outside the hospital than those admitted in this group under secondary diagnoses. During the survey period, a next-day admission screening program was initiated. (The screening team clarifies patient diagnoses, discharges patients admitted inappropriately, and begins treatment for the remaining patients.) Some patient diagnoses might have been changed when the more in-depth interview was done by the screening team on the next working day. Therefore, the collection of the primary and secondary screening diagnoses might provide a clearer association with patients' HIV antibodies status during a followup survey.

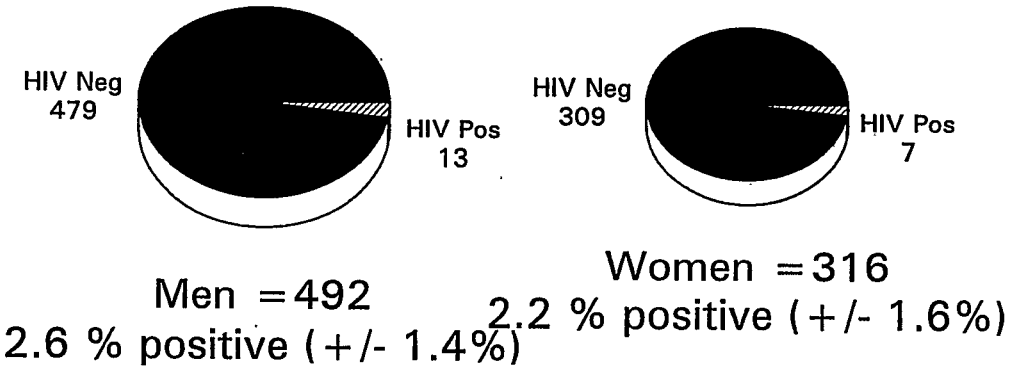
CONCLUSION. The survey at the DSH and the subsequent action taken by the staff proved the value of HIV seroprevalence surveys. The staff responded to the knowledge of HIV in the patient population by expanding HIV training programs for employees and planning for patient HIV education and counseling programs.

HIV Status by Category of Test
DSH Seroprevalence Study 3/90-10/90



Source: DHSS\APO DSH Seroprevalence Data
February 21, 1990

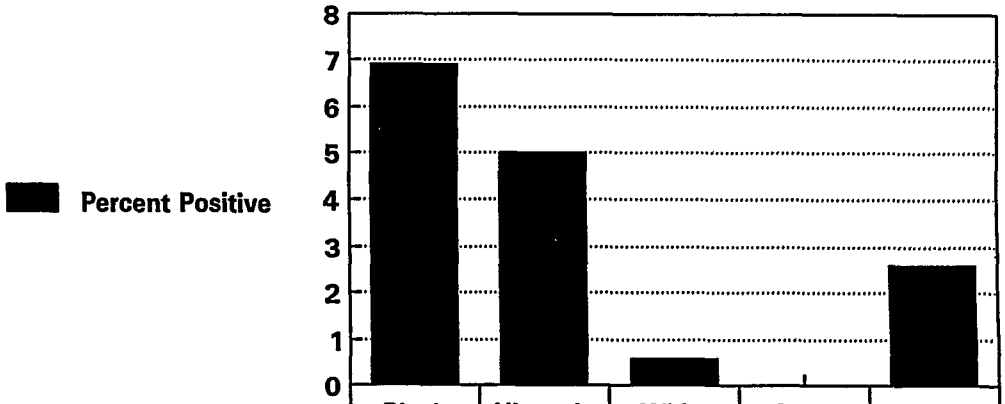
HIV Status by Gender
DSH Seroprevalence Study 3/90-10/90



Source: DHSS\APO DSH Seroprevalence Data
February 21, 1991
5 People had no gender listed one HIV+

HIV Seroprevalence by Race

DSH Seroprevalence Study 3/90-10/90



	Black	Hispanic	White	Other	Total
Percent Positive	6.9	5	0.6	0	2.6
Number of Positives	17	1	3	0	21
Number of Clients	246	20	523	24	813
95% CI +/-	3.2	9.6	0.6		1.1

Source: DHSS\APO DSH Seroprevalence Data
February 21, 1991

CONTINUOUS COLLECTION OF DATA ON AIDS-RELATED BEHAVIOUR IN THE UK

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INTRODUCTION

Our study at RUHBC has several distinctive features: 1) a population based survey which is comparable to behavioural risk factor surveys carried out in North America and other areas; 2) a Computer Assisted Telephone Interview (CATI) methodology; 3) collects data on a 'continuous' basis, interviewing has continued daily since the inception of the study in 1987; 4) an underlying theoretical perspective of a 'lifestyle and health' survey; 5) a significant focus on sexual behaviour related to AIDS and the spread of the HIV virus in the general population; 6) provides a laboratory to examine special topic issues as they occur in real time within the population; 7) provides a unique data-set which allows for considerable investigation of methodological issues concerned with the collection of behavioural data; 8) provides an insight into the issues associated with the collection of so-called 'sensitive' data; 9) provides a mechanism to inform policy makers and decision takers of up-to-date information on matters of health and behaviour; and 10) allows for the evaluation, either by design or by chance, of health intervention programmes and strategies occurring in the population. This paper is concerned with those sections of the questionnaire on attitudes and opinions about AIDS, AIDS-related behaviours and sexual behaviours. A further area of analysis reported here began in 1990, and continues: assessing the risk of HIV spreading in the general population. We set out to examine the RUHBC data with the idea of determining how best to use this data to assess risk based on self-reported sexual activity in the general population. One result has been the creation of risk indices using a Delphi technique and applying our data to this index.

METHODS

The RUHBC CATI survey is a long-term continuous monitoring survey. Initially interviewing was carried out in two metropolitan areas of central Scotland (Edinburgh and Glasgow) but in the autumn of 1989 the survey was extended to include the London metropolitan area. This paper concentrates on data collected in Scotland between April 1988 and March 1991. A total of 15,404 completed interviews were collected in this time. Response rates, calculated according to the CASRO (1) procedure were in the region of 76%. The CATI system uses CASS (2) software augmented by RUHBC programs. The questionnaire contains three types of questions, core questions which have remained unchanged since the beginning of the study, experimental questions which change from time to time in terms of their wording, response categories, placement or a combination of these, and opportunistic questions which enter from time to time because of topic relevance or to examine a new area.

All interviewing is conducted by specially trained interviewers and is carried out daily, excluding Friday evenings, Sundays and public holidays. The sample selection method is based on Waksberg's (3) RDD technique. A single household member is selected randomly from the household. All interviews are conducted with respondents aged between 18 and 60 years. Questions on personal sexual behaviour are not asked of respondents aged 51-60 years. The questions on AIDS and sexual behaviour occur in the latter part of the questionnaire after the sections looking at other health-related issues such as smoking, alcohol use, diet and exercise.

RESULTS

The data are considered under three topic areas, each discussed separately, although clearly there is often overlap between these areas: 1) Attitudes, opinions and beliefs about AIDS; 2) AIDS-related and sexual behaviour; and 3) Perception of risk.

Attitudes, Opinions and Beliefs about AIDS

This section of the questionnaire was introduced in March 1988 in response to a growing need for baseline information on the level of knowledge about AIDS in the general population. This section can be divided into three parts: 1) two general questions asking respondents about their perceived level of knowledge about AIDS and their main source of information about AIDS; 2) a series of questions relating to the perceived risk of contracting AIDS from a variety of sources, namely insect bites, blood donation, public toilets, eating food prepared by someone with AIDS and by kissing with exchange of saliva; and 3) a series of agree/disagree statements about AIDS. The questions in this third part were altered at specific times during data collection as part of an experiment into the effects of question wording. Consequently the analysis of time trend for these questions is very complex and is covered in more detail elswhere (4).

AIDS-Related and Sexual Behaviour

This section of the questionnaire is divided into two parts: 1) AIDS-related behaviour including questions on the perception of AIDS as a problem, frequency of talking about AIDS with family and friends, concern about getting AIDS and reported changes in behaviour attributable to AIDS; 2) sexual behaviour considering stablilty of sexual relationships, number of partners and condom use. In practice the refusal rate for questions on personal sexual behaviour, following informed consent, is very low (2% - 4% /month).

Perception of Risk

This was addressed in two ways: 1) the perception of AIDS as a risk in their local area, the respondent's level of concern that either they or someone close to them will get AIDS, and perception of personal risk; and 2) by the development of a 'Risk Index' for exposure to HIV which attempts to show what percentage of the general population are at risk of contracting AIDS based on their reported sexual behaviour, and whether this potential risk is high, medium or low.

1. Knowledge, Attitudes, Opinions and Beliefs about AIDS

In our survey questions on other 'risk' behaviours are followed by questions on general health publicity; then, following a short statement to the respondent explaining that they are now going to be asked a few questions about AIDS, there follows a series of knowledge and opinions questions. The first question asked is, "Compared to most people, how much would you say you know about AIDS?". Responses were categorised as 'A lot', 'some', 'a little' or 'nothing'. Trend analysis has shown no significant change in responses to this question between April 1988 and March 1991: approximately 28% of respondents report that they know 'a lot' about AIDS, 43% know 'some', 26% know 'a little' and only 3% to 4% of respondents report that they know 'nothing' about AIDS. Respondents are then asked where they get most of their information about AIDS, without prompting. Their stated 'most important source of information' is recorded. The trend analysis shows that there has been no significant change over time in the reported main source of information about AIDS, although the trend line indicates that the percentge of respondents who report getting most of their information from newspapers and magazines (29%) is rising, and the

percentage getting most of their information from leaflets and posters (9%) is falling. However there are considerable variations between months in the reported main source of information especially with regard to television and newspapers/magazines. Overall, about half (45%) of respondents report that they get most of their information about AIDS from television. The wide fluctuations between months might be a result of various campaigns, both Governmental and other, which were reflected in high levels of coverage about AIDS on television at various time points, and by national advertising campaigns, for example in newspapers, at other times.

Sources of infection with the AIDS virus

The most striking aspect with regard to five opinion questions on sources of infection with HIV is that there is no consistent trend common to them all. Three distinct patterns are discernable: 1) no change over time; 2) an increase in knowledge; and 3) a decrease in knowledge (level of knowledge being based on the generally accepted 'correct' answer to these questions at the current time).

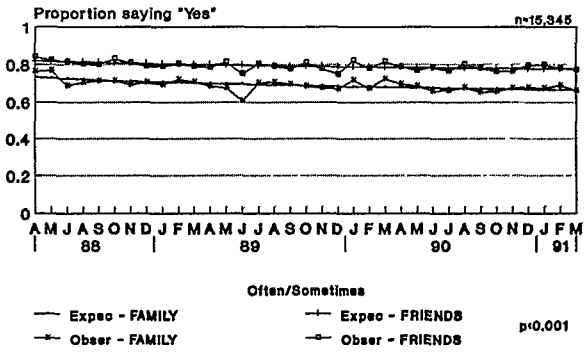
The opening for these questions is an introductory question, "In your opinion, can people become infected with the AIDS virus ....", followed by the source, namely '...from insect bites?'; '...from giving blood, for example at a Blood Donor Centre?'; '...by eating food prepared by someone with AIDS?'; '...from public toilets?'; and '...by kissing with exchange of saliva?'. Two of these questions, on 'public toilets' and 'food prepared by someone with AIDS', have shown no significant change over time. A very high percentage of respondents report that they do NOT think that you can become infected with the AIDS virus from public toilets (87%) or by eating food prepared by someone with AIDS (85%). The questions relating to 'insect bites' and 'giving blood' are both characterised by an apparent decrease in 'knowledge' among respondents. A Probit analysis shows that there has been a small but statistically significant increase of approximately 3% since March 1988 in the percentage of respondents who believe that you can become infected with HIV by donating blood ($t=2.21$; $d.f=33$; $p<0.05$). It is notable that a significant proportion of the population who were previously uncertain about the risk of donating blood now report that one can become infected in this way. Overall, about one fourth of our respondents (26%) report that you can become infected by donating blood and between one in ten and one in twenty (7%) are uncertain. With the question on infection from 'insect bites' there is increasing uncertainty shown by the rise in the 'don't know' category of response ($t=8.0$; $d.f=21$; $p<0.001$). The overall change over time is high at approximately 12% over 3 years. The biggest change took place between May 1988 and March 1989 when the percentage of 'don't know' responses increased from 15.1% to 28.8%; since March 1989 the percentage of 'don't know' responses has remained very high at around 30%.

2. AIDS-Related and Sexual Behaviour

Talking about AIDS

Between April 1988 and March 1991 there has been a significant decrease over time in the percentage of respondents who report that they talk about AIDS with their family ($p<0.001$) and in the percentage of respondents who report that they talk about AIDS with their friends ($p<.001$). Figure 1 shows this trend; the 'Yes' responses shown include those respondents who answer either 'often' or 'seldom' to each of these questions. The PROBIT analysis also shows a smaller but significant decrease in the percentage of respondents who report that they 'often' talk about AIDS with their family ($t=-2.27$; $d.f=35$; $p<0.05$), but there has been no significant decrease in the percentage who report that they 'often' talk about AIDS with their friends. In both cases then, the decrease can largely be attributed to a fall in the percentage of respondents who report that they 'seldom' talk about AIDS with either their family or their friends.

FIG 1 - Talk about AIDS with family and friends - LOG REGR



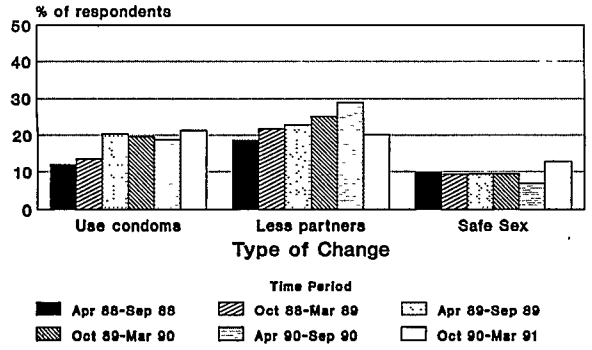
In order to determine what behavioural changes, if any, respondents are making in response to the AIDS problem, respondents are asked if they have changed anything in their daily life due to what they know about AIDS. If they answer 'Yes' to this question they are then asked what they have changed (an unprompted open-response item). Those not reporting a change are asked if they think there is anything that they will change, and those who report that they will change something are asked what they will change. There has been a small but statistically significant increase over time in the percentage of respondents who report that they have changed something in their daily life due to what they know about AIDS ($t=2.83$; $d.f.=35$; $p<0.01$). The PROBIT analysis shows that this increase is relatively steady with very little fluctuation in the percentage of changers from month to month. In total, over the 3 year period, the percentage of 'changers' has increased by approximately 3 percent. However, the percentage of respondents who report a change has remained low (about one in ten) and is highly influenced by the age of the respondent, and ranges from 15.9% of 18-29 year olds to 5.7% of 51-60 year olds ($p<0.001$; $g=.28$). There is also a significant gender difference with slightly more males (13.6%) than females (10.1%) reporting that they have changed something ($p<0.001$; $g=.17$). Among those respondents who report that they had not changed their behaviour a further 7% report that there is something that they will change but there has been no significant change over time in the percentage of 'potential' changers.

Actual changers are asked what they had changed. An open-ended response format was used for this question with the respondents answers being categorised by the interviewer into one of seven different categories depending on the type of change mentioned: 1) Use condoms; 2) Fewer partners; 3) 'Safe sex'; 4) Precautions at the workplace; 5) precautions in public places/outside home; 6) Educating/informing children of the risks; and 7) General attitude. Figure 2 shows the percentage of respondents in each of six time periods who report that they now use condoms, have fewer partners or practice 'safe sex'. As can be seen there has been a substantial increase in both the percentage of respondents who reported that they use condoms (up from 12% to 21.3% between 1988 and 1991) and in the percentage who report that they had fewer partners (up from 18.6% in summer 1988 to 28.9% in the summer of 1990). However, the percentage who report having fewer partners fell again to around 30% during the winter of 1990/91. The percentage of respondents who report that they practice 'safe sex' remained stable at around 9% until the summer of 1990 when it fell to 6.9% before rising sharply to 12.9% in the winter of 1990/91. This rise coincides with the sharp drop in the percentage of respondents who report having fewer partners during this period (down from 28.9% to 20.2%).

An analysis of reported changes in behaviour by gender shows that there are highly significant differences in response to this question, with a higher percentage of male than female respondents reporting that they use condoms (24% and 11.4% respectively), have fewer partners (28.3% and 17.3%) and practice 'safe sex' (13% and 6.4%), and a higher

percentage of female respondents reporting that they take work (35.5% and 16.1%) and public (14.8% and 7.6%) precautions or educate their children about the risks (6.4% and 2.3%). The type of change made is also significantly related to the age of the respondent with the numbers reporting that they use condoms and have fewer partners being highest in the 18-29 age group, and with work precautions predominating in all other age groups.

FIG 2 - WHAT HAVE YOU CHANGED? (because of AIDS)

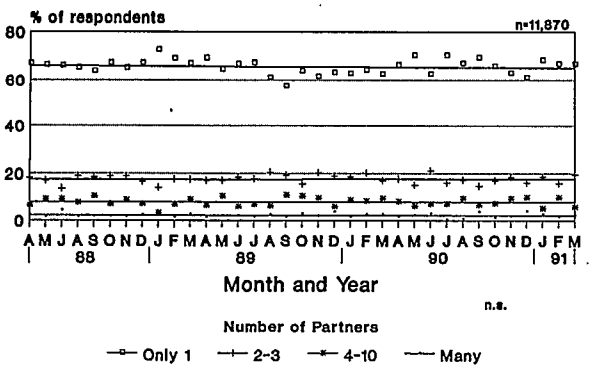


Sexual Behaviour

Questions on sexual behaviour follow a short 'informed consent' statement warning that questions on sexual behaviour will follow and asking permission to ask these questions; only 2-4% of respondents refuse to answer these questions (5). The first set of questions look at the stability of sexual relationships and the number of sexual partners and the second set look at past, present and future condom use. Overall, over three-quarters (78%) of respondents report having a steady sexual partner at the moment; a total of 73% of respondents report that they have been with their current partner for more than 5 years and 6% of respondents report that either they or their partner have had other partners in the past year. There has been no significant change over time in reported 'other' partners in the past year, the percentage of 'Yes' responders remaining remarkably stable over time. However, twice as many male (8.7%) as female respondents (4%) report that they or their partner have had other partners during the past year and in all months more males than females report having other partners.

The final question in this section asks respondents to recall how many sexual partners they have had altogether during the past 5 years. Respondents are requested to choose one of the following categories: none, only 1, 2-3, 4-10 or many. Figure 3 shows the results of this question for those who report that they have had at least one sexual partner in the past 5 years: there has been no significant change over time in the reported number of partners during the past 5 years for the 3 years under study. Overall, a total of 65.9% of respondents report only one sexual partner; 17.9% report 2-3 partners; 8.2% report 4-10 partners; and 2.1% report 'many' partners.

FIG 3 - Over the past 5 years about how many partners did you have altogether?

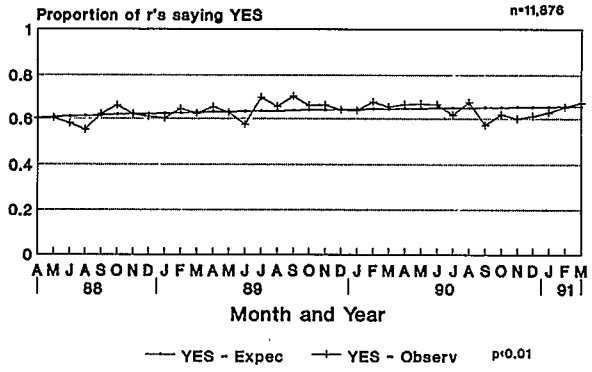


There is considerable gender difference with regard to the number of sexual partners over the past 5 years with a higher percentage of female than male respondents reporting only one partner (72.4% and 57.9% respectively) and a higher perentage of male than female respondents reporting 2-3 partners (19.2% and 16.9% respectively), 4-10 partners (14.1% and 3.3%) and 'many' partners (4.4% and 0.3%). However, there has been no significant change over time in the reported number of partners for either males or females. In sum, over 16% of respondents reported that they had had 4 or more partners over the past 5 years, with the great majority of these respondents being male.

A number of questions in this section look at past, present, and future condom use among respondents. The first of these asks: "Have you ever used condoms during sexual activities?". If a respondent answers 'Yes' to this question they are then asked whether they use them now; if they answer 'Yes' again they are asked whether they use condoms as a protection against infection. If the respondent answers 'No' to the question on ever used condoms or 'No' to the question on using condoms now they are asked whether they think they will use them.

Figure 4 shows the PROBIT analysis for the question, "Have you ever used condoms during sexual activities?". As can be seen there has been a small but statistically significant increase over time in the percentage of respondents who report that they have used a condom during sexual activities ($t=3.5$; $d.f=35$; $p<0.01$). However this increase is not steady but is characterised by short periods of considerable fluctuation interspersed with periods of relative stability. In total, in the 36 months since April 1988 there has been a 6% increase in the reported use of condoms in this sample of the general population. Overall, 63.6% of respondents report that they have used condoms at some time.

FIG 4 - Have you ever used condoms during sexual activities? LOG REGR



With regard to current condom usage the analysis indicates that there has been a statistically significant increase in the percentage of respondents who report that they use condoms now ($t=3.73$; $d.f=35$; $p<0.001$). Although this increase is characterised by considerable fluctuation from month to month, the underlying trend is upward. The increase over the last 3 years is around 7 percent. Over a third (37.5%) of those who report that they have ever used condoms report that they use them now, and this represents 23.8% of all respondents aged 18-50. Current condom users are then asked whether they use condoms as a protection against infection. The analysis for this question again shows that there has been a statistically significant increase over time in the percentage of respondents who use condoms as a protection against infection

(t=3.34; d.f=35; p<0.01). Those respondents who report that they have never used condoms and those who have used them but who do not use them now are asked if they think they will use them. There has been a significant increase over time in the percentage of respondents who report that they will use condoms (p<0/001; g=-.06) with a total of 30.9% of this group saying that they will use them.

3. Perception of and possible exposure to Risk

The questionnaire contains several questions related to the perception of the risk of AIDS: in the area in which the respondent lives; among the respondent's immediate circle of family and friends; and the risk to the respondent personally. In order to monitor the respondents' perception of the risk AIDS poses to either themselves or their family and friends respondents are asked "How concerned are you that you or someone close to you will get AIDS?" For the purposes of analysis responses for this question are divided into those who report that they are either 'very concerned' or 'quite concerned' ('concerned') and those who report that they are not concerned. The PROBIT analysis shows that there has been a statistically significant increase over time in the percentage of respondents who report that they are concerned that either they or someone close to them will get AIDS (t=4.12; d.f=35; f<0.001). Overall, the percentage of respondents who report that they are concerned has risen by approximately 6% since April 1988, with almost half (48.1%) of all respondents reporting that they are concerned. The percentage who report that they are concerned reached its highest point in August 1989 at 55.1%. It is interesting to note that the percentage of respondents who report that they think AIDS is a problem in their local area also peaked in August 1989 at 26.9%. An open-ended question asks respondents whether there is anything they do in their daily life that they think puts them at risk of getting AIDS. Roughly ten percent (9.3%) of respondents mention that there is something which they think puts them at risk of gettting AIDS; of these, a majority (88%) said that this was job-related.

The self-reported data on sexual behaviour of respondents between the ages of 18 and 50 provide some of the necessary empirical background to consider potential spread of HIV in the general population. Two members of the research team, Campostrini and McQueen, constructed a 'risk index' for HIV transmission which could be linked to the CATI data. The task was to create an index for the general population which measures not only 'high risk' categories of respondents but also behaviour considered at minimal risk of HIV infection. Although there are obvious limitations of self-reported behaviour on sexual behaviour two points should be emphasized: 1) no criteria exist on which to standardise the self-reported data concerning sexual behaviour; and 2) there is evidence that the accuracy and veracity of self-reported data on other behaviours, notably smoking and self-reported weight, are relatively good . Until proven otherwise, we assume that respondents are answering to the best of their ability when they are asked questions about their sexual behaviour.

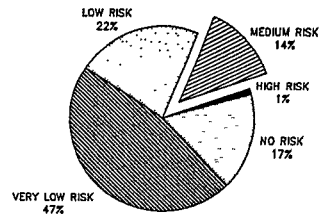
The perception of risk by individuals is highly subjective. Similarly, health professionals and 'experts' in the field of sexual behaviour and AIDS also have differing perceptions of the degree to which various sexual practices put individuals in the population at risk of exposure to HIV. The HIV infection-exposure risk index (VIRI) which was prepared has been constructed by an expert ranking of different sex-related categorizations constructed from variables found in the RUHBC-LAH study. The VIRI index is a delphi-based assessment of self-reported behavioural factors associated with HIV exposure and subsequent transmission. This technique gathers and synthesizes the judgements of several experts who constitute a research panel. The method uses a series of questionnaires filled in by a panel of experts to seek consensus; at every round the panel is informed of the results of the preceding round and a modified questionnaire for the next round is constructed. For the construction of the index presented here, eight researchers connected with the RUHBC survey were selected as members of the panel. This Delphi study had three rounds: Round 1) ranking the first 'tree' of sexual behaviours; Round 2) ranking the second tree; and Round 3) re-ranking the second tree considering the feedback from the second round.

Initially a combination of eight different sex related variables in a 'tree format' was given to the panellists to rank and this was reduced to 6 variables in the second round. The components of the tree were: 1) respondent reporting sexual activities with a person of their own sex in the past five years (asked of males only); 2) whether the respondent currently engaged in such activities; 3) whether the respondent has a steady sexual partner; 4) how long this relationship has lasted; 5) whether the respondent uses condoms; and 6) the number of sexual partners over the past five years. The different types of sexual behaviour were ordered, following the results of the final Delphi ranking, into 5 classes: 'high risk', 'medium risk', 'low risk', 'very low risk', and 'no risk'.

The index and the data

The value of this theoretical exercise is to put data, on sexual behaviour, collected over time, into this theoretical index. Figure 5 shows the risk index applied to the data collected in London, Edinburgh, and Glasgow during the year 1989 from 7,214 respondents between 18 and 50 years of age. It is notable that the percentage of the population considered at high risk is very low (1.2%) and this group consists only of males who report having engaged in same gender sex. This is an estimate of the proportion of people with a really consistent risk of becoming infected by the HIV virus because of their sexual behaviour. Of more concern for the heterosexual diffusion of HIV is the much higher percentage of respondents who are at 'medium' risk (14%). This group includes respondents who do not report engaging in same gender sex but who report multiple sexual partners over the last 5 years and who do not report using condoms.

Fig 5 – THE 'VIRI'
RISK INDEX APPLIED TO DATA
LONDON – GLASGOW – EDINBURGH 1989



Observing the VIRI index by gender, it appears that males are at considerably higher risk of being exposed to an HIV contact than females. It should be clear that this index is assessing risk of being exposed to HIV contact and that it does not take into account the subsequent biological differential risk of males and females. Thus it is a behavioural based exposure to infection risk that is being assessed. This higher risk for males is not only due to the presence of male homosexuals but also to the fact that males declare a higher number of partners compared to females.

This is an initial analysis based on a Delphi-constructed risk index for HIV transmission in the general population augmented by self-reported sexual behaviour taken from a continuous survey. The VIRI index allows an insight into the risk situation in the general population even though it is based only on the risks of getting infected which are connected with sexual behaviour as reported in a lifestyle and health study. The index adds new information to efforts to explain the diffusion of AIDS in the whole population and provides an instrument which can explore risk changes over time and changes in rates of risk in the population.

DISCUSSION

It is clear that trends over time in attitudes, opinions and beliefs about AIDS, AIDS-related and sexual behaviour and the perception of risk are very complex. Some behaviours have remained unchanged, some have changed slowly and steadily, others have changed but with considerable fluctuations from month to month and some show periods of activity interspersed with periods of relative calm.

Knowledge about AIDS overtime shows an elaborate pattern, but one aspect of knowledge that must continue to give concern is the very high percentage of respondents who think that you can get AIDS by giving blood (26.4% overall). This percentage is rising over time and the analysis indicates that the percentage of 'Don't know' responders is decreasing while the percentage of 'Yes' responders is increasing. It appears that knowledge levels are changing in the wrong direction in this particular case.

Some AIDS-related behaviours are changing over time: people are talking less about AIDS with family and friends, but are making changes in their daily life because of AIDS. As regards sexual behaviour, there has been a definate increase in the reported use of condoms and the use of condoms as a protection against infection. Although this increase has been slow and unsteady the underlying trend is upward. However, there is little evidence for any reduction in the number of partners over the past 3 years. Undoubtedly changes have occurred in some sub-groups of the population; this has been shown in other analyses, but there is a need for further analysis. Change in behaviour at the population level is small and occurs over a relatively long period of time. In our data changes of between 3% (for example, for changed behaviour because of AIDS) and 10% (for using condoms as a protection against infection) over a 3 year period have been recorded. Although apparently small, this level of change in a behaviour at the population level is very significant. However, these results must be interpreted with caution. It is quite possible that these changes in sexual behaviour are part of a secular trend over many years or even decades. Unfortunately, because of the lack of earlier data, it is difficult to deduce what part of this change is attributable to a long-term change in behaviour in contraceptive usage and what part is attributable to changes prompted by the advent of AIDS. Respondents who previously might have used condoms for birth control may now be using condoms to prevent the transmission of HIV.

Previous analysis of the data (RUHBC, 1991) has indicated that those respondents, particularly in the 18-29 age group, who were most at risk of contracting AIDS because they had multiple partners were the ones most likely to report a change in their behaviour.

Conclusions

1. Our results suggest that levels of knowledge about AIDS reached a plateau for most questions BEFORE the period covered by this analysis, ie prior to April 1988. However for certain items there is still considerable uncertainty among the general public, particularly with reference to the increasing numbers of respondents who report that they think you can become infected with the AIDS virus by giving blood.

2. The saliency of AIDS for the population appears to be declining, if one assumes that respondents talk about an issue when they are unsure what they think about it or when they are concerend about the subject. However, the majority of respondents still report that they talk about AIDS with either/or their friends and families.

3. Reported use of condoms and use of condoms as a protection against infection is increasing over time although it is not possible to state that this increase is due to AIDS.

4. There has been no change in the reported number of sexual partners, with young males reporting the highest number of partners. Numbers 3 and 4 above suggest that respondents who are changing their behaviour are tending to use condoms rather than reduce their number of partners.

5. The personal perception of risk of AIDS is very low indeed with only around 2% of respondents reporting that there is anything they do in their daily life that puts them at risk of getting AIDS that is not related to their job. If respondents report that they are at risk this is usually because of their job e.g being a health care worker.

6. The results obtained from applying the 'Risk Index' to this data suggest that there is a relatively high percentage of respondents in the general population who are at risk of AIDS because of their personal sexual behaviour, with around 22% of males and 8% of females classified as being at 'high' or 'medium' risk.

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A HOUSEHOLD HIV SURVEY FEASIBILITY STUDY: LESSONS FROM TWO COMMUNITY SURVEYS

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National Center for Health Statistics

In June 1987, the President called for a comprehensive effort to determine the nationwide prevalence of HIV infection. CDC was already developing an infection surveillance system. And as a part of this effort, the National Center for Health Statistics (NCHS) undertook a study to test the feasibility of adapting household survey methodology to measure HIV prevalence. In May 1988, Research Triangle Institute was selected to implement the study.

This presentation should actually have been titled lessons from **three** communities, because our first learning experience was in Washington, D.C., where the field work was originally scheduled to begin. We were aware that the survey was delving into sensitive areas but underestimated the impact on our plan. Our rush to get the first pilot into the field did not allow time to deal with community concerns, and growing controversy led to cancellation of the Washington survey. Needless to say, lesson number one is to take the time necessary to create an acceptable climate.

In the time I have with you today, I thought I might focus on some of the unique challenges of this survey and summarize the findings of our study.

The problems this survey presented were extremely difficult to resolve. Since the HIV infection rate in the general population is extremely low, a sampling strategy that would greatly increase the probability of inclusion on HIV-infected persons was needed. Even then, there was the troublesome prospect that infected people would be reluctant to participate, leading to a significant underestimate of HIV prevalence. This meant that a high response rate was imperative. But even good response would not be sufficient without some measure of the extent of response bias.

Added to these problems was the general climate surrounding the AIDS epidemic -- a public fearful of a deadly disease that had struck an already stigmatized segment of our population, confusion about just how easily it might be transmitted, concern about discrimination, the activist groups that had grown to protect the interests of people with AIDS and the HIV-infected. Our first experience emphasized the extent to which these problems would affect acceptance of our survey plans.

Our next step was to contact health departmenmts that would be willing to work with us on the survey implementation. The Allegheny County Health Department in Pittsburgh, PA, was interested and played a key role in community and media relations and in generating a climate conducive to conducting the study. Assisting the Health Department was a Community Advisory Committee consisting of 21 local civic leaders and representatives of concerned groups. Their role was to review and endorse all aspects of the study design and suggest ways to encourage community acceptance and participation.

Our advisors were particularly concerned about participants' privacy forcing us to respond with some elaborate procedures. Names were never recorded and address information was destroyed in the field.

In order to ensure privacy, we developed a self-administered questionnaire which the respondent completed in as much seclusion as the interviewer could establish. Upon completion, the questionnaire was placed in an envelope and sealed by the sample person for mailing to the study contractor.

In addition, an independent Privacy Committee made up of advisory group members was formed to assure that the privacy protection procedures were being carried out properly during survey operations.

Controversy arose among our over two proposals designed to overcome the problems of low prevalence and nonresponse bias. These were the allocation of sample based on assessment of potential risk of HIV infection, and the purposeful inclusion in the sample of persons whose HIV status is known.

The suggested sample stratification immediately raised concerns about "targeting" particular groups. Unable to convince them on the merits of the strategy, we agreed to a sample that would reflect the actual demographic distribution of households in Allegheny County.

In our efforts to assure a good response, we selected experienced interviewers and teamed them with professional phlebotomists to draw blood. We developed a videotape featuring the persuasive Surgeon General, Dr. C. Everett Koop, to explain the survey to each selected person, and offered $50 to those who chose to participate.

In January 1989, the survey teams visited each sample household. An age-eligible person was selected at random from each household. The phlebotomist collected a small blood sample, and the person completed the risk behavior questionnaire.

The Allegheny study was considered successful from both an operational and a

participation perspective. Eighty-one percent provided a blood sample and completed a questionnaire. Six percent of sample persons reported at least one of five selected HIV risk behaviors, suggesting that some persons who engage in HIV risk behaviors participated in the survey.

The Allegheny study taught us much about developing procedures for outreach to a community and established the feasibility of collecting blood samples and HIV risk behavior data in the homes of sample persons. Pittsburgh demonstrated that we could get response and protect privacy.

Dallas County, TX, was selected as the next site. The objectives for this field test were to refine further the methods and procedures applicable to a national survey, to estimate HIV prevalence in the county, and to address research questions related to participation rates and quality of self-reported risk behavior data that we were unable to address in the previous effort.

The Dallas County Health Officer was very receptive to the opportunity to measure infection in the area since, earlier, the Health Department had proposed a community survey, prevented by lack of resources. Our study was planned in close collaboration with local health officials and with a Community Advisory Panel of 29 members, representing a broad cross-section of groups and interests, appointed by the Dallas County Commissioners' Court. The Panel reviewed each aspect of the survey design, recommended modifications that reflected community values, approved the final set of survey procedures, and assisted in encouraging community acceptance of the survey.

The proposed design reflected several changes from the Pittsburgh study. These included:

- a larger sample
- construction of strata on the basis of expected HIV risk level
- oversampling in strata with higher expected prevalence of at-risk persons
- expansion of the questionnaire to include additional questions about HIV risk behaviors
- testing blood samples for hepatitis B virus infection
- a special follow-up study of a sample of nonrespondents

Our second objective, that of stratifying the sample, was achieved but not without considerable discussion. Once again, this procedure which is done routinely in other circumstances became an issue. Advisory panel members were concerned about what information would be used to identify high risk areas and that it not "target" particular racial or demographic groups. Agreement was reached by using aggregate health data readily available to everyone and applying these geographically to establish areas of high, medium, and low risk. By oversampling in areas presumed to contain larger numbers of high-risk persons, we hoped to increase the number of sample persons at risk for HIV over that expected in a proportionately allocated sample of the same size.

The field procedures were much the same as used in Allegheny County, with additional precautions taken in the field to give added assurance of privacy protection.

Of interest to survey scientists was the perception of our community advisors that several contacts of selected persons represented "badgering" of respondents, and they were not convinced by our explaining that such attempts at "refusal conversion" was standard survey procedure. Eventually a compromise was reached, and recontact was allowed as part of a special follow-up study of nonrespondents, or Quality Assessment Study (QAS). Sample persons who refused to participate were not recontacted during the main survey data collection period.

Ninety-six percent of the sample households were successfully screened in the main survey and 79 percent of identified sample persons provided both a blood sample and a questionnaire.

Our follow-up study was crucial to determining the extent to which lack of participation was related to HIV risk behavior. The objective of the QAS was to collect the survey data from enough main survey nonrespondents to provide a basis for estimating and adjusting for response bias in the survey estimates. A decision was made to significantly increase the monetary incentive to encourage participation.

The QAS was conducted with a sample of 30 screening nonrespondents and a sample of 175 persons who had been screened but refused to participate. Half of the QAS sample persons was asked to provide both a blood sample and a risk-behavior questionnaire and offered a $175 incentive to do so; 26 percent of those complied. Each person in the other half of the QAS sample was offered $100 to complete only the questionnaire, and 55 percent complied.

Table 1 Percent of Persons Answering Questionnaire and Giving a Blood Sample

Subpopulations	Questionnaire	Blood Sample
Total	90%	84%
Sex		
Male	87%	82%
Female	92%	86%
Marital Status		
Married	90%	80%
Not Married	90%	90%
Age		
18-24	96%	87%
25-34	92%	85%
35-54	85%	81%

Dallas county 1989

Survey participation in Dallas was similar to that in the Pittsburgh pilot, with an overall rate of approximately 80 percent. Table 1 shows the Dallas weighted sample person response rates for various demographic subgroups for questionnaire and blood. The rates do not include the two percent screening nonresponse. Interestingly, for those giving blood and answering the questionnaire, the response rate for both male and female single persons was higher than for those married -- a good sign for our survey. Response rates for questionnaire and blood decreased with age.

An important element of the survey, and one that makes it unique among seroprevalence surveys, is the collection of risk behavior data. Tables 2 and 3 show the percent of the surveyed population reporting risk behaviors associated with transmission of HIV.

Table 2 Percent of Males Reporting Risk Behaviors

Risk Behaviors	Percent Since 1978
Sex with 5+ Women	40.1
Gave Female Money or Drugs for Sex	11.1
Sex with 1+ Men	7.7
IV Drug Use	5.3
Receptive Anal Sex	4.5
Sex with 5+ Men	3.4

Dallas County 1989

Questions about number and sex of partners, condom use and anal sex were asked for two different time periods: since January 1978 and during the last 12 months. The tables show the percent since 1978. Almost eight percent of the men reported having sex with at least one male since 1978; 3.4 percent reported 5 or more partners. Approximately 40 percent of the men had sex with five or more women since 1978, and eleven percent reported giving money or drugs to women for sex.

Among females, 21 percent reported having sex with five or more men since 1978, almost 20 percent reported anal sex, and 10 percent reported sex with an IV drug user.

Table 3 Percent of Females Reporting Risk Behaviors

Risk Behaviors	Percent Since 1978
Sex with 5+ Men	21.3
Receptive Anal Sex	19.9
Sex with IV Drug User	10.0
Sex with Bisexual	5.2
IV Drug Use	2.7
Received Money or Drugs for Sex	2.2

Dallas County 1989

Table 4 relates rates of HIV infection to sexual behaviors. The infection rates associated with the known high-risk practices were greatly elevated. Males reporting receptive anal intercourse had a rate of 14 percent, and those reporting male-to-male sex, a rate of almost 9 percent.

Table 4 Percent of HIV Infection by Risk Behaviors, Dallas County 1989

Reported Risk Behavior	Percent Infection
Total	0.42
Male Receptive Anal Intercourse	14.02
Male to Male Sex (No Drug Use)	8.68
IV Drug Use (No Male to Male Sex)	0.99
Sex with At-Risk Person	0.98

Findings from the Dallas study indicate that persons will report risk behaviors for HIV infection. Review of the survey data demonstrates consistency with previous reports, and the serologic and behavioral findings are as expected. However, it was not possible to measure the extent of under-reporting because comparable data are not available for Dallas County.

The survey estimate of HIV prevalence was low compared to back-calculation model estimates even after nonresponse adjustment. It remains to be seen which estimates are closest to reality.

The data collected in the household HIV survey can provide useful information for planning prevention programs and estimating future resource needs.

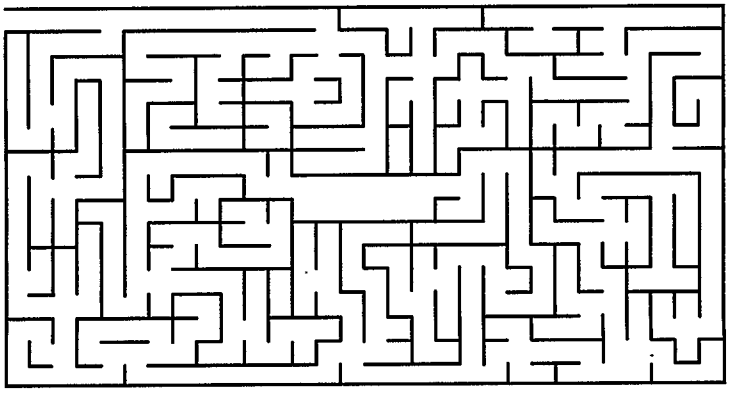
In the current controversial climate, considerable work and resources are needed to implement household HIV surveys although these would be small compared to overall expenditures on the epidemic.

The use of advisory groups is helpful in obtaining local legitimacy and community support. It can prove to be a roadblock to implementing some survey methods, and it lengthens the planning period.

Methodology combining a special population frame, such as STD clinics, drug treatment centers, and hospitals, with a general population sample may be effective in improving the quality of current estimates.

Session N

Injuries, Homicides, and Suicides



SURVEILLANCE OF INJURY MORBIDITY USING HOSPITAL DISCHARGE DATA

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Introduction. Injuries are increasingly being recognized as a national health problem with specific needs in the areas of surveillance and epidemiology (*1*). A variety of existing and potential data sources are available for injury surveillance. The following have been suggested as the highest priorities for development, based on expected cost-effectiveness (*2*):

1. Hospital discharge data with cause-of-injury codes.

2. Trauma-related registries, including trauma care, burn, head injury, and spinal cord injury registries.

3. Sentinel injuries, based on the sentinel event concept of Rutstein et al.(*3*).

4. Making selected injuries universally reportable at all levels of care.

Computerized, population-based hospital discharge data systems are potentially a major resource for injury surveillance at the state level and are second only to death records in their ability to address injury issues. This is true for a number of reasons.

1. Legislative mandates to collect data from hospitals exist in 34 states, and 28 states mandate the submission of data at the level of the individual discharge (*4*).

2. There are many more hospitalized injuries than injury deaths in a given population, typically 25 to 40 hospitalizations for each death. The larger numbers allow analysis of injury patterns in small geographic areas and among population subgroups.

3. Hospital discharge data include all or nearly all of the most severe non-fatal injuries, such as head injuries, spinal cord injuries, and severe burns. As such, they represent a paticularly valuable surveillance source for these injuries.

4. The spectrum of injury causes for hospitalizations is different from the spectrum for injury deaths. Thus, hospital discharge data provide information on types of injuries not covered by mortality data. (Table 1)

Table 1: Proportions of Injury Deaths and Injury Discharges, by Selected External Causes of Injury, Rhode Island, 1985-1987

Cause of Injury	Deaths (1985-87)	Discharges* (1985)
Motor Vehicle	29%	19%
Fall	13%	33%
Self-inflicted	25%	11%
Assault	9%	5%
Adverse Drug Reaction	<1%	8%
All Other Causes	23%	24%

*Includes principal diagnosis injuries with E-codes recorded

5. The critical step necessary to make hospital discharge data useful for injury surveillance is already in place, since there is a well-developed coding system for external cause of injury. This system is well documented and familiar to most hospital medical records departments. (The International Classification of Diseases, 9th Revision, Clinical Modification (*5*), the disease coding system used with medical care data, has two parallel ranges of codes for injuries and poisonings: the nature of injury codes, or N-codes, which include codes 800-999, and the external cause of injury codes, or E-codes, which include codes E800-E999. Hospitals record N-codes predominantly, because of their relevance for treatment and reimbursement. Injury surveillance and epidemiology require the reporting of E-codes in addition for all injury hospitalizations.)

6. Hospital discharge data can be used to support injury control efforts in a variety of ways, including (a) measuring the incidence of severe, non-fatal injuries, (b) measuring the severity of injuries, (c) monitoring outcomes of severe injuries, (d) exploring the epidemiology of injuries, and (e) evaluating injury control efforts.

In this investigation, we have used Rhode Island data to examine selected indicators of data quality that affect the usefulness of hospital discharge data for measuring injury incidence and severity. In measuring injury incidence for purposes of surveillance and epidemiology, two major issues arise when using hospital discharge data. First, the initial injury event must be identified from potentially multiple hospital admissions and linked to a reference population. The complexities of this step have been addressed elsewhere (*6*). Second, the reporting of E-codes must be characterized for completeness and quality. The latter issue is one focus of this work.

In order to use hospital data to measure severity of injuries, the completeness and quality of the N-codes necesary to identify severe injuries must be characterized. The issue of severity is particularly relevant for those injuries where there is a high probability of permanent or lengthy impairment for the most severe injuries, such as head injuries, spinal cord injuries, and burns. These are also the types of injury for which registries have been proposed to monitor treatment and outcomes (*2*). The quality of the coded information on severity for these types of injury is the second focus of this work. It should be noted that specific coding in such areas is also necessary to compute injury severity scores (*7*).

Methods. Hospitals in Rhode Island began reporting discharge data voluntarily in 1968 for use in public health efforts. A majority of hospitals reported E-codes for many or all of the years they submitted data under the voluntary system. As of October 1, 1989, direct submission of hospital discharge data to the Rhode Island Department of Health was mandated, and E-codes were made a required data item in the reporting regulations. This study focuses on data from the 1988 fiscal year for hospitals in Rhode Island (October 1, 1987, through September 30, 1988), with retrospective data from calendar years 1979 through 1986, i.e., entirely from the period prior to regulations. Hospital practice has been to report E-codes along with N-codes in the data fields specified for additional diagnosis codes (up to six additional codes are provided for). E-codes may not be assigned as the principal diagnosis, and each E-code is supposed to be entered in the diagnosis field directly following the associated injury N-code(s). No exceptions are made to assigning E-codes for all injury discharges, including readmissions, transfers from and to other acute care facilities, complications, and late effects.

In the investigation of the completeness and quality of the reported E-codes, injuries have been defined according to the definition of "true" injuries developed previously (*6*). The definition comprises all N-codes in the Injury and Poisoning section of ICD-9-CM (800-999) excluding late effects codes (905-909), codes for complications of medical and surgical care (996-999), and selected subdivisions of the code for miscellaneous adverse effects (995). Primary attention has been given to discharges with a principal diagnosis of injury. Discharges with only an additional diagnosis of injury have been investigated briefly, primarily for purposes of description. For analysis, discharges with a principal diagnosis of injury have been grouped by nature of injury following the section headings in ICD-9-CM. The measure of quality employed for reported E-codes is the proportion of codes within a particular cause of injury heading (e.g., Accidental Falls (E880-E888)) that has been given a non-specific code (e.g., E887 "Fracture, cause unspecified" or E888 "Other and unspecified fall"). Other non-specific codes investigated include E819.9 "Motor vehicle traffic accident of unspecified nature", E899 "Accident caused by unspecified fire", E958.9 "Suicide and self-inflicted injury by unspecified means", and E968.9 "Assault by unspecified means".

In the investigation of the reporting of severe injuries, discharges with principal diagnoses of head injuries, spinal cord injuries, and burns have been examined. For each of these types of injuries, there is a range of possible N-code subdivisions available to indicate severity of injury. For head injuries, the severity measure is length of time unconscious; for spinal cord injuries, it is the nature of the spinal cord lesion; and for burns, it is the degree of burn. The measure of quality employed for reporting of severity is the proportion of codes within a particular type of injury range that falls in the N-code subdivision(s) for unspecified severity level.

Results. The reporting of E-codes has varied over time for hospital discharges in Rhode Island with a principal diagnosis of injury. (Figure 1) From a reporting rate of 73 percent in 1979, the rate fell gradually to 59 percent in 1984, then rose before falling to 55 percent in 1988. For discharges where the principal diagnosis was other than injury and one or more additional diagnoses was an injury, the rate of

FIGURE 1
PERCENTAGE OF INJURY DISCHARGES
(PRINCIPAL DIAGNOSIS)
WITH E-CODE RECORDED, RHODE ISLAND, 1979-1988

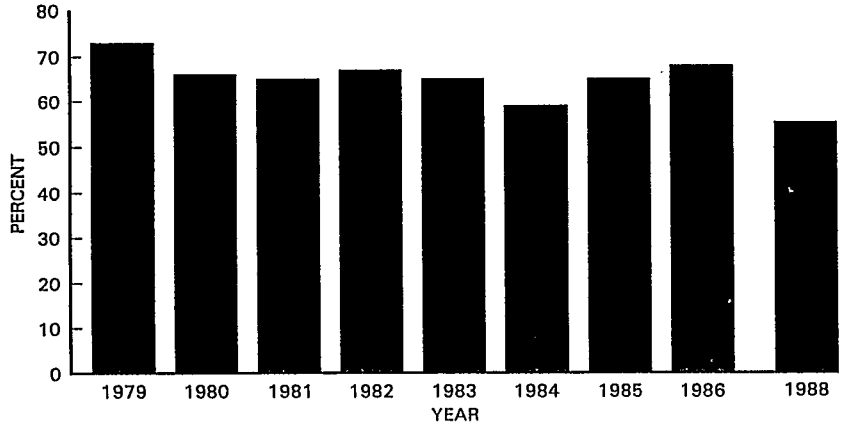


FIGURE 2
PERCENTAGE OF INJURY DISCHARGES
(ADDITIONAL DIAGNOSIS)
WITH E-CODE RECORDED, RHODE ISLAND, 1979-1988

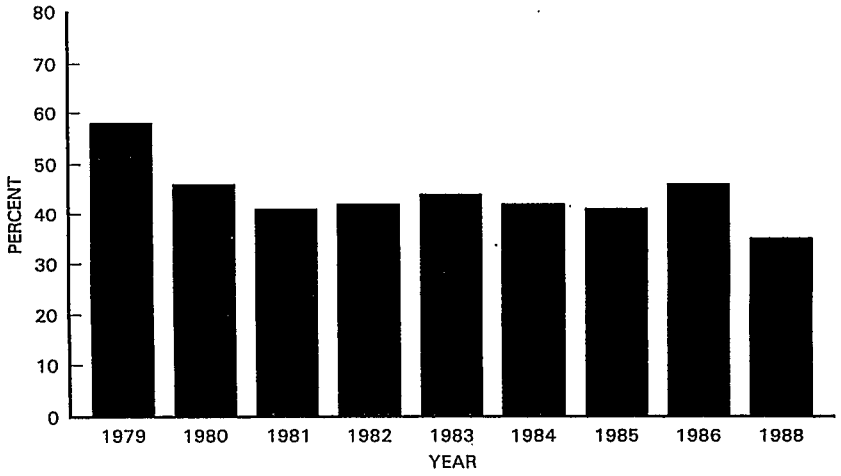
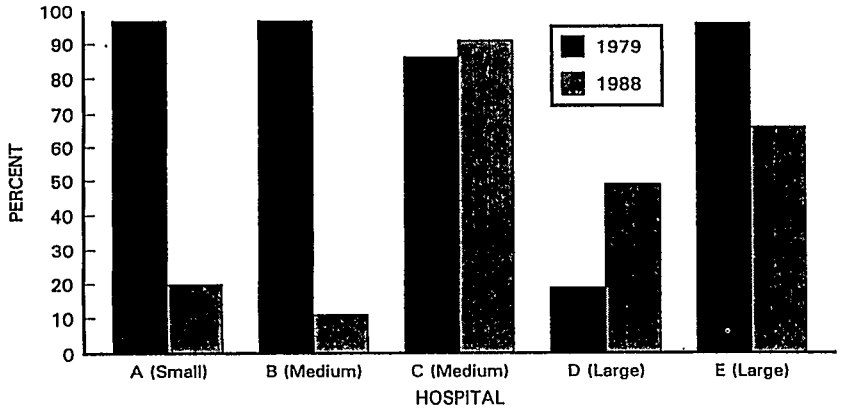


FIGURE 3
PERCENTAGE OF INJURY DISCHARGES
(PRINCIPAL DIAGNOSIS)
WITH E-CODE RECORDED, SELECTED HOSPITALS,
RHODE ISLAND, 1979 AND 1988



E-coding followed a similar pattern over time, but at levels of reporting that fall below the rates for principal diagnosis injuries by approximately 20 percentage points. (Figure 2) The principal diagnosis for those discharges where there was only an additional diagnosis of injury was examined for evidence that these cases exhibited patterns that would illuminate the difference in E-coding rate. No such pattern arose, as principal diagnoses from all sections of the ICD-9-CM except injuries were found. (Table 2)

Table 2: Distribution of Principal Diagnoses for Discharges with Additional Diagnosis of Injury, Rhode Island, 1988

Principal Diagnosis Group	Discharges
Diseases of Circulatory System	17%
Symptoms, Signs, Ill-defined Conditions	11%
Mental Disorders	11%
Diseases of Musculoskeletal System	10%
Diseases of Respiratory System	9%
Supplemental Classifications	8%
Other Categories	34%

E-coding rates for discharges with a principal diagnosis of injury were examined for individual hospitals for the period 1979 through 1988. The rate of E-coding varied widely among hospitals and over time for individual hospitals. (Figure 3) In 1988 rates for individual hospitals ranged from 2 percent to 91 percent. Despite the relative constancy of the statewide rate over time, the coding practices of individual hospitals have been changeable, with both increases and decreases in coding observed.

Different rates of E-coding were observed according to the nature of injury recorded as the principal diagnosis. (Figure 4) Highest rates were found for poisonings, followed by such relatively severe types of injuries as open wounds, intracranial injuries (excluding fractures), and burns. Relatively low rates of E-coding were found for less severe injuries, such as superficial injuries, dislocations, and effects of foreign bodies entering through orifices (e.g., choking). The high rate for poisonings is largely due to the organization of the ICD-9-CM codebook -- the E-codes for poisonings appear in the same table of drugs and other substances as the N-codes, whereas coding other external causes requires referral to a separate chapter with its own index.

The quality of the information represented by the reported E-codes was found to vary by cause of injury. (Figure 5) Over half of all falls, which represent a substantial proportion of injury discharges, were coded to one of two non-specific codes, E888 "Other and unspecified fall" or E887 "Fracture, cause unspecified". The proportion of motor vehicle injuries given non-specific codes is also a concern because of the large number of discharges represented. It should be noted that the E-codes for motor vehicle injuries require identification of the injured person (e.g., driver, passenger, motorcyclist, pedestrian) through a coding subdivision; codes that are non-specific in this dimension only are not included in the rates shown in Figure 5.

Codes necessary to identify the most severe injuries were found to be generally well-specified for burns but often vague for head and spinal cord injuries. Only two percent of N-codes for burns did not specify the degree of the burn as either first, second, or third degree. For the small number (24) of discharges with spinal cord injuries for which code subdivisions for severity (i.e., extent of spinal cord lesion) are allowed in ICD-9-CM, fully 75 percent lacked such information. Similarly, for discharges with a principal diagnosis of head injury (skull fracture or other intracranial injury), the state of consciousness was not specified in 43 percent of cases, another 16 percent of cases were coded as "concussion, not otherwise specified," and 7 percent were reported unconscious for an unspecified period of time.

Discussion. The use of hospital discharge data for injury surveillance and epidemiology is made complex by the lack of uniformity in reporting such key data elements as cause of injury and injury severity. These data elements are necessary for detailed studies of injury (*6,7*). In Rhode Island the reporting rates for E-codes have been found to vary with reporting period, position of the injury diagnosis, hospital, and type of injury. These results are interpreted to mean that injury discharges for which E-codes are reported are different in important respects from injury discharges lacking E-codes; therefore, the subset of E-coded discharges cannot be used to approximate all injury discharges. Furthermore, reported E-codes and N-codes have both been found to lack specificity in critical areas for injury applications. A previous study also found E-codes to be less well reported for the most severe injuries and for the elderly, in part because all available diag-

FIGURE 4
PROPORTION OF INJURY DISCHARGES
(PRINCIPAL DIAGNOSIS)
WITH E-CODE RECORDED, BY NATURE OF INJURY,
RHODE ISLAND, 1988

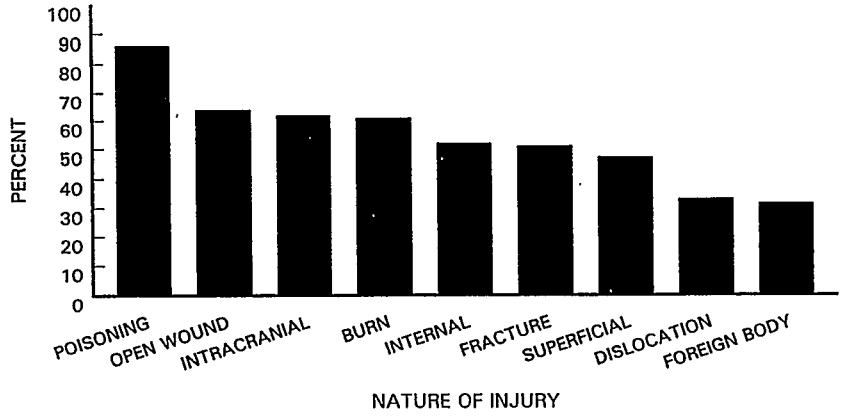
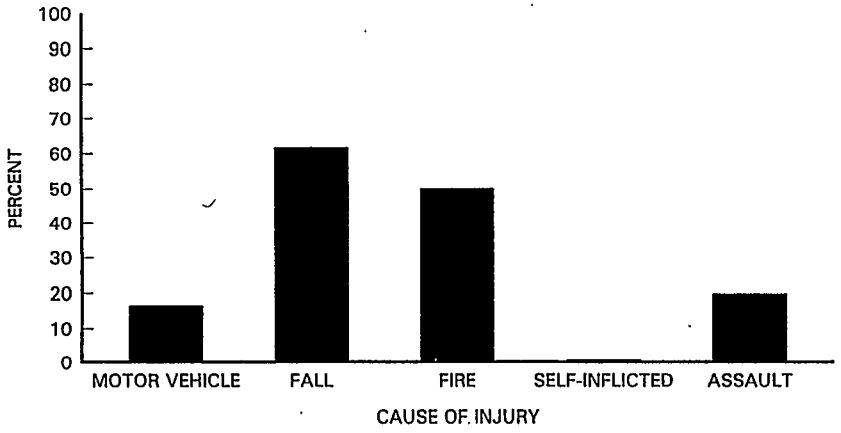


FIGURE 5
PERCENTAGE OF E-CODES LACKING SPECIFICITY
SELECTED CAUSES OF INJURY, RHODE ISLAND 1988



nosis fields on the discharge abstract were occupied by N-codes (*8*). These deviations from full, high-quality reporting require that users of these data document and make allowances for the reporting patterns within the database before using the information to support injury control programs.

In Rhode Island these problems are being addressed in several ways. As of October 1, 1989, the reporting of external cause of injury codes for all hospital discharges with any diagnosis of injury became mandatory. Rhode Island is one of five states that have taken this step to date (*4*). By itself, this action is expected to improve E-code reporting rates and with associated training and support may yield higher quality data as well.

Several efforts have also been initiated in the state to obtain further information about problems in the data and their causes. Among these are (a) further descriptive analysis of hospital discharge data, both pre- and post-regulation, (b) selective reabstracting of records to distinguish coding problems from deficiencies in underlying documentation, (c) linkage of hospital discharge records for in-hospital deaths to medical examiner reports to verify information on intent to injure, (d) identification of structural barriers to good documentation within hospitals, and (e) performance of a cost study of E-coding to identify financial barriers. This additional information will be critical for addressing the problems with appropriate interventions and to evaluating their success in supporting injury control efforts in the state.

Progress is also being made at the national level. One action already taken is the recent recommendation (*4*) by the National Committee on Vital and Health Statistics that the external cause of injury be added to the Uniform Hospital Discharge Data Set (UHDDS), which is the model for data collection in this country. With the adoption of a national recommendation should come the development of standardized definitions and instructions for collecting and coding external cause of injury and support for training those who collect and use these data for injury control efforts.

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SMALL AREA INJURY SURVEILLANCE: DECISIONS USING MORTALITY DATA-- THE BALTIMORE COUNTY INJURY SURVEILLANCE SYSTEM

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(Not available for publication)

POLICE PROTECTION AND THE INPATIENT COSTS OF TREATING VICTIMS OF VIOLENT CRIME IN MASSACHUSETTS

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John A. Rizzo

1) INTRODUCTION

Providing inpatient treatment for increasing numbers of violent crime victims may result in serious financial difficulties for hospitals. Severely injured victims often require expensive, high-technology care. Unfortunately, many cannot afford to pay for their treatment because they have no insurance. Rising levels of uncompensated care have led some hospitals to refuse treatment for these patients.[1]

Various solutions to these financial problems have been proposed. For example, ability to pay could be facilitated by creating risk pools among area hospitals. More active interventions, however, would attack the problem at its source by promoting programs designed to reduce violent crime. One example is to deter criminal activity by increasing police protection. If police prevent criminal behavior, they may also influence the total costs of treating victims of crime in the hospital. This paper provides some descriptive information about levels of violent crime and hospitalized victims of such crimes. It then discusses the effects of police protection on criminal activity and its associated hospital charges.

The rest of this paper is divided into four parts. Section 2 provides background information and a critique of the deterrence literature. Section 3 defines variables and data sources and specifies the empirical models of deterrence activities. Section 4 provides descriptive information on hospitalized victims of violent crime and presents the empirical results of tests of the deterrence hypotheses. Section 5 offers a brief discussion.

2) BACKGROUND AND LITERATURE REVIEW

Understanding the effectiveness of interventions to deter violent crime has been a traditional topic in law and economics and public finance. This topic is also a prominent issue of public health. A recent forum on violence and public health was sponsored by the Centers for Disease Control and the Minority Health Professions Foundation.[2] The 110 participants at this forum met to reach two objectives. The first was to "summarize what is known about violence prevention so that this information can be applied immediately by minority communities" (p. 227). The second objective was to "determine priorities for the evaluation of violence prevention programs so that future research can be appropriately targeted" (p. 227).

In this section, we proceed along these lines by offering a brief summary and critique of the methods used in the economic literature to study the affects of law enforcement on crime. The rest of the paper evaluates police protection as a deterrent of violent crime and its associated inpatient hospital charges.

Previous Research

Most empirical work on the deterrent effect of law enforcement uses cross-sectional data. Typically, levels of police or police expenditures are related to contemporaneous levels of crime.[3] Early studies used ordinary least squares (OLS) to investigate these relationships. Unfortunately, OLS gives rise to potential simultaneity bias. For instance, high levels of crime may lead to increases in expenditures for police protection. In such models, therefore, inferring the direction of causation is quite difficult.

Recognizing this problem, some researchers have employed two-stage or simultaneous equations methods. Efforts to deter crime, such as investment in police protection, are treated as endogenous. While this approach is conceptually superior to OLS, it also has problems. In particular, such models have been criticized because there is often little justification for the methods used to identify the deterrence equations.[4]

Partly due to identification problems, there is no consensus about whether efforts to deter crime are effective.[5-7] Fisher and Nagin[4] state that analyses using aggregate non-experimental data "must also have a time-series component," and the "estimation must account for the possibility of serial correlation in the stochastic components of the empirical specification" (pp. 396-397).

Our empirical analyses follow the suggestions of Fisher and Nagin. We employ pooled cross-section and time-series data to estimate dynamic models of criminal deterrence. A similar estimation approach was used recently in another area where simultaneous equation approaches have often failed--assessing the effects of unionization on earnings or employment.[8]

3) DATA SOURCES, VARIABLES, AND ESTIMATION

Data Sources

To test the deterrent effects of police protection, we use information on violent crime and local police forces provided by the Federal Bureau of

Investigation (FBI). Variables measuring the inpatient charges for treating violent crime victims and the characteristics of these patients are developed from patient discharge abstracts maintained by the State Hospital Data Project (SHDP) of the Agency for Health Care Policy and Research. SHDP data from Massachusetts are used for this study.[9] Local area characteristics are measured with data provided by the Bureau of Health Professions' Area Resource File (ARF).

All variables except those from the ARF are measured for 105 cities or towns in Massachusetts with populations of 10,000 or more. The ARF variables are county-level aggregates which are used when comparable information at the town or city level is not available. The period of the analysis is 1982-1986.

Variables

We estimate two multiple regression equations at the city or town level. These equations test the hypotheses that police protection deters violent crime and reduces the growth in hospital charges for treating crime victims. The first equation (1) relates annual changes in violent crime ($VC_t - VC_{t-1}$) in a city or town to the pre-determined levels of several variables. These variables are the number of violent crimes in the locale (VC_{t-1}), the interaction between crime levels and police protection ($PolVC_{t-1}$) in the locale, and several control variables ($\mathbf{X}_{i,t-1}$).

$$(1)\quad VC_t - VC_{t-1} = a_0 + a_1 VC_{t-1} + a_2 PolVC_{t-1} + a_i \mathbf{X}_{i,t-1} + e$$

The predetermined level of crime is a proxy variable for the supply of criminals. It adjusts for positive relationships between crime levels and the size of the police force. Thus it mitigates reverse causation effects.

The interaction term allows us to test the deterrence hypothesis. If police protection deters violent crime, the coefficient of this term (a_2) will be negative and statistically significant.

In equation (1), $\mathbf{X}_{i,t-1}$ denotes a set of controls for other factors influencing changes in crime. The first control factor measures nonviolent criminal activity. The total annual number of nonviolent crimes in the city or town is included to control for substitutability between violent and nonviolent crime. As police protection increases, potentially violent criminals may revert to nonviolent crimes. Such crimes may be more difficult to solve and are less likely to result in lengthy jail terms.

The second control factor is an index of the relative arrest rate among cities and towns. This index is measured as the annual arrest rate for violent crimes in a locale divided by the annual arrest rate for such crimes in all locales. It is a measure of the relative efficiency of police. We expect this index to have a negative effect on changes in violent crime.

Socioeconomic characteristics may also influence changes in crime levels. Our prior expectation is that crime will grow more slowly in areas where population characteristics indicate favorable economic status.[10,11] Economic status tends to be better in areas characterized by higher median levels of education and per capita income, and by a higher proportion of the population in white-collar jobs. Economic status tends to be less favorable in areas with higher percentages of blacks, those below the poverty level, and the unemployed.

We also include total population in the city or town, to adjust for differences in scale. The annual change in population is included because the growth in criminals should be directly related to the growth in the population. Finally, a variable indicating the year is included to measure any time-specific effects on violent crime patterns.

Equation (2) was estimated to assess the effects of police protection on aggregate annual changes in hospital charges ($Ch_t - Ch_{t-1}$) for discharges with injuries resulting from violent crime. These injuries were identified by ICD-9-CM E-codes 960 - 969 on discharge abstracts.

$$(2)\quad Ch_t - Ch_{t-1} = b_0 + b_1 Ch_{t-1} + b_2 PolCh_{t-1} + b_i \mathbf{Y}_{i,t-1} + e$$

For equation (2), we use the same pre-determined explanatory variables, with a few substitutions and additions. In place of the total number of violent crimes, we substitute total inpatient hospital charges incurred by discharges from a given city or town who were treated for injuries from violent crime (Ch_{t-1}). These charges are also interacted with the size of the police force ($PolCh_{t-1}$). If the coefficient of this interaction term (b_2) is negative and statistically significant, police protection deters growth in aggregate inpatient charges for victims of violent crime.

In addition to the control variables used in the violent crime equation, the hospital charge equation also controls for characteristics of these victims and various attributes of their treatment. All of these control variables are represented by $\mathbf{Y}_{i,t-1}$ in equation (2).

To control for changes in case mix and severity of illness that may affect changes in hospital charges, we include six variables. These are the percentages of violent crime patients who are over age 65, male and uninsured, the average number of surgical procedures per patient, the percentage of patients admitted from the emergency room, and the percentage of

patients treated in intensive care units in each year. These characteristics may be associated with more severe and more costly violent crime injuries. Thus, with the exception of the insurance variable, differences over time in patients with these attributes should have a positive influence on total inpatient charges.

While those who are uninsured may have more costly medical problems, hospitals do not always bill these patients. The costs of their treatment will therefore be understated. Thus the sign of the insurance variable is ambiguous.

The annual percentages of patients treated in large hospitals (e.g. ≥ 300 beds) and at facilities belonging to the Council on Teaching Hospitals are also included. Charges tend to be higher in these types of facilities.[12]

Estimation

Analysis of variance is used to investigate trends in violent crime and in the inpatient charges for those treated for violent crime-related injuries. Student's t-tests are used to weigh differences in the characteristics of discharges treated for injuries resulting from violent crime.

The two deterrence equations are estimated with panel data from 105 cities and towns in Massachusetts, over the 5 year period. Because we are pooling observations from cross-sectional units over time, multiple regression error terms for adjacent cross-sectional units and years may be correlated. This would be likely if efforts to deter crime in some areas drive criminals to other areas where enforcement is more lax. Failure to adjust for these possibilities could lead to an overestimate of the true deterrent effect of police protection. To control for these problems, we estimate a model suggested by Kmenta which corrects for timewise autoregressive and cross-sectionally correlated regression errors.[13,14]

3) RESULTS

The average annual number of violent crimes in the cities and towns in our sample was 318.6. The average increase over time in crime levels was a rather modest 21.2. Analysis of variance indicated that, by itself, the year of the analysis did not account for this growth in crime ($p>0.05$).

Aggregate inpatient charges for discharges with violent crime-related injuries grew substantially over time in Massachusetts cities and towns. In nominal dollars, the mean aggregate charge in 1983 was $26,293.59, compared to $42,038.87 in 1985. Overall the growth in charges was volatile; the coefficient of variation for the aggregate hospital charge variable was 501.9. However, the analysis of variance showed that, by itself, the year of the analysis did not explain a significant amount of this variation ($p>0.05$).

Table 1 shows the characteristics of discharges treated for violent crime-related injuries in Massachusetts hospitals in 1982-86. Most discharges were male and white, but non-whites were represented disproportionately with respect to their population in the community. Males and non-whites had significantly higher charges for inpatient care, compared to females and whites. Nearly 48% of the discharges were uninsured. Inpatient charges for the uninsured were significantly higher than for those with insurance coverage. Most discharges were admitted through the emergency room and were treated in hospitals with more than 300 beds. Hospital charges did not differ between those admitted through the emergency room and other sources. Charges were significantly higher for those treated in larger hospitals. Contrary to other studies,[12] charges were significantly lower for those treated in teaching facilities.

Police Protection and Violent Crime

Is it reasonable to expect increases in police protection to affect changes in crime over time? To answer this question, we turn to our first test of the deterrence hypothesis.

The first column of numbers in Table 2 presents the model estimates for the violent crime equation. The estimated coefficients for violent crime and its interaction with police protection have the expected signs and are statistically significant. These results indicate that, in areas having similar preexisting levels of violent crime, more police protection will significantly reduce the growth in violent crime.

The *magnitude* of this relationship is quite small, however. In fact, for a city or town with the average amount of violent crime in our sample, 50 additional police officers would be required to reduce the number of violent crimes by one.[15]

As expected, areas where nonviolent crime levels are high show significantly lower growth in violent crimes. However, this effect is also quite small.

Surprisingly, the unemployment rate shows a negative and significant effect on growth in violent crime. Perhaps people leave areas of low employment for more economically attractive areas, and this migration effect is being picked up by the unemployment variable.

The yearly change in the population of the city or town has a positive and highly significant effect on violent crime. One interpretation is that in areas where the total population is growing, the criminal population is

Table 1. Characteristics of discharges hospitalized for injuries related to violent crime, and mean inpatient charges.*

Characterstic	Number	Percent of Discharges	Mean Charge ($)	T-test p-value**
Male	4330	81.6	5985.48	< 0.01
Female	977	18.4	4694.53	
White	2035	57.5	4175.80	< 0.01
Nonwhite	1506	42.5	6788.55	
Insured	2749	52.4	5445.90	< 0.05
Uninsured***	2490	47.6	6138.36	
Admitted through emergency room	3041	57.2	5517.97	> 0.05
Admitted from other source	2269	42.8	6056.84	
Treated in large hospital	4238	80.4	6544.63	< 0.01
Treated in small hospital	1036	19.6	2622.74	
Treated in teaching hospital	2112	39.9	4415.49	< 0.01
Treated in non-teaching hospital	3181	60.1	6648.71	

* Observations with missing values are deleted.
** Student's t-test for differences in hospital charges.
*** Expected primary payor is "self-pay" or "no charge."

growing as well, so that violent crime rises. None of the other explanatory variables have a significant effect on changes in violent crime.

Police Protection and Inpatient Charges

Table 2 also provides the results for the hospital charge equation. As in the crime equation, police protection has a deterrent effect. As for changes in violent crime, however, the size of the deterrent effect is very small. For a city or town with the average inpatient charges for violent crime victims, adding an additional police officer would lower aggregate charges by only about $15.[16]

The number of non-violent crimes in the city or town is associated with an increase in the growth in inpatient charges. This is unexpected, especially in light of the significant *negative* effect it had on changes in crime levels. Apparently, when non-violent crimes rises, fewer but more serious and therefore more costly violent crimes are committed.

Other results show changes in hospital charges to be decreasing where median educational levels and per capita incomes are high, but increasing in areas where there is a high percentage of white collar workers. The explanation for this puzzling pattern is uncertain. One possibility is that white collar workers may be concentrated in metropolitan areas where violent crime may still be prevalent.

As expected, the yearly change in the population of the city or town is positively related to changes in hospital charges. As population grows, so may violent crime and its associated hospital charges.

The aggregated characteristics of hospitalized violent crime victims bear little relation to changes in inpatient charges. Admission source, however, appears to have some effect. In particular, the growth in charges is less when violent crime victims are admitted from the emergency room. Personnel in emergency units may have developed more expertise in treating violent crime victims, and could simply be more efficient in providing care to this group.

4) DISCUSSION

We provided descriptive information about annual crime levels, hospitalized victims of violent crime, and trends in the charges for their inpatient care. We also estimated dynamic models of violent crime deterrence, to see if increases in police protection would have any effect on crime levels and changes in inpatient charges. Our results confirm that police deter the growth in violent crime and reduce the growth in aggregate hospital charges for treating victims of such

Table 2. Regression Results.*

Independent Variable	Estimated Effect on Annual Change in Violent Crime	Estimated Effect on Annual Change in Hospital Charges
Crime, Charge, and Police Variables		
Number of violent crimes in city/town	0.31***	----------
Interaction of police force size and number of violent crimes in city/town	-0.00007***	----------
Total hospital charges for victims of violent crime in city/town	----------	-0.30**
Interaction of police force size and total hospital charges	----------	-0.0005***
Number of nonviolent crimes in city/town	-0.03***	13.01***
Index of relative arrest rate in city/town	-29.23	18700.10
Area Characteristics		
Median educational level in county (years)	19.23	-253487.06***
Median county income ($)	-0.02	-35.82***
Percent unemployed in county	-27.14**	-3940.86
Percent of county residents who are black	-2.40	-5904.24
Percent of county residents living below poverty level	-3.31	10232.99
Percent of county residents with white collar jobs	2.07	22494.25***
Yearly change in population of city/town	0.20***	110.40***
Population in city or town	-0.0003	0.73
Time Trend		
Year	-1.22	30507.09**
Characteristics of Hospitalized Violent Crime Victims in City/Town		
Average number of surgical procedures	---------	53.68
% ≥ 65 years old	---------	673.46
% admitted through emergency room	---------	-445.53**
% treated in intensive care units	---------	-185.61
% male	---------	-6.80
% uninsured	---------	-1.22
% treated in hospitals belonging to Council on Teaching Hospitals	---------	-494.55
% treated in large hospitals	---------	272.89
Number of observations	420	420
Adjusted R-square	0.76	0.65

*Differences in the magnitudes of the coefficients in the two equations are striking. These differences remain in unweighted analyses and in estimates derived from an error components model.
**Statistically significant at the 5 percent level, two-tailed test.
***Statistically significant at the 1 percent level, two-tailed test.

crimes. However, the magnitudes of these effects were very small.

While these results are suggestive, national estimates of the deterrent effect of police would provide a sense of how generalizable our results are. It would be also useful to examine how police deter specific types of violent crimes.

The most urgent work to be done, however, concerns *why* the deterrent effects of police protection are so small. Our estimation approach mitigates reverse causation effects present in much of the earlier work in this area. However, several other factors may be important.

First, the crime data we rely on are based on reports to police departments. While this is the best available cross-section and time-series data for studying the deterrent effects of law enforcement, there is evidence that such data understate the true incidence of crime and the deterrent effect of police work.[10,17]

Second, some hospitals do not report the ICD-9-CM E-codes used to determine patients with injuries resulting from violent crime. Thus, we probably underestimated the number of violent crime victims treated in the hospital, as well as their associated inpatient charges. This measurement error may result in an underestimate of the deterrent effects.[13]

Third, people who commit violent crimes are often viewed as mentally ill.[18] Such individuals may be less responsive to factors like increased police protection, which would create strong incentives to refrain from criminal activities among more rational people. However, several studies have found little difference in the incidence of mental illness between criminals and the general population.[18]

Fourth, even in Massachusetts, where a gun control law exists, the ready availability of hand guns may account for the meager success police may have in controlling violent crime. Formal empirical research in this area is limited.[19] Nevertheless, some evidence suggests the availability of weapons instigates violent behavior[20] and increases the severity and lethality of such behavior.[21,22]

Hopefully, the present study will promote further research into the deterrence hypotheses. At present and at least in Massachusetts, it does not seem realistic to expect increases in police protection to have much effect on the growth of violent crime or the inpatient costs of treating victims of violent crime in the hospital.

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3) Some studies used clearance rates (the ratio of arrests to crimes committed) instead of police variables.

4) Typically, the crime equation is identified by excluding socioeconomic variables that are included in the remaining equations in the model. However, as Fisher and Nagin note, it makes little sense to assume these variables have no effect on crime rates. For a more complete discussion, see: Fisher F and Nagin D, On the feasibility of identifying the crime function in a simultaneous model of crime rates and sanction levels. In Blumstein A, Cohen J, and Nagin D (eds.), Deterrence and Incapacitation: Estimating the Effects of Criminal Sanctions on Crime Rates. Washington, DC: National Academy of Sciences, 1978.

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14) In fact, the crime equation corrects for timewise autoregressive and heteroscedastic errors. The hospital charge equation corrects only for the latter, because a Durbin-Watson test indicated no first-order autoregression in that equation.

15) This result was obtained by differentiating the crime equation with respect to police protection and evaluating this derivative at the mean level of violent crime (318.6).

16) This result was obtained by differentiating the hospital cost equation with respect to police protection and evaluating this derivative at the mean level of aggregate hospital costs ($69,894).

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ECONOMIC RISK FACTORS FOR INFANT HOMICIDE

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Introduction

Homicide is a major cause of the difference in the life expectancy of black and white Americans. In 1980, homicide accounted for approximately one-fifth of the difference between the life expectancies of black and white males (1.3 years out of 6.6 years; Keith and Smith 1988: Table 2). Blacks are only 12% of the U.S. population, but they suffer 50% of the homicide mortality (National Center for Health Statistics 1989a).

Racial disparities in socioeconomic status are often used to explain the excess homicide mortality among blacks (see, e.g., Hawkins 1983; Wilson 1987; Palley and Robinson 1988). Surprisingly, however, no research has examined the simultaneous effects of socioeconomic status and race on homicide using individual-level data.

All existing studies of the independent contributions of race and socioeconomic status to homicide are based on areal units, such as states, metropolitan areas, or census tracts. A few examples include Parker and Smith (1979), Messner (1982), Centerwall (1984) and Loftin and Parker (1985). There are many inconsistencies in the findings, but this research generally suggests that socioeconomic factors do account for much of the difference between the races.

Whatever their support for the socioeconomic explanation, interpretations of the existing studies are complicated by the problem of aggregation bias. Aggregate data confound the impact of individual-level attributes with the effects of living in certain types of communities. The relationship obtained at the aggregate-level may therefore be very different from that observed among individuals (Langbein and Lichtman 1978). A more confident conclusion that socioeconomic status accounts for the racial differences in homicide would require the use of data collected at the individual level.

In this study we use national individual-level data to estimate the effects of race and socioeconomic status on the risk of infant homicide. The findings cover a specialized portion of the homicide spectrum, and it may not be possible to generalize them to other age groups or other types of assaultive violence. Nevertheless, the analysis suggests an interesting and complex relationship between socioeconomic status and race. At low levels of socioeconomic status there are large differences between the homicide rates of black and white infants. At high levels of socioeconomic status the two rates substantially converge.

Methods

Infant homicides classified by mother's race and education were obtained from the national linked birth and infant death data sets distributed by the National Center for Health Statistics (NCHS). These data include all linkable birth and death records for infants who were born in 1983, 1984 or 1985 and who died before reaching one year of age (NCHS 1989b, 1989c, 1990a). Birth records were located for 98% of the infant death records (98.4% in 1983, 97.8% in 1984, and 98.1% in 1985). Excluded were deaths that occurred outside the U.S. to U.S.-born infants; deaths that occurred in the U.S. to foreign-born infants; and births and deaths that occurred outside the U.S. to U.S. residents (NCHS 1990b).

Socioeconomic status was measured by the years of education completed by the mother. Education is generally regarded as among the best single indicators of social status, and it is highly correlated with alternative measures (see, e.g., Liberatos, Link and Kelsey 1988). Despite that, other possible indicators--principally, income and occupational prestige--make independent contributions to socioeconomic well-being (Campbell and Parker 1983). If additional indicators were available, the use of multiple measures would clearly be a more desirable strategy.

Homicide was defined according to the International Classification of Diseases (9th revision) as external causes 960-969. Of the 117,188 linked birth/death records, 581 were homicides (182 in 1983, 200 in 1984, and 199 in 1985). All 581 homicide victims could be classified by race, but only 417 could be classified by mother's educational attainment. Most of the missing data (141 cases) are accounted for by three states that did not record maternal education: California (66 cases), Texas (64 cases) and Washington (11 cases). The other 23 cases were scattered across the remaining states and the District of Columbia, with no more than 2 in any jurisdiction.

Processing the millions of records in the natality (denominator) files requires a daunting amount of computational time. To avoid this problem, we obtained total births by race and mother's education from a table in the *Vital Statistics of the United States* (NCHS 1987: 179, 1988a: 179, 1988b: 179). The categories used in the analysis of education are dictated by this table (in years): 0-8, 9-11, 12, 12-15, 16 or more, and "not stated." With regard to race, we focus only on whites and blacks because there were too few persons of other races to analyze separately. They are included, however, in analyses of "all races."

Results

Infant Homicides

First, before presenting the results of the linked birth/death data, it will be useful to put the infant homicides in the context of a larger set of age-specific homicide rates. A surprising feature of the distribution

(see Table 1) is that homicide mortality is higher in the first year of life than at any other pre-adolescent age. For blacks, the excess of infant homicides over rates in other pre-adolescent age groups is about 10 per 100,000; for whites it is about 4 per 100,000 (Table 1).

At most ages, males have higher rates of homicide mortality than do females. In the peak age group (25-34), the rate for white males exceeds that for white females by 8.6 homicides per 100,000 persons; for blacks the difference is 76.5 homicides per 100,000 persons. The pre-adolescent years (including infants) are an exception to this pattern, and here the excess of male deaths is extremely small for both races (Table 1).

Table 1. Homicide Mortality Rates (per 100,000) by Age, Race, and Gender: United States, 1987

Race	Age Group	Male	Female	Difference
White	Under 1	6.0	4.2	1.8
	1-4	1.8	1.5	0.3
	5-14	0.8	0.8	0.0
	15-24	11.2	3.9	7.3
	25-34	13.2	4.6	8.6
	35-44	10.2	3.5	6.7
	45-54	8.3	2.7	5.6
	55-64	6.3	1.9	4.4
	65-74	4.2	2.4	1.8
	75-84	4.9	3.1	1.8
	85+	5.4	3.8	1.6
Black	Under 1	19.4	18.7	0.7
	1-4	4.8	7.2	-2.4
	5-14	4.3	2.0	2.3
	15-24	85.6	17.7	67.9
	25-34	98.9	22.4	76.5
	35-44	78.4	14.4	64.0
	45-54	46.0	10.5	35.5
	55-64	32.8	7.6	25.2
	65-74	28.0	6.9	21.1
	75-84	29.5	10.4	19.1
	85+	29.0	10.5	18.5

Source: National Center for Health Statistics 1990c: 139 (Table 33).

The higher risk for blacks is evident in all the age and gender categories in Table 1. For male infants, the black rate exceeds the white rate by more than 13 homicides per 100,000 infants; for females the difference is more than 14 homicides per 100,000 infants.

Some information about offenders can be obtained from the Federal Bureau of Investigation's Uniform Crime Reporting system. Ignoring age, family members and close friends are responsible for about a third of homicides where the relationship between the victim and offender can be determined (U.S. Department of Justice 1989). Among young children, however, the proportion is much greater. Jason, Gilliland and Tyler (1983) report that between 1976 and 1979 the offender was a family member in about 80% of infant homicides with a known victim-offender relationship (our calculations from Table 1 in Jason et al.).

Race and Mother's Education

The infant homicide rates by race and mother's education for the three birth cohorts are presented in Table 2. Before pursuing these results, it should be emphasized that about 5% of the cases fall into the "not stated" category of education. These missing observations are in addition to the ones lost because Texas, California, and Washington do not record the educational attainment of mothers. It is likely that the pattern of missing data is not random, and this should be considered in interpreting the results.

Table 2. Infant Homicides Per 100,000 Live Births by Race and Years of Maternal Education: 47 States and the District of Columbia, 1983-1985[1]

Maternal Educational Attainment	All Races[2]	Whites	Blacks
0-8 years	8.98 (28)[3]	6.30 (14)	21.05 (14)
9-11 years	11.33 (167)	7.03 (70)	21.40 (92)
12 years	4.24 (154)	3.11 (90)	9.70 (62)
13-15 years	2.74 (46)	2.04 (28)	6.27 (16)
16 or more years	1.59 (22)	1.47 (18)	3.83 (4)
Not stated	18.25 (23)	12.55 (12)	36.37 (8)

[1] California, Texas and Washington did not report maternal educational attainment.

[2] Includes races other than blacks and whites.

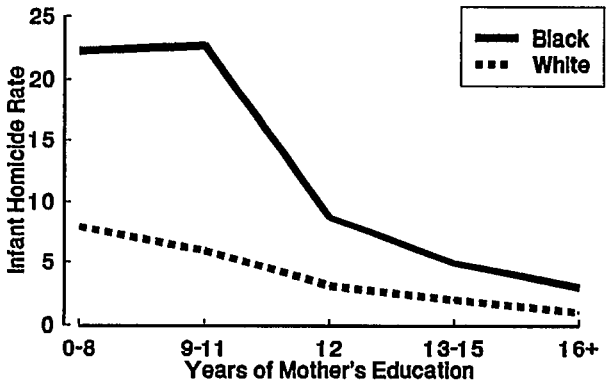
[3] Values in parentheses are the recorded number of infant homicides.

Among the cases with information on all variables, there is a pattern of declining risk of homicide with increases in mother's education (Table 2). Disregarding race, the homicide rate for infants of mothers with a twelfth-grade education is less than half the rate for infants of mothers at lower educational levels. In turn, infants of mothers with the equivalent of a college degree have less than half the risk of infants

whose mothers completed the twelfth grade. Clearly, mother's education is strongly related to infant homicide. The relative difference in infant homicides between the extreme categories of education is also larger than the relative difference between the races. The ratio of black-to-white infant homicide rates is 3.73 (19.06/5.11; our calculations from NCHS 1989a: 32-33 and NCHS 1990c: 91). In contrast, the ratio of infant homicide rates for 0-8 and 16 or more years of mother's education is 5.04 (8.32/1.65; our calculations from Table 2 and NCHS 1987: 179, 1988a: 197, 1988b: 179). At the extremes, mother's education appears to have more influence on infant homicide than does race.

More important for our purposes, there is an interaction between race and mother's education, i.e., mother's education modifies the effect of race and vice versa (Figure 1). At the lowest levels of education the difference between the black and white rates is about 14 homicides per 100,000. The difference narrows as mother's education increases. It is 6.6 for high school graduates; 4.2 for those with some college, and only 2.4 for those in the highest education category. Among infants whose mothers obtained little education, race is strongly related to homicide risk. At the highest levels of educational attainment, the racial differences are essentially trivial.

Figure 1. Infant Homicides Per 100,000 Live Births by Race and Years of Mother's Education: United States, 1983-1985.



We have not attempted to assess the statistical significance of these differences. Uncertainty about the effects does not derive primarily from sampling variability. Differential ascertainment of homicide and the measurement of economic status are much more important concerns.

Infant homicides are under-reported due to the difficulty of discovery and an unwillingness to consider homicide as a diagnosis (Jason, Carpenter and Tyler 1983). Some researchers believe that race and socioeconomic status are among the factors that may influence the scrutiny of medical authorities. Further, as noted earlier, maternal education is only one possible measure of socioeconomic status, and it is not recorded for all cases.

Despite these limitations, the data suggest that the racial disparity in homicide declines as socioeconomic status increases. The magnitude of the education effect is large and indicates that, in the absence of low socioeconomic status, black and white infants experience little difference in homicide risk.

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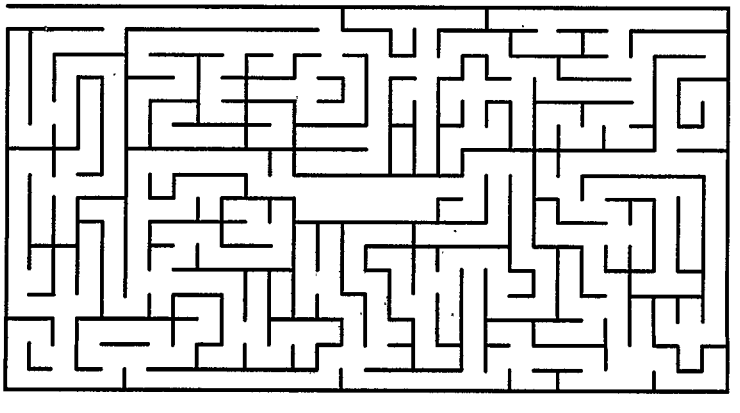
Session 0

Substance Abuse in the Community



DEVELOPMENT OF A DATA BASE TO MONITOR SUBSTANCE ABUSE TRENDS IN TEXAS

J. Kavinsky, M.A., Texas Commission on Alcohol and Drug Abuse

PRECIS

The Texas Commission on Alcohol and Drug Abuse (TCADA) relies on data from a variety of sources to determine the extent and nature of substance use and related behavior in the state of Texas. Following is a brief description of the ways in which the data collected are used, and a summary of findings from the latest available data sources.

DATA USES

Substance Abuse Trends in Texas are analyzed using longitudinal data compiled from a variety of state and local sources including data drawn from publicly-funded treatment programs, surveys conducted by TCADA, death records, consumption data, and federal, state and local law enforcement information. This series has been compiled annually since 1985.

The Treatment Process is evaluated by analyzing clinical data for approximately 40,000 clients admitted annually to treatment programs for adults and youth funded through TCADA. Client characteristics, substance use patterns and problems, services received, and improvement at follow-up are analyzed.

Treatment Effectiveness is being ascertained in a new multi-year project. Plans include detailed, long-term followup on 600 individuals admitted to treatment. Assessment and followup instruments are also being studied for possible widespread use by treatment and prevention programs in the state.

Estimates of Needs for Services are derived from the data resources described above and from population surveys.

DWI Recidivism is being studied in a long-term research program that will compile state level sources of information on DWI and DWI recidivism in order to identify efficient and cost-effective DWI recidivism countermeasures.

OVERVIEW OF TEXAS

The population of Texas is distributed among 28 metropolitan statistical areas and 254 counties. The ethnic/racial composition is 67 percent White, 21 percent Hispanic, and 12 percent Black. The border with Mexico, which stretches 889 miles along the Rio Grande River, and the coastline of the Gulf of Mexico, which runs 367 miles, provides a vast potential for clandestine transportation of illicit substances into Texas. TCADA estimates that in 1991 there were 1,004,000 Texas adults and 138,000 Texas youth who were chemically dependent and in need of treatment.

TCADA DATA SOURCES

1. CODAP

Background

The original version of CODAP (Client-Oriented Data Acquisition Process) was developed by the National Institute on Drug Abuse in 1973 as a required reporting system for all drug treatment programs receiving federal funds. This system was originally used by the state's drug abuse agency, and in 1983 the alcohol agency also began using CODAP to collect data on its clients.

In 1986, after the Texas Commission on Alcohol and the Texas Department of Community Affairs/Drug Abuse Prevention Division merged to form TCADA, the original CODAP forms were revised. Two forms, an adult version

FIG A PERCENT OF CLIENTS ADMITTED TO TREATMENT BY PRIMARY SUBSTANCES 1ST QUARTER 1974-1ST QUARTER 1991 (ALCOHOL CLIENTS WERE NOT ADDED TO CODAP UNTIL 1983)

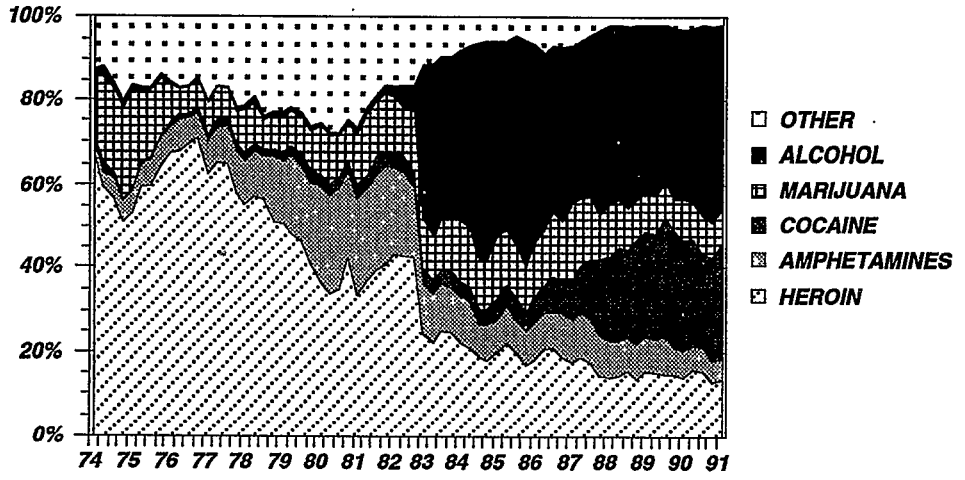
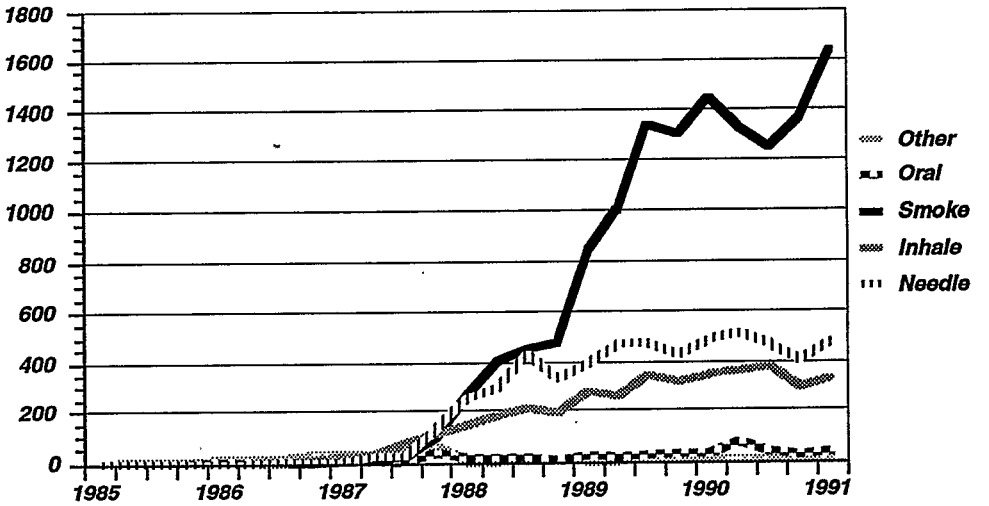


FIG B ROUTE OF ADMINISTRATION OF COCAINE
BY CLIENTS ADMITTED TO TREATMENT
4TH QUARTER 1984 - 1ST QUARTER 1991



and a youth version, were created. Both continued to report all the data contained on the original form, but the adult version added questions about physical and social problems so the extent of alcohol abuse could more accurately be measured. The youth CODAP form asked questions about the child's family, school performance, and peer groups. Other than these adjustments for alcohol clients and for youth, the CODAP form has remained the same since 1973, and the data has remained longitudinally comparable.

Unlike federal CODAP, which looked at client characteristics at discharge, the Texas system contacts the client for a followup sixty days after release. TCADA then measures followup information including employment at followup, percent unemployed at admission who gained employment since release, percent arrested before admission not arrested at followup, percent not impaired at followup, percent improved physical problems, percent improved social problems, and percent abstinent at followup. Looking at these outcome measures by various parameters gives information about which treatment modality has the best outcome rates, which substance of abuse seems to cause the most relapse, how clients who were referred from the criminal justice system compare to clients who entered on their own, and many other areas of analysis.

Using the federal grant for the "new" CODAP, the Client Data System, TCADA will rewrite the CODAP software to allow an automatic merger of CODAP with client billing data. By having data on client characteristics, treatment outcomes, services provided, and cost easily available, TCADA will be able to measure treatment in terms of both effectiveness and efficiency.

Brief Summary of Trends

Looking at the Texas data from 1973 to 1991, there are some interesting trends. As the peaks in the mid-1970s indicate (Figure A), heroin was the primary drug of abuse and indeed the main reason for drug treatment programs; fear that Viet Nam veterans were bringing heroin habits back to the States prompted the creation of programs to treat the epidemic. The addition of alcohol abusers to the CODAP base in 1983 accounts for the drastic increase in the percent of clients identified with a primary problem of alcohol abuse. Since 1983 the percentage of alcohol, marijuana, and amphetamine abusers have remained relatively stable, whereas the percentage of heroin abusers has gone down, and the percentage of cocaine abusers has significantly increased. It is interesting to note that prior to the mid-1980s, cocaine represented a consistently small percentage (less that 3 percent) of total admissions, whereas in 1991 cocaine abusers constitute over 20 percent of total treatment admissions. This increase is due to "crack" cocaine.

Alcohol is the predominant problem that brings clients to substance abuse treatment programs. Alcohol admissions in the first half of FY91 constituted 46 percent of all admissions. The average alcohol client is 34 years old and has been using heavily for 18 years; 25 percent are married, 41 percent are employed, 42 percent are criminal justice referred and 7 percent are homeless.

In 1991, cocaine continued to be the number one illicit substance abuse problem for clients admitted to substance abuse treatment programs in the state. The number of cocaine admissions declined during the last two quarters of 1990, but they increased to their highest level yet during the first quarter of 1991; cocaine accounted for 46 percent of non-alcohol admissions in the first half of the state fiscal year 1991 (September 1990 through February 1991), but increased to 49 percent during the first quarter of calendar 1991. Over the past three years, the average age of cocaine clients at the time of admission and the average

length of time between first use and admission has increased by one year. Currently, the average client admitted for a primary problem with cocaine is almost 30 years old and has been using cocaine for six years. Some 59 percent are Black, 27 percent are employed, and 69 percent live with their family. Only 7 percent are homeless. Since 1987, an increasing percentage of cocaine admissions report smoking as the primary route of admission (Figure B).

Heroin is the number two illicit drug problem for clients admitted to substance abuse treatment, accounting for 23 percent of non-alcohol admissions in the state during the first half of FY91. The typical heroin client at admission is 35 years old and has been using heroin for 13 years. Some 48 percent of heroin clients are Hispanic, 21 percent are employed, 74 percent live with their families and 5 percent are homeless. Marijuana is the number three illicit drug problem for treatment clients, and was the primary problem for 16 percent of non-alcohol admissions to treatment programs during the first half of FY91. Marijuana clients are on average about 28 years old at the time of admission and have been using for 11 years. Some 81 percent are male, 48 percent are employed, and 72 percent are referred to treatment through the criminal justice system. Amphetamines are the number four illicit drug problem for treatment clients, accounting for 10 percent of non-alcohol admissions during the first half of FY91. The average client is 29 years old, has been using for 10 years, and uses the drug intravenously. Some 92 percent are White and 59 percent are criminal justice referred.

2. ADULT SURVEY

Background

In the spring of 1988, adult Texans were surveyed to measure their use of alcohol and other psychoactive substances. The survey, a joint effort between TCADA and Texas A&M University's Public Policy Resources Laboratory (PPRL), was funded using the U.S. Department of Education's Drug-Free Schools and Communities Block Grant. The questionnaire, though designed specifically for the adult survey, was based on previously tested instruments and was compatible with other national and state surveys regarding questions about the types and levels of drug and alcohol use.

The sample of 5,156 adults 18 years of age and older, selected from randomly generated telephone numbers, was stratified for three racial and ethnic groups, three age groups, and eight geographical regions. Persons asked to participate were assured confidentiality, and the cooperation rate was 75 percent. A Spanish version of the questionnaire was administered, as needed, by bilingual interviewers.

Brief Summary of Findings

- In 1988, adult Texans reported higher rates of lifetime prevalence but lower rates of current prevalence of illicit drug use than in 1980.
- 88 percent of Texas adults have drunk alcohol at some time during their lives, and 31 percent of Texas adults have used illicit substances (Figure C).
- 46 percent of adults drank alcohol and 3 percent of adults used marijuana within the 30 days prior to the survey.
- About 19 percent of adults reported experiencing at least one alcohol-related problem during the past year, and over 3 percent reported at least one problem related to other drugs.
- About one-half of adults who had used illicit drugs during the past year reported experiencing one or more drug-related problems.
- About one-third of adults who drank alcohol during the past year reported experiencing one or more alcohol-related problems.

3. SCHOOL SURVEYS

Background

During the spring of 1990 TCADA, in conjunction with PPRL, conducted the second statewide assessment of

FIG C PERCENT OF ADULTS WHO HAVE EVER USED SUBSTANCES
TCADA ADULT SURVEY, 1988

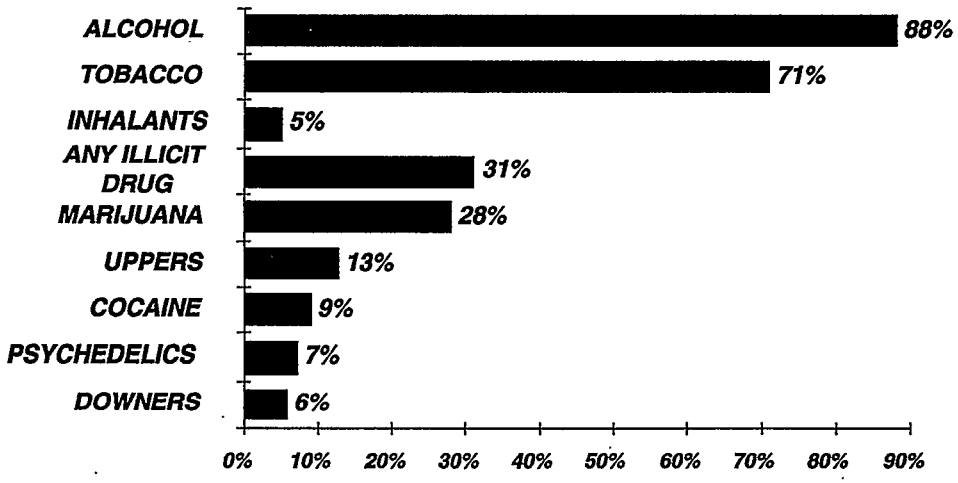
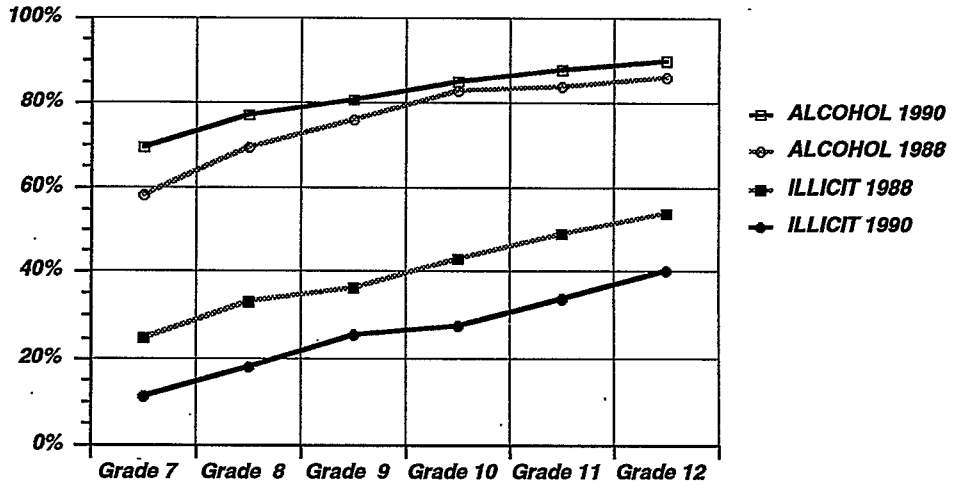


FIG D LIFETIME USE OF ANY ILLICIT DRUG AND ALCOHOL, 1988 AND 1990: TEXAS SECONDARY STUDENTS



substance use among public school students in Texas. This *Texas School Survey of Substance Use* was first administered in 1988. The initial investigation provided baseline information about frequency and prevalence of use among students in grades seven through twelve. The 1990 effort provided follow-up data showing changes over the past two years and expanded the data base to include grades four through six. In both surveys, students selected through a multi-stage probability sample completed a questionnaire in Scantron format which included questions pertaining to correlates of substance abuse, problems relating to substance abuse, and sources of information about and help for substance abuse-related problems.

The Texas School Survey results for grades 7 through 12 (secondary students) are based on a total sample size of 110,451 students; results for grades 4 through 6 (elementary students) are based on data collected from a total sample of 108,033.

Brief Summary of Findings

- Between 1988 and 1990, alcohol and tobacco use among secondary students increased and use of most other substances declined (Figure D).
- The percentage of secondary students who smoked cigarettes during the past month increased between 1988 and 1990, from 17 to 22 percent (21 to 26 percent among seniors).
- Although secondary students in 1990 seemed to be responding to messages about the dangers of street drugs, they continued to drink alcohol: 81 percent of secondary students have drunk alcohol in their lifetime, up from 76 percent in 1988.
- Drinking was more prevalent among groups in 1990 that were among the lowest users in 1988: lifetime alcohol consumption among seventh graders rose from 59 to 69 percent, among Blacks it rose from 64 to 83 percent, and among females it rose from 74 to 81 percent.
- Lifetime prevalence rates among secondary students decreased between 1988 and 1990: marijuana dropped from 32 to 23 percent, uppers from 17 to 7 percent, downers from 13 to 5 percent, and lifetime use of any illicit drug dropped from 39 to 25 percent.
- Sixth grade marked a substantial increase in both lifetime and past school year substance use compared to fourth and fifth grades.
- 31 percent of fourth graders, 39 percent of fifth graders, and 57 percent of sixth graders have drunk alcohol; 21 percent of fourth graders, 28 percent of fifth graders, and 38 percent of sixth graders drank alcohol during the past school year.

4. OTHER SPECIAL POPULATION SURVEYS

Background

TCADA has conducted a number of studies among special populations, including a survey of substance use and correlates among inmates entering the Texas Departments of Corrections (TDC) in 1988, a survey of substance use and correlates among youth entering Texas Youth Commission (TYC) facilities in 1989, an analysis of DWIs and correlates using information from Texas drivers' license records in 1990, and a survey of substance use patterns and prenatal environment among women giving birth in Texas public hospitals in 1990. The TDC and TYC surveys were administered face-to-face using a version of the adult survey that was expanded to include information about criminal activity. The DWI study utilized a unique software program, the DWI Recidivism Tracking System, to gather information from over 526,000 driving records that contained evidence of DWI-related activity. The postpartum survey combined self-reported data, hospital chart information, and chemical analysis of umbilical cord blood to ascertain levels of substance use during pregnancy, the nature of prenatal care sought and received, and the birth outcomes of the women in the sample.

Brief Summary of Findings

TDC Inmate Survey

- When compared to adults in the general population, TDC inmates are more than seven times as likely to have used illicit drugs in their last month on the street (47 percent of inmates compared to 6 percent of adult males) (Figure E).
- Inmates are over six times more likely to be current users of marijuana (32 percent vs. 5 percent), 15 times more likely to be current users of powdered cocaine (22 percent vs. 1 percent), over 40 times more likely to be current users of crack cocaine (10 percent vs. less than .5 percent), 16 times more likely to be current amphetamine users (10 percent vs. less than 1 percent), and more than one hundred times more likely to be current heroin users (8 percent vs. less than .5 percent) than adult males in Texas.
- 23 percent of inmates, compared to 7 percent of adult male Texans, drink alcohol daily.
- 36 percent of inmates injected illicit drugs at some point in their lives, 20 percent within their last month on the street. 23 percent of inmates have shared needles, 9 percent within their last month on the street.

TYC Youth Survey

- Many TYC youth are daily substance users: 28 percent drink alcohol or use one or more illicit drugs daily; 35 percent used a substance at least 20 times in their last month on the street.
- TYC youth are more than three times as likely as in-school youth to be current tobacco smokers, three times more likely to have used an illicit drug in the past 30 days, and 16 times more likely to be current users of crack (Figure F).
- Current illicit drug use is slightly higher among TYC youth than adult inmates: 51 percent of TYC youth and 47 percent of TDC inmates reported current use of at least one illicit drug in their last month on the street.

DWIRTS Study

- Over 326,000 drivers caused nearly 384,000 DWI events in Texas between 1985 and 1988.
- DWI arrests in Texas declined from nearly 150,000 in 1983 to 103,000 in 1989, probably due to declining alcohol consumption.
- DWI arrests in Texas of *first offenders* declined by 34 percent between 1985 and 1988, but arrests of *repeat offenders* remained unchanged; this suggests that there is a persistent population of Texans who repeatedly drink heavily and drive drunk (Figure G).

Postpartum Study

- 14 percent of the women in the postpartum study drank alcohol while they were pregnant.
- 28 percent of the women in the study used a licit or illicit substance (alcohol, cigarettes, inhalants, and/or an illicit drug) during their pregnancy. Women who used a licit or illicit drug during pregnancy were more likely to lack adequate prenatal care compared to non-users, more likely to have maternal complications, more likely to have infants with complications, and more likely to deliver premature infants.
- Rates of self-reported alcohol use were three times higher for White women than Hispanic women and significantly higher than Black women.
- Women who received adequate prenatal care had healthier babies than women who had not received adequate care; even substance users who received adequate prenatal care had slightly better birth outcomes than non-users who had not obtained adequate care.

FIG E LIFETIME SUBSTANCE USE
TDC MALE INMATES AND TEXAS MALE ADULTS, 1988

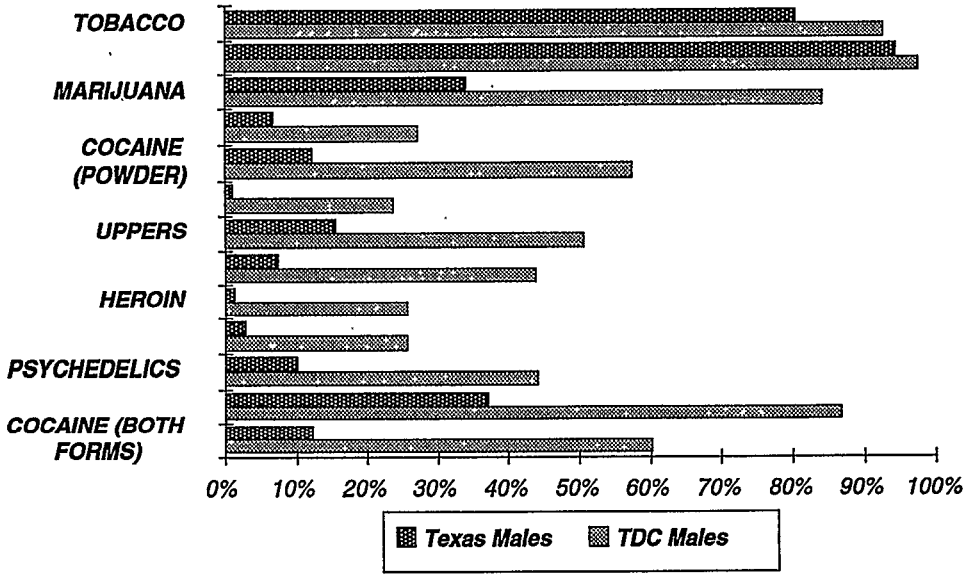


FIG F LIFETIME SUBSTANCE USE
TYC YOUTH (1989) AND TDC INMATES (1988)

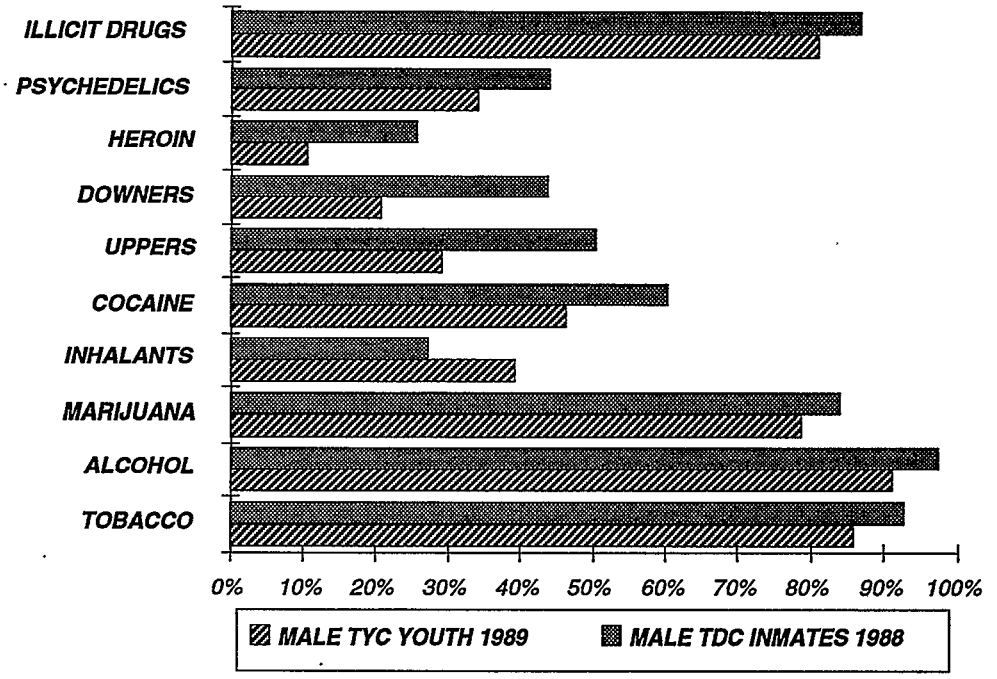
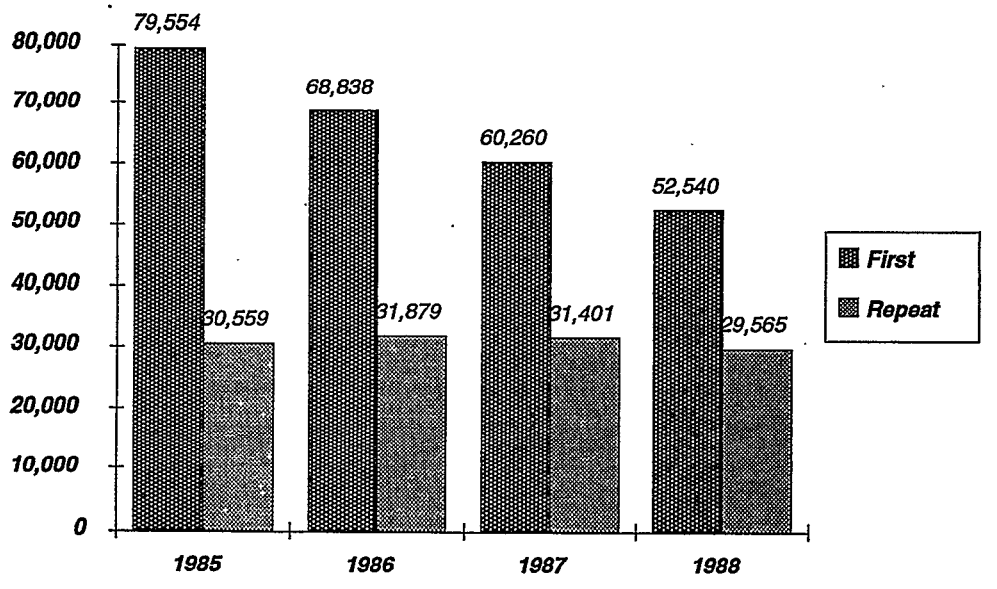


FIG G NUMBER OF FIRST AND REPEAT DWI OFFENDERS
TEXAS, 1985-1988



TRENDS IN DRUG AND ALCOHOL USE IN A RURAL COLORADO SCHOOL DISTRICT

Olive M. O'Donnell
Mesa County Valley School District Number 51

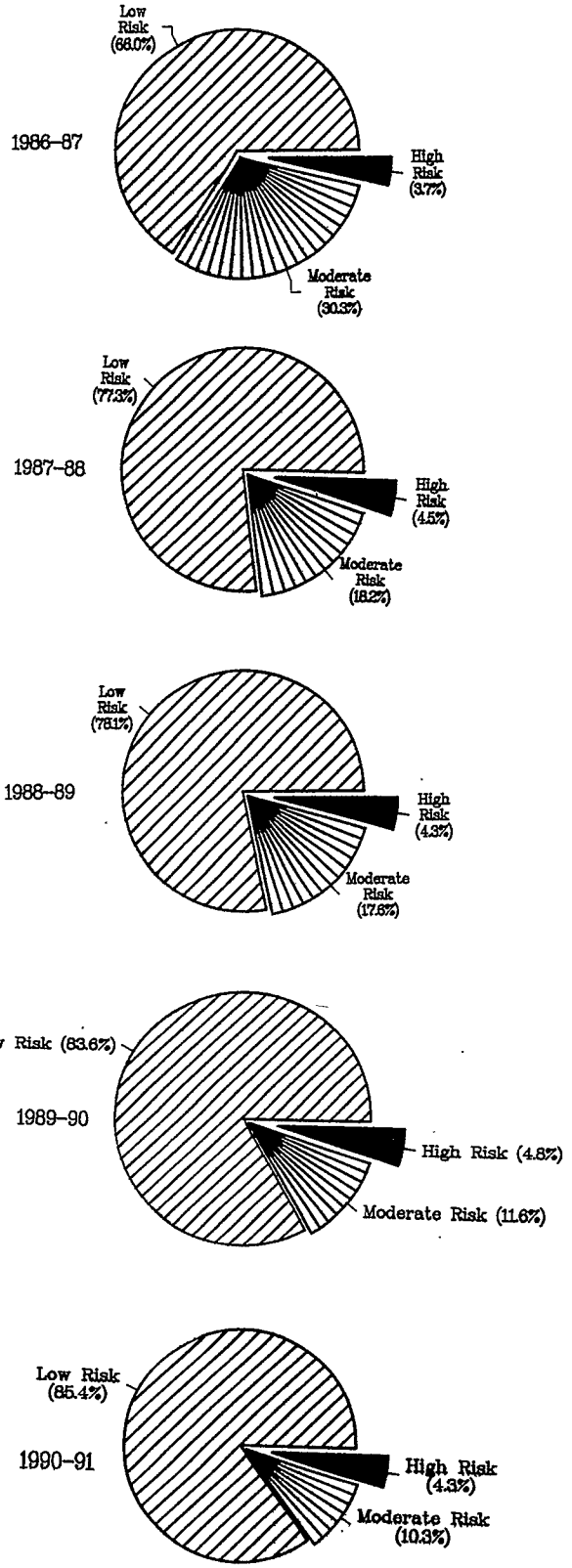
For the past five (5) years the American Drug and Alcohol Survey has been administered to 5th, 8th and 12th grade students in School District #51, a rural Colorado school district. It is now possible to make observations based on the trends in drug use among these students.

The most salient data is reflected at the 8th grade level. There have been significant and consistent reductions in the use of the most commonly used drugs among the District #51 8th graders over the past five (5) years. Especially notable is the dramatic reduction of drug use in the moderate risk group. The use at this level has dropped off every year without any fluctuations. Beginning at 30.3% rate of drug use in 1987, and declining to 18.2% in 1988, to 17.5% in 1989, to 11.6% in 1990 and finally to 10.3% in 1991 the pattern of reduced use is clearly shown. One can surmise that this may, in part, be due to the comprehensive, collaborative prevention efforts expended by not only the School District, but by law enforcement, business entities, parents and social service agencies.

Using data generated by this survey, prevention and intervention strategies are implemented, revised or discarded. Because of overwhelmingly positive response to this survey by the community at large, it has been deemed not only cost effective, but a necessary part of our evaluative process in determining the direction of our drug and alcohol use prevention strategies.

NOTE: Moderate Risk is defined as occassional drug use or experimental drug use.

Percent of Mesa County Valley School District No. 51 8th Graders At Risk From Drug Use



Mini-DAWN in New York State: Reporting Drug-Involved Hospital Emergencies

Blanche Frank, New York State Division of Substance Abuse Services
Deborah Gohs and Julius Klein, The Information Exchange, Inc.

Background and Rationale

This paper describes an adventure of several years in putting together an information-gathering system based on drug-involved emergencies reported by hospitals in upstate and downstate areas in New York. We call the project Mini-DAWN.

To appreciate the need for such an effort, it is important to understand the larger difficulties involved in monitoring the problem of drug abuse in a State as large and diverse as New York. Drug abuse is a behavior that is clandestine, illegal and stigmatized. Yet it cuts across both genders, all age groups and all social strata, and exists in every geographic area, sometimes in similar ways and sometimes in very different ways. Nevertheless, questions on the part of planners, policymakers, decision makers and government and community leaders are very clear and direct. How many drug abusers are there? How bad is the problem? Is it getting worse? Is it getting better? What are the latest trends? The epidemiologic researchers of the New York State Division of Substance Abuse Services (DSAS) are charged with the responsibility of coming up with answers to these very difficult questions while using strategies and methods that are scientifically defensible.

Since no one strategy or data base can answer all the questions, a multiplicity of strategies and information sources are used. Much effort, however, has been concentrated in New York City. We at DSAS monitor the trends very closely. We look at what are called indirect indicators, and in New York City there are many such indicators for drug abuse. Since drug abusers surface in many agencies in New York City, these agencies monitor the trends in their own system. Thus, the New York City Police Department issues data on arrests that are drug-involved. The New York City Health Department monitors deaths due to drug dependence and overdoses using the International Classification of Diseases. The same agency also monitors, via self-report, births to drug-using women. These indicators, however, come and go and are collected by agencies in ways that are not always communicated.

There are other trend data that are derived from systems that are more directly concerned with the drug abuse problem. DSAS, itself, oversees drug abusers in treatment, using a management information system that is very comprehensive. Treatment program data, however, monitors events that "lag" the trend and more likely indicate the later stages of a problem than a problem that might just be emerging.

That brings us to DAWN, the Drug Abuse Warning Network, sponsored by the National Institute on Drug Abuse. DAWN concentrates mainly in 21 metropolitan areas. The system gathers reports of drug-involved emergencies from emergency departments of acute-care hospitals. The New York City and Buffalo metropolitan areas are the areas in New York State that participate in the DAWN system. Although the DAWN system also includes the reporting of drug-involved deaths by medical examiners and coroners, for the New York City metropolitan area the drug-involved emergency room data were available continuously for a longer period of time. In following the trends derived from DAWN emergency room reporting, there were several advantages that were apparent. First, drug abuse emergencies were often early warning indications, signaling the beginning of a trend or an emerging pattern of use. Second, the data were collected primarily for its own purpose or its relevance to drug abuse concerns with associated demographics of the patient and characteristics of the event while maintaining anonymity. Third, DAWN data were more likely to reflect information on a cross section of the general population than are other indicators such as law enforcement and public treatment data. The 24-hour hospital emergency room is widely accepted as the place to get help for all kinds of medical emergencies.

In addition to monitoring trends by using indirect indicators, we in New York State also conduct major surveys of the population. These include a survey of youth between the ages of 10 years and 18 years and a survey of adults 18 years and older. These surveys are usually conducted every five years. Over the past decade it has become clear that the drug abuse problem is not limited to New York City and that a significant problem was developing in other parts of the State.

Another information-gathering tool are annual Regional Epidemiology Workshops, which confirmed the problem we could document only every five years or so using surveys. Our Regional Epidemiology Workshops are convened each year at four locations in upstate and downstate areas outside New York City to gather information from county representatives about local drug abuse problems. Although the information generated by these workshops is a mix of data, observation and anecdotes, the general conclusions have been that a very serious drug abuse problem was developing throughout the State. It became clear that we needed to be able to monitor this growing problem in a more effective and ongoing way.

In summary, then, the rationale for a DAWN-type system stems from the intrinsic worth of the indicator and the need for more effective monitoring in areas of the State outside New York City.

Mini-DAWN, 1987

Given the rationale, DSAS set to work implementing a pilot DAWN emergency-room

reporting system in upstate New York which we called Mini-DAWN. First, we decided on a sampling design that ultimately included all the acute-care hospitals having 24-hour emergency departments in just three upstate counties: the relatively urban county of Onondaga where the city of Syracuse is located; the semi-urban or suburban county of Rensselaer outside Albany County where the State capital is located; and the rural county of Cattaraugus in the western part of the State. Sampling is always an important consideration when a complete enumeration is not possible.

Second, we sought the collaboration of the State Department of Health (DOH) to help us in turn secure the cooperation of the 10 hospitals that would be invited to participate. Although DOH supported our effort, the many meetings and the delays caused us to go directly to the hospitals' administrators to explain our intent. Despite the fact that we were not going to pay the hospitals for the staff time involved in participation, the 10 hospitals were willing to report to us for a period of one year. We did promise, however, that we would return findings to each hospital, which could possibly help them document the need for a detoxification unit or perhaps a treatment program associated with the hospitals.

Once written consent was received, we asked that some reporter would be assigned for each hospital with a backup, if possible. Training in completing the forms for each drug-involved emergency took place in each of the three counties for the designated hospital reporters. The forms would be completed based on the review of emergency room records, usually once a week.

In general, the cooperation was excellent. Each month, we at DSAS sent to the hospitals a batch of forms and stamped self-addressed envelopes with the expectation that once a week the reporters would return a completed form for each drug-involved emergency and a log sheet for each week indicating the total number of all emergencies each day. (An example of the emergency department case report form appears on the following page.)

By the end of the year, some interesting aspects of the drug abuse problem upstate could be documented. First, the rate of drug-involved episodes per 1,000 emergencies for the three pilot counties was very similar to the rate for the Buffalo metropolitan area. In 1987, federal DAWN recorded a rate of 6 per 1,000 emergencies for the Buffalo area compared to 6.3 for Mini-DAWN's three upstate counties. The rates per county were 8.4 for Rensselaer, 5.7 for Onondaga and 5.5 for Cattaraugus--the most rural county. Interestingly, the comparable DAWN rate for the New York metropolitan area was 9.4 per 1,000 emergencies. Second, the drugs most frequently reported by the 10 participating hospitals were cocaine (22 percent of all drugs mentioned) and tranquilizers and related substances (20 percent).

Third, there were many commonalities about the patients presenting with drug-involved emergencies. Overall, males were as likely as females to report with these emergencies. The most popular age range was 21 years through 30 years for these patients, and whites usually predominated. Some notable exceptions and findings were the following:

- Cocaine users with emergencies, however, were much more likely to be male, to be between the ages of 21 years and 30 years, to report dependence, and to have used alcohol-in-combination than were other patients with drug emergencies. The route of administration when reported was usually injection.
- Valium users with emergencies were more likely to be male, to be white, to report dependence, and to have used alcohol-in-combination with the tranquilizer than were other patients with drug emergencies.

Our own perceptions at the end of the year indicated that the voluntary system that showed enthusiasm at the start of the year was now breaking down. There was turnover in hospital staff and interest in the project appeared to be waning. In order to evaluate the project, a survey was conducted among the reporters for the 10 participating hospitals. The findings indicated the following:

- An average of 3 hours per week was spent completing the form, with a range of 1 to 14 hours depending on the volume of the reports.
- Some monetary compensation would be required if the project were to continue. The suggested hourly pay ranged between $5 and $25 per hour with an average of $10.
- Reports for the individual hospitals' own emergency room activity were sent to each hospital. These proved important to some of the hospitals in documenting need for a detoxification unit and for quality assurance purposes.
- Most of the hospitals would continue to participate in the future should money become available for staff time.

Mini-DAWN, 1990-1991

Based on the importance of the findings from the 1987 Mini-DAWN project and the apparent need to pay the hospitals some remuneration for continued involvement, DSAS eventually found money in a very tight budget to support this reporting system. A contract to carry out the project for one year was negotiated in 1989 with The Information Exchange (TIE), a private, non-profit organization that already was under contract with New York State.

Together, DSAS and TIE, worked out a sampling design for a new Mini-DAWN panel for upstate and downstate areas outside New York City. Since federal DAWN would soon be geographically redefining the New York metropolitan area, some very important counties would be dropped and other counties

New York State Drug Abuse Warning Network (Mini-DAWN)*
Emergency Department Case Report

1. PROVIDER NUMBER

2. CROSS REFERENCE (Facility Use Only)

PATIENT INFORMATION

3. DATE OF VISIT — Month | Day | Year

4. TIME OF VISIT — Hours | Minutes (Mark [X] 1 [ ] am 2 [ ] pm 3 [ ] mil.)

5. AGE (Must be 06-97 yrs.)

6. SEX 1 ___ Male 2 ___ Female

7. RACE
1 ___ White, not of Hispanic origin
2 ___ Black, not of Hispanic origin
3 ___ Hispanic
4 ___ American Indian or Alaskan Native
5 ___ Asian or Pacific Islander
6 ___ Unknown

8. PATIENT HOME ZIP CODE
1 ___ Unknown 2 ___ No Fixed Address

9. REASON FOR TAKING SUBSTANCE(S) (Mark (X) one response)
1 ___ Dependence
2 ___ Suicide Attempt or Gesture
3 ___ 'Recreational Use' (e.g., to get high, kicks)
4 ___ Other Psychic Effects
5 ___ Unknown
6 ___ Other (Specify) _____

10. REASON FOR PRESENT CONTACT
A. Was this an Overdose? 1 Yes ___ No ___
B. If "No", mark one response
2 ___ Unexpected Reaction
3 ___ Chronic Effects (See reverse side)
4 ___ Withdrawal
5 ___ Seeking Detoxification
6 ___ Accident/Injury
7 ___ Unknown
8 ___ Other (Specify) _____

11. DISPOSITION
1 ___ Treated and Released or Referred
2 ___ Admitted as Inpatient to This or Any Hospital
3 ___ Left Against Medical Advice
4 ___ Died

DRUG/SUBSTANCE INFORMATION

12. ALCOHOL INVOLVED
1 ___ Yes 2 ___ No 3 ___ Unknown (Mark (X) one response)

13. LIST EACH DRUG/SUBSTANCE SEPARATELY; (Generic, Trade, or Street Name); (Do NOT list alcohol)

T.I.E. USE ONLY

1
2
3
4

For each non-alchohol substance listed above, mark (X) one answer in each data item below.

14. FORM IN WHICH DRUG WAS ACQUIRED

		Substances 1	2	3	4
Tablet/Capsule/Pill	1				
Aerosol	2				
Liquid (oral)	3				
Powder (crystal)	4				
Paper (e.g., LSD/Acid)	5				
Pieces/Chunks (e.g., Crack)	6				
Injectable Liquid	7				
Cigarette	8				
Plant Material	9				
Unknown	10				
Other	11				

15. ROUTE OF ADMINISTRATION

		Substances 1	2	3	4
Oral	1				
Injection	2				
Inhaled (e.g., fumes)	3				
Smoked (includes freebase)	4				
Sniffed/Snorted	5				
Unknown	6				
Other	7				

16. SOURCE OF SUBSTANCE

		Substances 1	2	3	4
Legal Rx	1				
Forged Rx	2				
Street Buy	3				
O.T.C.	4				
Stolen	5				
Gift	6				
Unknown	7				
Other	8				

17. CODED REMARKS
(If case involves a drug user diagnosed with AIDS, please write "AIDS" in first four spaces below.)

* Sponsored by the New York State Division of Substance Abuse Services under contract with The Information Exchange, Inc.
151 S. Main St., Suite 212, New City, NY 10956, (914) 634-0050

would be included. In the new design, 16 hospitals were recruited for Mini-DAWN based on levels of urbanicity in the State's several Health Service Areas, and, also, to represent the important counties that federal DAWN was planning to drop.

Since we now would be paying the hospitals through TIE, there were issues of quality assurance and completeness of coverage that we needed to address based on our earlier experience. It was decided that quality assurance would be monitored through reabstracting studies similar to federal DAWN. A two-day sample of all emergency department records would therefore be reviewed at each hospital and abstracted by an auditor who would complete a form for each drug-involved episode found. The exercise was implemented and the auditors' findings were subsequently compared with those submitted by the hospital reporters. In this way, it was possible to check on the accuracy of the reporter and any evidence of systematic bias or sources of error. The findings did show that for nine of the 16 hospitals the auditors found one or two more drug-related episodes than were reported by the hospital. One explanation was the fact that episodes involving accidents or psychiatric symptoms were not always reviewed to determine whether the non-medical use of drugs was involved in some way. It appeared that reporters need to be reminded that almost any type of emergency might be drug-involved.

The issue of motivating the reporters was also addressed. In order to ensure accuracy, completeness and timeliness of reporting, it was important that ongoing contact with the reporters be maintained. In the 1987 Mini-DAWN effort, the DSAS staff did not have the time to visit the hospitals or to maintain telephone contact with the reporters. The TIE staff, however, made it a priority. With a few exceptions, TIE staff visited each hospital twice. In addition to site visits, there were frequent telephone and written contacts with facility staff regarding the content of case reports as well as "tardiness" in the reporting process. There were problems in several areas. Hospital reporters to Mini-DAWN found that patient charts were often difficult to read. Also, toxicology reports (when available) were delayed from time to time. Often, case records had to be retrieved from distant medical records departments or inpatient floors. Reporters were not always familiar with the names of various substances so verification of drug names was sometimes necessary. These, and similar problems, indicated that the institutionalization of a valid and reliable reporting method is more of a process, and less of an event, than was apparent at the beginning of Mini-DAWN.

Throughout the entire year, however, relationships with all of the facilities were good. Staff and administration were courteous and responsible despite the fact that the Mini-DAWN program was not a top priority. The frequent expression by TIE staff of their appreciation and support of hospital recorders helped to create a cooperative atmosphere. This cooperation is apparent when the number of missing reports is explored. For the entire year, only one of the 16 facilities failed to submit all reports. (Two weeks of reports were not submitted by this facility.) The federal DAWN program discusses missing reports in terms of "months reported". A month is counted as "complete" if the facility reported for at least one day of the month. The 1989 federal DAWN program had 74 percent of its facilities submit reports for all 12 months. In comparison, Mini-DAWN had 100 percent of its facilities submit reports for all 12 months.

The findings of the 1990-1991 Mini-DAWN effort continued to shed light on the impact of the drug abuse problem in areas outside New York City. Overall, the rate of drug-involved emergencies was 4.8 per 1,000 hospital emergency episodes in the 16 hospitals in the latest Mini-DAWN from mid-March 1990 to mid-March 1991. For calendar year 1989, federal DAWN recorded a comparable rate of 4.4 for the Buffalo metropolitan area. Within Mini-DAWN current sample, the hospitals in Regions 1 and 2--the western third of the State--recorded a rate of 8.8 for drug-involved emergencies. This very high rate was closer to the rate for the New York City area of 9.3 than for any other upstate or downstate area.

A second significant finding showed that the leading drugs involved in these emergencies remained cocaine and tranquilizers and related substances. Overall, cocaine-involved episodes represented a somewhat smaller proportion of drug-involved emergencies in this panel than in the 1989 panel--19 percent vs. 22 percent. Nevertheless, within the latest Mini-DAWN panel, Regions 1 and 2 showed a rate of cocaine emergencies that approximated the rate for the New York metropolitan area. The rate for Regions 1 and 2 was 36 cocaine emergencies per 10,000 emergencies; the comparable rate for the New York City area in 1989 was 43.

A third finding of interest is the large variety of psychotropic substances that were reported in the 1990-91 Mini-DAWN panel as compared to the 1987 panel. In January 1989, New York State enacted a law placing a triplicate prescription requirement on the prescribing of benzodiazepines including Valium. Although Valium remains the most frequently mentioned psychotropic substance, this most recent Mini-DAWN study does show proportional reduction in the emergencies involving Valium when compared to the former panel. However, there was a noticeable increase in the involvement of other anti-anxiety agents (e.g., Soma and Vistaril) and in anti-depressant agents (e.g., Elavil and the newer drug, Prozac). Whether this finding may be attributed to the change in the panel of hospitals or to a real change in physicians' prescribing behavior over time or to some other causes is not known. This possible trend should certainly be observed.

In any case, Mini-DAWN continues to identify certain general characteristics of drug-taking behavior in New York State outside

New York City. For example, usually more than one drug is involved in drug-involved emergencies--in both 1987 and 1990-91, an average of 1.5 drug mentions appeared in each episode. Also, alcohol is frequently an additional substance mentioned, occurring in 43 percent of these episodes in Mini-DAWN 1987 and 36 percent in Mini-DAWN 1990-91. The characteristics of patients with these problems continue to show that females are as likely as males to present with drug-involved emergencies, with females more involved with prescription psychotropics and males more involved with illegal drugs. Young adults between the ages of 18 years and 34 years usually constitute the majority of patients. Finally, whites constitute the majority of these patients followed by blacks.

The information yielded by Mini-DAWN continues to be meaningful, and the project has been funded for another year. All the hospitals in the recent Mini-DAWN panel have agreed to continue reporting for other year.

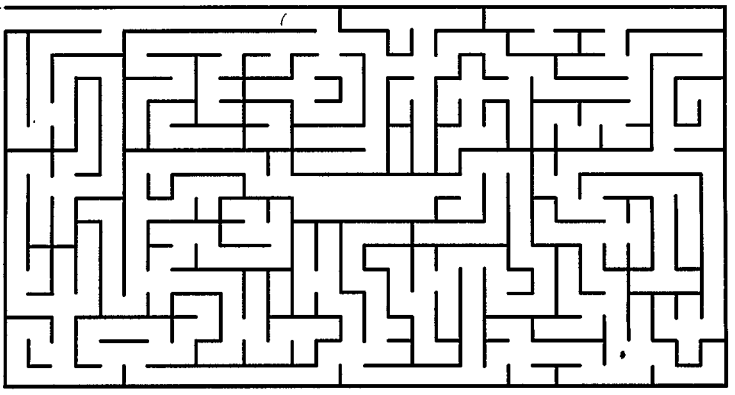
INFANT MORBIDITY AND MORTALITY ASSOCIATED WITH PRENATAL COCAINE AND CRACK ABUSE IN NEW YORK CITY, 1978-1989

Karla Damus
New York City Department of Health

(Not available for publication)

Session P

Data for International Comparisons



RECENT COMPARATIVE STUDIES AT THE NATIONAL CENTER FOR HEALTH STATISTICS: INSIGHTS GAINED, LESSONS LEARNED

Francis C. Notzon, National Center for Health Statistics

This presentation deals with international research conducted at the National Center for Health Statistics (NCHS). Before discussing these studies, however, I would like to raise several questions that one should answer before embarking on any international study.

1. First of all, why should we conduct international comparative studies, in this case of health measures or practices? What can we reasonably expect to learn from such studies? While the answers may seem obvious to many of us, especially those who work in the international area, these questions are worth asking. Indeed, the second question -- what can we expect to learn -- is of course one we should ask before embarking on any research, international or domestic.

Some of the justifications for international studies are well known. First, international comparisons may identify large and heretofore unknown differences in certain health measures between two or more countries, inspiring additional research to uncover the causal mechanism. A classic example is the detection of large differences in cardiovascular disease between Japanese and Japanese-Americans. This led to a comparison of coronary heart disease, stroke, and suspected risk factors among Japanese and Japanese-Americans in Hawaii and the U.S. mainland, and was an important step in identifying causal factors in the development of cardiovascular disease.

Second, unusual but similar findings in several countries also may inspire further research, such as the recent reports on upturns in brain cancer rates in the elderly in many industrialized countries.

In areas where we feel we are lagging behind other countries, we may compare ourselves with these other countries in an effort to apply -- in whole or in part -- their solutions to our problem. An obvious example is the issue of infant mortality.

By implementing changes in its health care system, another country may thereby serve as a laboratory for health policies or practices under consideration in the U.S. In this case, a comparison of U.S. health measures with those in the other country may provide insight into the possible effect of, for example, the introduction of universal health insurance on the utilization of various medical procedures, the impact of vaccination programs on levels of measles morbidity in children, and the like.

As another example, we may want to carry out international comparisons not to identify health problems, but to emphasize the extent of the U.S. problem, thereby generating domestic interest in a particular health issue.

Although not a true justification, another reason for such studies may be relatively important side benefits, such as uncovering problems in our own data systems, learning new ways to make use of data, or learning of new data sources, inspired by other countries.

Finally, an important reason for carrying out international studies is to provide a new perspective to those engaged in research on a given topic on the domestic side. In health research as in many other areas, many Americans tend to limit their consideration of an issue to domestic findings.

2. What countries should we use for comparison?

The next question concerns which countries we should compare ourselves to. The basic requirement, of course, is that the comparison countries should have comparable data. While this would exclude most developing countries, it may also exclude a surprising number of industrialized countries. Studies of birth-weight-specific infant mortality, for example, require linked birth and infant death files, a requirement that would exclude Germany, France, and Canada, who do not link files (although the Canadians are now developing linked files), and the Netherlands, where information on birth weight is not available for the 35% of births occurring at home. In addition, very few countries invest the resources we do in health data collection, and so few countries will possess routinely collected data comparable to, for example, the Health and Nutrition Examination Survey conducted by NCHS. Thus, certain types of comparative studies will only be possible with countries that have carried out special studies to collect the necessary data.

Among countries with the required data, we may want to limit the comparisons to certain types of countries. As mentioned earlier, one might select comparison countries with better outcomes, to learn from their approach to the problem, or countries with poorer outcomes, to identify what they are doing wrong. In either case,

the comparison is with countries that are different from our own. Another approach is to select comparison countries that are very similar to ours, so as to limit the number of "other" factors that may compromise the quality of the comparison. Typical examples involve neighboring countries, such as the U.S. and Canada, or Norway and Sweden, that have similar cultures, educational systems, and other factors, but also have some important differences in outcomes.

3. What are the pitfalls?

The third question refers to the problems that may arise in these studies. The major types of methodological problems in fact tend to overlap, and cannot be easily classified into a single category.

The first type of problem, differences in the coverage of data systems, includes some obvious as well as not-so-obvious problems. For example, comparisons of hospital discharge data are complicated by differences in coverage. While the Center's Hospital Discharge Survey produced data on short-stay hospitals only, many other countries include information on certain types of long-term care facilities in their discharge statistics (1). In some instances, this problem may be resolved by obtaining special tabulations from the other country or countries. Even if special tables cannot be obtained, the comparison may still be worth making, although this will depend on the extent to which the measures being compared are affected by the inclusion of long-term-care facilities. In general, discharge rates are not greatly affected by inclusion of long term care data, while measures of average length of stay are much more sensitive to these data.

Other examples of this type of problem include differing definitions of the study population in various surveys, including or excluding institutionalized populations, setting different age limits, and the like.

In the second category -- differences in definitions -- the most insidious problems are not with definitions per se, but <u>how</u> these definitions are operationalized. For example, the definition of a live birth is largely the same in most Western industrialized countries, but the interpretation of this definition may vary significantly across countries. The Center's International Collaborative Effort, or ICE, on Perinatal and Infant Mortality has found strikingly large differences across countries in the proportion of infant deaths weighing less than 500 grams (2). These differences -- on the order of 1,000 percent -- are so large that they far exceed any conceivable real differences in mortality, and almost certainly are largely due to cross-national differences in the interpretation of the definition of a live birth. Such differences may be impossible to correct, but may be dealt with by excluding the problem events from the analysis -- in this case, limiting comparisons of infant mortality to births weighing 500 grams or more.

Differences in procedures -- the third type of problem -- are numerous. Discharge data in the U.S. are obtained from a sample survey covering all types of hospitals, while in France, discharge data are based on a complete count of discharges from <u>public</u> hospitals, only half of which respond in a given year (1). As another example, linked birth and infant death files for the U.S. are obtained from vital registration systems that capture virtually all events. In Sweden, the linked birth-infant death files are provided by the Birth Registry, which is unable to link a small but important proportion of infant deaths with the corresponding birth records (2).

A final pitfall is not related to differences in the comparability of the data being compared, but to the method of analysis and the interpretation of results. Typically, international comparisons are based on grouped data, rather than unit-record data. Information sources of this type lend themselves to straightforward comparisons of measures in the countries under study. While these comparisons are valid in and of themselves, the interpretation of such results can lead to serious errors. For example, strong positive correlations can be shown between national infant mortality rates and the proportion of births to single women, and the same correlation is found among U.S. whites and blacks. However, to use these findings to infer that infants born to <u>single</u> teenage black women in the U.S. are at higher risk of death than births to <u>married</u> women of the same race and age group would be incorrect. More careful analysis yields the surprising finding that infant mortality rates for births to single teenage black women are actually lower than for married teenage blacks (3). Again, the original findings are correct; it is the interpretation that is off base.

NCHS International Comparisons.

Now I will review recent international comparative studies conducted at NCHS. In presenting the highlights of these reports, I will use them to illustrate the points made earlier in this presentation.

Jean Kozak and Eileen McCarthy of the Division of Health Care Statistics compared hospital use by children in Canada and the United States, in an excellent example of how secondary data can be used to answer important research questions (4). The study attempted to explain why the U.S. discharge rate for children under 15 years of age in the late 1970s was substantially lower than in many other industrialized countries -- 30% lower than in Canada -- despite an overall U.S. discharge rate that was one of the highest in the world at that time. U.S.-Canadian comparisons focused on the areas of children's hospital use, child health status, and aspects of the health services systems. In each area, possible explanations for the lower U.S. discharge rate for children were presented and carefully assessed, using hospital discharge data, vital statistics, and other sources.

The authors were able to demonstrate that an important reason for the lower U.S. rate was the significantly lower rate of hospital episodes among U.S. children in families with annual incomes below $10,000 and without insurance coverage (figure 1). At the time this study was carried out, the issue of children living in poverty was reaching national prominence, along with concerns about the proportion of the U.S. population not covered by health insurance. Thanks to its international approach, this report was able to provide a concrete demonstration of the likely impact of these two issues on one segment of the American population.

In terms of comparability issues, this study was enhanced by the willingness of Statistics Canada to produce special tabulations on short-stay hospital discharges. Data comparability was also improved by using the same adaptation of the ICD to code discharge diagnoses and surgical procedures in Canada and the U.S.

A recent international study of young male homicide by Lois Fingerhut and Joel Kleinman provides a perfect example of the use of international comparisons to promote domestic interest in a health issue (5). In this case, the authors were able to use routinely produced vital statistics data to focus on an issue of special importance in the United States.

While it is well known that homicide mortality is very high among young American males, to make the statement that U.S. homicide mortality for this group is 4 times as high as in any other industrialized country, and 60 times the level of the country with the lowest rate -- as Fingerhut and Kleinman did -- is a sure way to raise domestic interest. Although some differences in the definition of homicide may exist across countries, they are certainly overshadowed by the extremely large differences in homicide mortality rates.

Tom Stephens and Charlotte Schoenborn's U.S.-Canada comparison focused on the prevalence of several important health practices in the two countries in 1985 (6). Using the U.S. National Health Interview Survey of Health Promotion and Disease Prevention and the Canadian Health Promotion Survey, they found lower rates of smoking and drinking in the U.S., and higher rates of regular exercise and seat belt use in Canada (figure 2). The higher seat belt use in Canada was expected, given differences in seat belt laws in the two countries in 1985. The higher rates of drinking and smoking in Canada were unexpected and difficult to explain. Some unexpected similarities in health practice also were found, including the proportion with a recent blood pressure checkup or a recent pap smear (figure 3). The authors had hypothesized that important differences would be found in these two measures, because of the much greater level of health insurance coverage in Canada.

The study included a careful assessment of various factors to the national differences in health practices, including the contribution of population differences and the relationships between sociodemographic characteristics and good health practices in the two countries. The authors carefully assessed the comparability of the two survey instruments, identifying certain health practices where modification of question wording would improve comparisons. Finally, they provided a very thoughtful review of the value of comparisons between national populations.

Along with Paul Placek and Selma Taffel, I have carried out comparative studies of cesarean section in industrialized countries (7). We were able to show that, in the 1970s and early 1980s, cesarean section rates were growing at roughly the same pace in most industrialized countries, regardless of the current level of cesarean deliveries, the malpractice environment, level of technology, or other factors commonly associated with rising cesarean rates. Our efforts to compare cesarean rates by type of complication however, ran into serious comparability problems related to differences in coding practices in the various countries.

A long-term international activity is the Center's International Collaborative Effort on Perinatal and Infant Mortality, or the ICE. Composed of subject area experts from the U.S. Department of Health and Human Services and ten other industrialized countries, the ICE on Perinatal and Infant

Mortality maintains a database with information from each of the member countries, and promotes comparative analyses conducted by members of the group.

ICE findings presented in a recent symposium include the existence of strong socioeconomic differences in infant or postneonatal mortality in the Scandinavian countries (8). As shown in figure 4, postneonatal mortality rate ratios as large as 1.6 were found in Norway between social groups. In Denmark, even after controlling for maternal age and parity differences, relative risks of fetal or infant death of 1.6 were reported for the lowest social group as compared to the highest group (figure 5). Despite universal access to health care in both countries, these differentials approach the level of the black-white differences in infant mortality found in the United States (figure 6), and illustrate that equal access to health care alone may not close this gap.

Although the ICE group makes use of existing data, its longevity has permitted it to begin making improvements in the quality of fetal and infant mortality data collected by the member countries. Extreme cross-country differences in the proportion of live births below 500 grams were discussed above. Evidence on the need to begin compulsory registration of fetal deaths at very early gestational ages has led directly to the recommendation by NOMESKO, an organization of Nordic countries, that fetal death registration in the Nordic countries begin at 22 weeks of gestation. In the U.S., ICE analysts detected errors in the calculation of first-day deaths in California.

A more recent international collaborative group at the Center is known as the ICE on Aging (9). The focus of this group is not on the development of a common database, but on the promotion of cross-national research on a variety of topics related to aging. The various research groups that comprise the ICE on Aging are still developing their research projects, and will make an interim report on their progress in a symposium to be held in September 1991.

A final international group in the Center is the Inter-Country Working Group on Comparative Health Statistics, or IWG, that was established specifically to promote international comparability of health data. The next speaker will provide details on one of the activities of the IWG.

Conclusion.

In conclusion, international comparative studies can provide a variety of benefits, as long as they are carefully chosen. The ground rules for international comparisons are:

- select meaningful issues;
- choose variables least likely to be affected by comparability issues;
- verify all definitions, levels of coverage, and other issues that may affect data comparability;
- recognize beforehand that accurate and meaningful comparisons may require substantial time, effort, and expense;
- and finally -- be very, very patient.

In a sense, these are the same rules one would apply in domestic comparative studies. The difference lies primarily in the potential for comparability problems, as there are so many unknowns concerning the other societies, their health care systems, and other factors, that can undermine the accuracy of the comparisons. Compensating for these technical problems, of course, is the value of findings from international studies.

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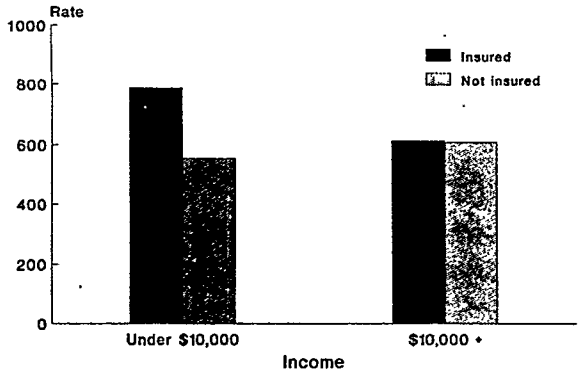
FIGURE 1

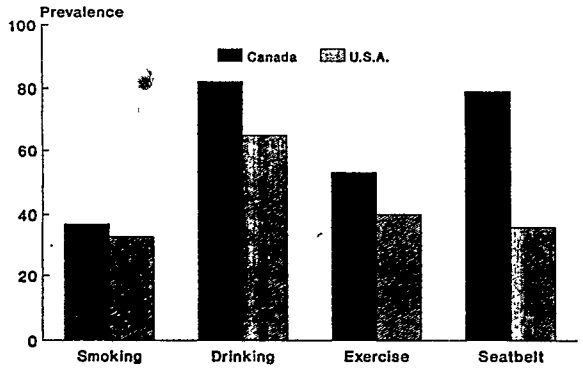
Rates of hospital episodes, children under 15, United States



Source: NCHS, HDS.

FIGURE 2

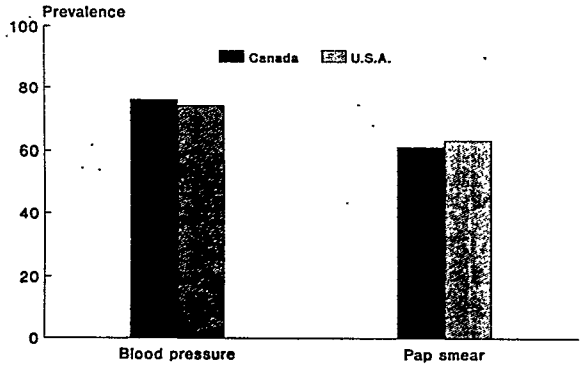
Prevalence of adult health practices Canada and the United States, 1985



SOURCE: NCHS, NHIS; Canada, HPS

FIGURE 3

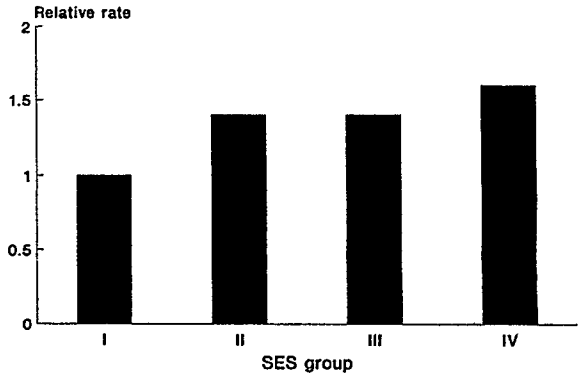
Prevalence of adult health practices Canada and the United States, 1985



SOURCE: NCHS, NHIS; Canada, HPS

FIGURE 4

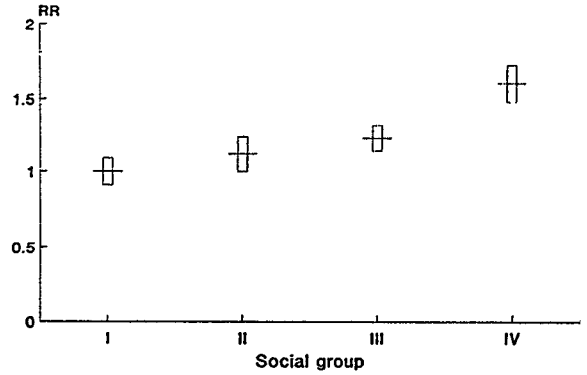
Relative postneonatal mortality by socioeconomic status, Norway 1979-82



SOURCE: Norwegian Medical Birth Registry

FIGURE 5

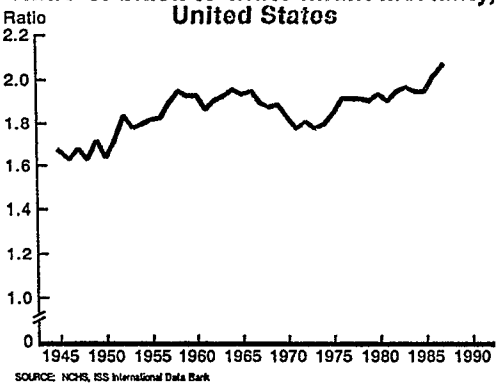
Risk ratio of stillbirth or infant death Singletons, Denmark 1983-87



SOURCE: Danish Medical Birth Register

FIGURE 6

Ratio of black to white infant mortality, United States



SOURCE: NCHS, ISS International Data Bank

A METHODOLOGY TO ASSESS THE AVAILABILITY AND COMPARABILITY OF PUBLIC HEALTH STATISTICS: AN INTERCOUNTRY INITIATIVE

Mark S. Eberhardt, National Center for Health Statistics, CDC
Thomas Hodgson, Manning Feinleib, Jacob Feldman, Gail Fisher

Comparing national health statistics between countries is a common approach to assessing the relative importance of health conditions. However, underlying this process is the basic principal that these statistics measure the burden of disease in a comparable manner. The assumption that national health statistics are of similar quality must be validated before appropriate comparisons can be made.

This validation requires detailed information on how the health-related data are collected and maintained. These details are not always readily available or recorded in a uniform manner. Moreover, this issue has become more difficult to overcome during the expanding age of computerized datasets, which often lack the needed documentation. It is for this reason, that a methodology is proposed to assess the availability and comparability of public health statistics between countries.

This methodology was initially discussed in 1990 at a meeting in Orlando, Florida by representatives or consultants for some of the national health statistical agencies in North America and Europe. At this meeting, consensus was reached that a collaboration should continue to assess the availability and comparability of national health statistics from a broader perspective. It was envisioned that a general "checklist" could be developed which could be applied to statistics related to many aspects of health. Representatives from Canada, England and Wales, and the United States of America (U.S.A.) made a commitment to collaborate on this project.

The approach often used to consider data comparability is summarized in Figure 1, and is contrasted with the strategy commonly used by others. The previous approach is seen on the left. First, a disease such as cancer or an event such as homicide is identified by researchers, who are interested in making international comparisons. They might assess the comparability of the datasets containing the data, or they might simply state differences in these disease specific estimates, overlooking fundamental differences between the data systems which maintained the data, i.e. coding schemes used in different countries. Conversely, those interested in data systems, such as hospitalizations or mortality data, might select a disease or set of conditions to assess the comparability of the specific data system, and overlook fundamental differences in the disease specific issues, for example clinical criteria used in different countries. In both cases, the comparisons are focused on specific topics, so general recommendations to improve data availability and comparability may or may not result from these efforts.

The proposed strategy, on the right of Figure 1, is to begin with a thorough list of data needs. Lung cancer and diabetes were selected as model conditions to develop concrete examples of data needs. The former has a rapidly fatal course after diagnosis, and the latter often results in a long-term illness with multiple long-term complications. Comprehensive sets of questions were developed for each disease which would provide the key health statistics that should be available on a national level. Approximately 175 questions were identified for each disease. Some questions were similar for both diseases. For example, "What is the incidence of disease by age, race and sex?" In contrast, some questions were disease specific. For example, "What is the average duration of diabetes before long-term complications are manifested?" OR, "What percentage of patients with early versus late stage lung cancer at diagnosis knew the warning signs for lung cancer?"

These specific questions can be categorized into several general groups (See Table 1). Once outlined, these categories will be used to select a broad subset of questions which can be used to assess the availability and comparability of the health statistics. The actual method used to assess comparability is presented below. Once assessed, it will then be possible to objectively determine if meaningful comparisons can be made. Then it should be possible to take steps that can improve access and utility of the needed data. The key point to remember is that the proposed approach considers more than what is currently available. It is therefore possible to more easily identify gaps in existing data systems.

To assess the comparability and availability of health statistics, a "checklist" was developed which provides a standard format to evaluate the characteristics of individual health statistics. This "checklist" is presented in Table 2.

To evaluate the utility of this checklist a subset of questions from the broad categories of disease burden will be selected from those enumerated for lung cancer and diabetes. In this paper, two common measures of disease impact from the list will be discussed. They are hospitalizations and mortality due to diabetes. The data were obtained from final published documents from Canada, U.S.A., England and Wales for the years 1981, 1985, and 1988.

Figure 2 presents the age standardized death rates due to diabetes. When underlying cause of death is considered, it appears that death rates due to diabetes increased very little during this time period, except for England and Wales. A large increase in diabetes mortality can be seen from 1981 to 1985 in England and Wales.

When the checklist is applied to this data several difference in data characteristics are observed. Multiple race categories are recorded on death certificates in the U.S.A., but Canada, England and Wales do not record race. In the U.S.A., England and Wales, it is possible to examine relatively small geographic units from published material, that is counties (or urban places > 10,000) in the U.S.A. and local districts in England and Wales. However in Canada, provinces which might be equivalent to states in the U.S.A. are the smallest units routinely published. Also noted was the fact that the release of published final documents containing mortality data vary between counties. For most of the remaining items on the checklist, these countries appears to have similar data. Two key issues have yet to be explored to consider biases in the data. They are whether diabetes is coded in the same order on the death certificate by the respective countries and whether undiagnosed diabetes is equally common in these countries. In the U.S.A., we know that nearly half of the people with clinical diagnosed diabetes, are unaware that they have the disease.

The second health statistic considered was the hospitalization rate for diabetes. When first listed diagnosis was considered, marked differences in rates appeared to exist, Figure 3. Rates in the U.S.A. decreased rapidly during this time period, but rates for the other countries were relatively stable.

When the checklist was applied to these data, the following differences in data characteristics were observed. U.S.A. data are restricted to civilian hospitals, and data from England and Wales exclude maternity and psychiatric hospitals. Published data for 1988 were not yet available for Canada, England and Wales. Available data from the respective countries are in different formats. More detailed coding for diabetes is available from U.S.A., England and Wales, and English and Welch data are more detailed geographically. And after 1982, England and Wales report data separately. As with mortality, the criteria in the various countries for coding diabetes on hospital discharge abstracts remains to be defined.

These results should be viewed as preliminary. It is the intention of the authors to continue refining this methodology and to apply it to the broader subset of health statistics in collaboration with the statistical agencies in Canada, England and Wales. Conclusions about the utility of this methodology are therefore reserved until this work is complete.

Difference in data comparability observed thus far are noteworthy. It appears that data from the different countries have varying degrees of detail. This will make it more difficult to interpret observed difference between countries. For example, the "checklist" highlighted that race is not available from Canada, England and Wales. Without this demographic factor, it may not be possible to compare the mortality data for diabetes between countries. We know in the U.S.A., that black Americans have a higher diabetes mortality compared to white Americans, so observed differences between countries may be due to racial composition.

Nevertheless it is possible to make several conclusions regarding this work. Foremost is that NCHS is strengthening its long-term effort to improve availability and comparability of national health statistics for intercountry comparison. As you know, the Year 2000 health objectives for the U.S. have included goals to improve availability and comparability of the national health statistics. This project will proceed in concert with this objective. The project has received a commitment from several countries and interest of others. Only with this high level commitment will it be possible to develop a consensus approach for data comparability of national data systems. A framework for a standard method to assess the availability and comparability of national health statistics has been proposed, and comments are being received and considered for improving the comparability assessment approach.

If this method proves useful, it may be possible to make recommendations and modify U.S. data systems to improve the availability and comparability of data, and to develop recommendations for intercountry comparison criteria which could be used to determine if comparisons are valid. It also seems reasonable to suggest that this comparability assessment approach should have practical applications for comparison of data between states and within states.

Figure 1
Approaches to Assessing Data Comparability

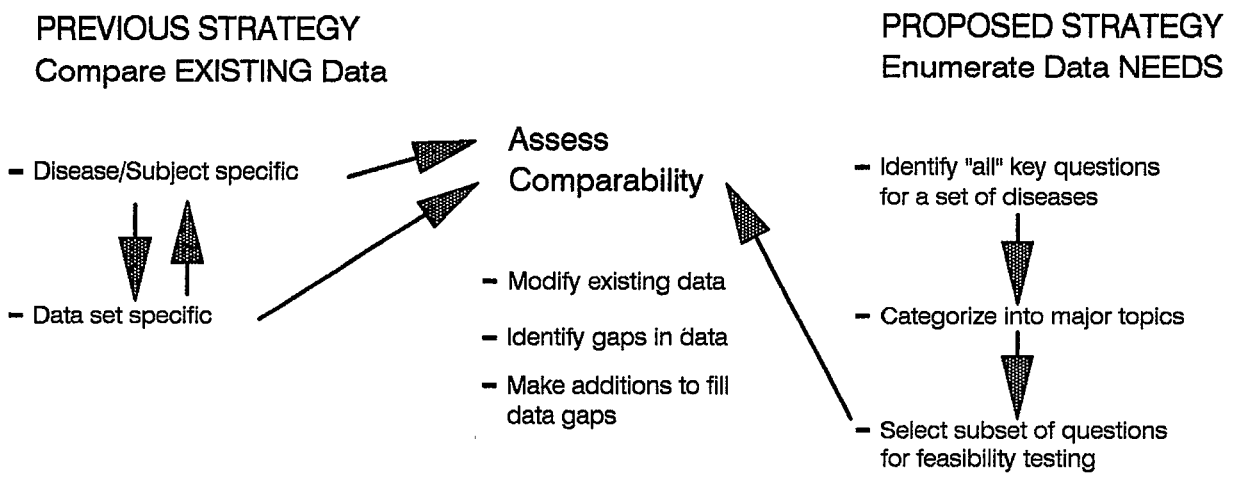


Table 1
General Measures of Disease

MAGNITUDE OF THE CONDITION

- Natural history
- Descriptive epidemiology

BURDEN OF THE CONDITION

- Quality of life
- Health care utilization
- Cost

PREVENTION AND CONTROL OF DISEASE

- Risk factors
- Screening and diagnosis
- Treatment and preventive services
- Knowledge, attitudes, and practices
- Health care funding mechanisms
- Barriers to care
- Research

Table 2
Data Comparability Checklist

1) Data obtained through:

a) Vital records
b) Examination survey
c) Household interview survey
d) Health provider survey
e) Health facility record survey
f) Health program
g) Health registry
h) Combination (specify)
i) Other (specify)

2) Participation in survey or dataset:

a) Voluntary (Compensated)
b) Voluntary (Uncompensated)
c) Mandatory
d) Combination

3) Data coding schemes used:

a) Specify (i.e. ICD 9-CM, In-house codes, etc.)

4) Geographic scope of dataset:

a) National
b) Sub-national (multiple sites)
c) Sub-national (one site)

5) Smallest geographic estimate possible with data:

a) National
b) Region
c) State, Province, District
d) County
e) Other (specify)
f) Unknown

6) Coverage of database:

a) Total national sample
b) Total sample of sub-national group
c) Probability sample (specify)
d) Convenience sample (specify)

7) Limitation of generalizability of data:

a) None
b) Age limitations
c) Gender specific
d) Income limitations
e) Race or ethnic specific
f) Program eligibility
g) Institution/non-institution
h) Civilian/military limitations
i) Other (specify)

8) Possible to link individual records to other data:

a) Yes b) No c) Unknown

9) Possible to trace individual person/event longitudinally:

a) Yes b) No c) Unknown

10) Relative standard error of statistic:

a) <10% b) 10-30% c) 30-60% d) >60% e) Unknown f) Not Apply

11) Criteria for minimum statistical reliability in publications:

a) Specify b) Unknown c) Not apply

Table 2 (continued)
Data Comparability Checklist

12) Specify results of validity study of data for:

a) Sample bias
b) Misclassification bias
c) Unknown
d) Not apply

13) Percent of national estimate contained in sample:

a) <1% b) 1-5% c) 5-25% d) >25% e) Unknown

14) Frequency of data collection:

a) 3 months or less
b) Yearly
c) Every 2-4 years
d) Every 5-10 years
e) > every 10 years
f) Once
g) Never

15) Minimum time for public release of non-stratified estimates:

a) <3 months
b) 3 months - 1 year
c) 2-4 years
d) 5-10 years
e) >10 years
f) Unknown

16) Minimum time to release demographic-specific estimates:

a) <3 months
b) 3 months - 1 year
c) 2-4 years
d) 5-10 years
e) >10 years
f) Unknown

17) Year(s) of most recent data: 19__ - 19__

18) Year that next available data will be release: 19__ - 19__

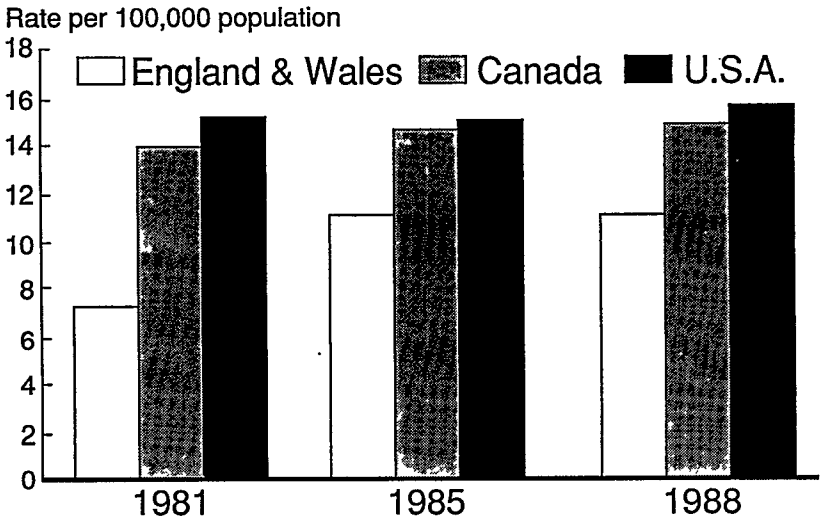
19) Format of available data in hardcopy format:

a) Computer printout
b) Published tables
c) Agency report
d) Journal article
e) Microfilm
f) Log books
g) Not available
h) Other (specify)

20) Format of available data in machine readable format:

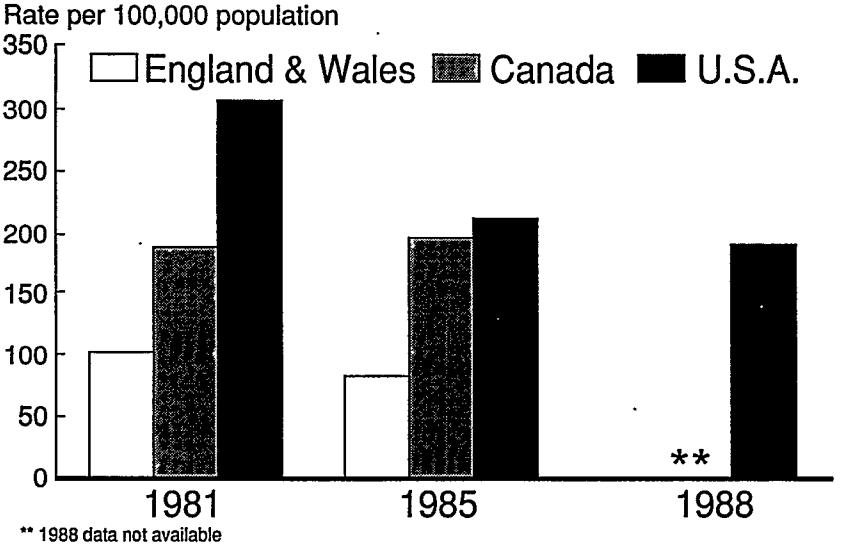
i) Reel tape
j) Cassette tape
k) Diskette (specify size)
l) Network bulletin boards
m) On-line
n) CD-ROM
o) Not available
p) Other (specify)

Figure 2
Death rates for diabetes mellitus



Age standardized to IARC European population
SOURCE: NCHS, National Vital Statistics System; Statistics Canada; England and Wales Office of Population Censuses and Surveys.

Figure 3
Hospitalization rates for diabetes mellitus



** 1988 data not available
Age standardized to IARC European population
SOURCE: NCHS, National Vital Statistics System; Statistics Canada; England and Wales Office of Population Censuses and Surveys.

REGIONAL VARIATIONS IN SOVIET MORTALITY IN INTERNATIONAL PERSPECTIVE

W. WARD KINGKADE, U. S. BUREAU OF THE CENSUS

Background

Mortality decline in the developed countries has been associated with a specific course of evolution in the structure of mortality by cause of death. The preindustrial mortality pattern was characterized by high mortality from infectious disease. The historical decline in mortality has been brought about largely by increased control over infectious disease, due as much to improvements in public sanitation and rising living standards as to vaccines (Goldscheider, 1971; United Nations, 1973). Throughout the industrial world degenerative diseases are now the leading causes of death. These differ from infectious disease in that they involve processes which are typically irreversible and which are difficult to detect until they have progressed into rather advanced stages. It is generally agreed that prevention of these diseases requires subtle adjustments in lifestyle that fall outside the scope of traditional medical approaches to health care.

While increases in mortality from degenerative disease and accidents are a familiar element of the epidemiological transition in the West, a distinctive aspect of the recent history of Eastern Europe is that in several countries in this region, including the Soviet Union (Andreyev and Dmitriyeva, 1987), these trends have resulted in an overall rise in mortality from all causes combined. East European demographers have coined the term "civilization diseases" to cover the types of mortality which become more prevalent with societal modernization (Tolokontsev, 1987). They are the dominant feature in recent Soviet mortality experience.

Among countries of the world, the Soviet Union encompasses one of the most heterogenous populations geographically, socioculturally and socioeconomically. This diversity is reflected by systematic variations in demographic behavior between different segments of the Soviet population. It is widely held that the indigenous populations of the various regions of the Soviet Union are at different stages of the demographic transition from natural to controlled reproduction, one element of which is the shift in etiological structure of mortality from primarily exogenous to endogenous causes of death (Vishnevskiy and Volkov, 1983; Bednyy, 1979; Karakhanov, 1983). In particular, respiratory disease mortality figures more prominently in the Central Asian mortality pattern than in those of the european regions of the USSR. Certain Soviet authors have attributed the differential importance of this cause category, which tends to play a greater role in Third World mortality patterns than those of highly industrialized countries, to the Central Asian population's lower level of development (Vishnevskiy and Volkov, 1983).

Until lately, analysis of regional differentials in Soviet mortality by cause of death has been hampered by scarcity of available data. Goskomstat's 1988 population handbook (Goskomstat, 1989) is certainly a welcome contribution, representing the first publication since the Second World War of comprehensive data on the cause structure of mortality for the various regions of the USSR. The data are provided in age and sex detail separately for the urban and rural populations of each union republic as of 1987 and 1988. In the analysis below these data are utilized to assess the respective cause-specific mortality levels of these republics, both relative to one another and in comparison to various industrialized countries.

Methodology

Several alternative methodologies for comparison of cause-specific mortality levels across populations are available. One of the soundest is the familiar technique of direct standardization, in which age schedules of cause-specific mortality rates are applied to a standard age distribution in order to control for differences in age structure between populations (Lilienfield and Lilienfield, 1980). The standardized cause-specific death rates, which represent the overall death rates for each cause category which would prevail if each population possessed the standard age distribution, can be compared to one another to assess relative mortality levels accross populations. However, this methodology is subject to the criticism that by weighting all deaths equally it does not accurately reflect the losses of potential life implied by the given mortality schedules.

A second approach is the methodology of single decrement life tables, which purport to measure the gains in life expectancy that would result from elimination of various causes of death (Elandt-Johnson and Johnson, 1980). A serious obstacle to modern applications of this methodology is the problem of competing risks of mortality from the various causes, which necessitates an assumption about the form of interdependence between the respective cause-specific mortality schedules. Unfortunately, the traditional assumption of independence among causes of death, although suitable with respect to the infectious diseases to which the methodology was originally applied, is untenable in relation to the degenerative conditions fundamental to modern mortality patterns.

The measurement of years of potential life lost (Garcia Rodriguez and da Motta, 1989; Romeder and McWhinnie, 1977) developed in the literature on preventable mortality provides another option. In this methodology, age-specific death rates for various cause categories are weighted by the difference in years of the midpoint of the given age interval from some specified maximum age. The weighted rates can then be applied to the age distribution of the observed population or to that of any standard population. This approach to measuring loss of life has been adopted in the analysis which follows.

In order to implement the years of potential life lost (YPLL) methodology, the maximum age used to calculate potential loss must be chosen. Typically, the life expectancy of the observed population or a population at a similar level of development is employed on the argument that the attainable maximum is constrained by the state of the country's health system (Lopez, 1989). While

this solution is appropriate for health planning assessments of the performance of national health systems, the sacrifice of global perspective is unsatisfactory for present purposes. Analysis of Soviet mortality in international perspective is better served by choosing a maximum in terms of the present experience of low mortality countries. Currently attainable minimum mortality schedules implying life expectancies of 81.6 years and 87.2 years respectively for men and women have been obtained by selecting for each of 15 cause of death classes the minimum death rates for each age and sex category in a sample of low mortality countries, summing across causes to obtain overall mortality rates. The life expectancies derived from these schedules, which are higher than any thus far observed (see table A), may be considered indicative of the best attainable under the present state of the arts of medicine and public health.

Years of Potential Life Lost

Estimates of annual years of potential life lost for the USSR and union republics are compared to those obtained for the US and several european countries in table 1, where the figures are expressed relative to the appropriate mid-period populations. The countries have been chosen to represent average to poor performance among developed countries, while providing regional variety. The data reveal that injuries together with neoplasms and diseases of the circulatory system account for the majority of potential years of life lost for either sex in every country, including the USSR, while respiratory disease generally makes the smallest contribution. Diseases of the circulatory system are especially prominent among males, contributing the greatest share of YPLL in the four industrialized countries, both in the observed populations and after controlling for differences in age composition through standardization. The departure of Soviet males from this pattern in the actual population is a result of their age distribution, which remains relatively young in comparison to those of the other countries and hence engenders a greater frequency of injuries. As the standardized values demonstrate, the circulatory component of Soviet male YPLL would exceed those of the other cause categories if Soviet males followed the WHO European Standard age distribution. Among females neoplasms become more important than diseases of the circulatory system in three of the industrialized countries, while the USSR and Hungary continue to exhibit greater losses of potential life through circulatory system disease.

When compared to the four industrialized countries in table 1, the USSR is found, unsurprisingly, to bear the closest resemblance to Hungary. In most instances the YPLLs for the USSR are intermediate between the (typically higher) hungarian values and those of the remaining countries. What distinguishes the Soviet case is the vastly higher loss of potential life through respiratory system disease. In addition, the USSR exceeds the other countries in YPLL due to injuries, particularly among males. Among women the Soviet Union also ranks highest in YPLL from diseases of the circulatory system.

Systematic variations between regions of the USSR in loss of potential life by cause of death are evident in the union republic data in table 1. Respiratory disease exhibits the most pronounced regional differentials in YPLL, ranging from levels in the Baltic republics comparable to (among females, frequently lower than) those of the four industrialized contries to values many times greater in Central Asia; the european union republics fare considerably better than other union republics on this indicator. The unusually high YPLLs through injuries in Armenia undoubtedly reflect the effect of the December 1988 earthquake[1]. With this exception, the european union republics are distinguished by the highest male YPLLs from injuries; no comparable disadvantage is apparent for the female population of the european republics. Loss of potential life from neoplasms tends to be lower in Transcaucasia and Central Asia than in the european republics, as well as the four industrialized countries in many instances. In general, circulatory system disease accounts for greater loss of potential life in european union republics than elsewhere in the Soviet Union, although standardization reduces the differential. Curiously enough, when differences in age composition between republics are controlled by standardization the greatest circulatory disease YPLLs appear in Turkmenia, whose neighbouring republics exhibit some of the lowest YPLLs for this cause category.

The figures in table 1 highlight the role of age structure in loss of potential life in Soviet Central Asia. The republics in this region, whose fertility levels resemble those of many Third World countries, are growing rapidly through natural increase and have age distributions weighted heavily in favor of infants and children. As a result, these republics register substantial loss of life from causes of death whose incidence is high in infancy, such as diseases of the respiratory system. According to table 1, the central asian populations would experience major reductions in YPLL if there age distributions came to resemble the WHO European Standard. Thus, one benefit of the fertility decline that is now occurring in Central Asia will be the forseeable reduction in the child dependency burden, whose health dimension finds expression here in the loss of human potential inherent in infant and child mortality.

The measure of potential life lost employed thus far expresses annual loss of life relative to the mid-period population, indicating the intensity of loss of life per average person at risk. An alternative measure with a different interpretation is YPLL per death, which reflects the differing losses entailed by deaths in the various cause categories. When standardized, this measure becomes a sensitive indicator of the youthfulness of the given mortality schedules; in unstandardized form it reflects the youthfulness of the observed age distributions of deaths. Estimates of YPLL per death are presented for the USSR and its union republics along with the four industrialized countries in table 2.

According to the figures in table 2, the average death entails a greater loss of potential life in the USSR than in any of the four contries. Some of the differential based on observed deaths is due to the USSR's more youthful age structure, as comparison of the standardized with the unstandardized values indicates. Nevertheless,

when differences in age composition are eliminated the Soviet Union continues to exhibit a mortality pattern making for more loss of potential life. The importance of respiratory disease and injuries in the Soviet mortality profile undoubtedly contributes to the greater overall loss of life in the average Soviet death, since mortality from these two causes tends to have a younger incidence than mortality from the other causes. However, within cause categories the Soviet average losses are often significantly greater than those obtained for the other countries. This is especially graphic in the case of respiratory disease, suggesting a reserve of "preventable" infant and child mortality which has been substantially reduced in the four industrialized countries.

The union republic estimates in table 2 reveal major regional variations in the loss of potential life associated with deaths in the respective cause categories, particularly injuries and respiratory disease. Differences in age structure between republics explain much of the interrepublic differentiation in YPLLs per average observed death. Standardization substantially reduces the variability in union republic values. However, sizeable differentials persist in several cause categories after population age structures have been equated. The central asian/transcaucasian (Armenia excluded) respiratory disease mortality pattern evidently entails a considerably younger average age at death than that of european union republics, since the average death from respiratory disease in the former regions would exceed the corresponding average in the latter republics by some 15 to 25 years if each population followed the standard age distribution. Appreciable differentials remain after standardization in YPLLs per death from circulatory system diseases and injuries as well, particularly among women, with Central Asia and Transcaucasia again registering greater average loss than european union republics.

Conclusion

A country's achievements in mortality reduction are limited by the present state of technology and medical science, among other things. The measure of preventable mortality developed in this paper has sought to quantify a society's potential for mortality reduction subject to these constraints. Analysis of Soviet mortality employing this device has indicated the possibility for substantial savings of human potential through mortality reduction. Whether these savings are realized will depend on the progress and quality of Soviet efforts to develop the health care system, such as the ambitious campaign to provide the population with medical checkup examinations, as well as the Soviet Union's general economic development.

[1]The annual data reveal an upsurge of accident deaths in this republic in 1988, principally in urban areas.

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Table A. Life Table Constructed from Minimum Mortality Schedule.

MALE

Age	m(x)	q(x)	l(x)	L(x)	T(x)	E(x)	k(x)
0	.00357	.00356	100000	99663	8155549	81.56	.05
1	.00011	.00044	99644	398473	8055886	80.85	1.64
5	.00009	.00045	99600	497890	7657412	76.88	2.50
10	.00007	.00035	99556	497691	7159522	71.91	2.50
15	.00036	.00180	99521	497156	6661832	66.94	2.50
20	.00053	.00265	99342	496051	6164676	62.06	2.50
25	.00043	.00215	99079	494862	5668624	57.21	2.50
30	.00045	.00225	98866	493775	5173762	52.33	2.50
35	.00073	.00364	98644	492321	4679987	47.44	2.50
40	.00110	.00548	98284	490075	4187666	42.61	2.50
45	.00195	.00970	97745	486356	3697592	37.83	2.50
50	.00330	.01636	96797	480025	3211236	33.17	2.50
55	.00571	.02815	95213	469364	2731211	28.69	2.50
60	.00869	.04253	92533	452826	2261847	24.44	2.50
65	.01431	.06908	88598	427688	1809020	20.42	2.50
70	.02500	.11765	82478	388130	1381332	16.75	2.50
75	.04273	.19303	72774	328753	993202	13.65	2.50
80	.06628	.28429	58727	251895	664450	11.31	2.50
85	.10188	1.00000	42031	412555	412555	9.82	2.50

FEMALE

Age	m(x)	q(x)	l(x)	L(x)	T(x)	E(x)	k(x)
0	.00301	.00300	100000	99718	8721577	87.22	.06
1	.00007	.00028	99700	398730	8621859	86.48	1.52
5	.00004	.00020	99672	498310	8223129	82.50	2.50
10	.00002	.00010	99652	498235	7724819	77.52	2.50
15	.00009	.00045	99642	498098	7226584	72.53	2.50
20	.00014	.00070	99597	497812	6728486	67.56	2.50
25	.00012	.00060	99528	497488	6230674	62.60	2.50
30	.00019	.00095	99468	497103	5733186	57.64	2.50
35	.00035	.00175	99373	496432	5236083	52.69	2.50
40	.00060	.00300	99200	495255	4739651	47.78	2.50
45	.00114	.00568	98902	493107	4244395	42.91	2.50
50	.00193	.00960	98340	489341	3751288	38.15	2.50
55	.00300	.01489	97396	483354	3261948	33.49	2.50
60	.00474	.02342	95946	474111	2778593	28.96	2.50
65	.00773	.03792	93699	459611	2304483	24.59	2.50
70	.01356	.06558	90146	435950	1844872	20.47	2.50
75	.02382	.11241	84234	397500	1408922	16.73	2.50
80	.04338	.19568	74766	337254	1011421	13.53	2.50
85	.08920	1.00000	60136	674168	674168	11.21	2.50

Table 1. Years of Potential Life Lost by Cause of Death, USSR and Selected Industrialized Countries. (figures per 100000 population)

Male	All Causes (Actual)	Circu-latory (Actual)	Neo-plasms (Actual)	Respir-atory (Actual)	Injur-ies (Actual)	Resid-ual (Actual)	All Causes (Stand.)	Circu-latory (Stand.)	Neo-plasms (Stand.)	Respir-atory (Stand.)	Injur-ies (Stand.)	Resid-ual (Stand.)
Hungary (1988)	22126	7454	4787	869	4184	4832	23351	7800	5035	941	4181	5395
England (1987)	12632	4736	3207	770	1554	2367	12643	4697	3183	740	1495	2529
Spain (1985)	11531	2959	2899	749	2188	2736	12510	3264	3202	822	2144	3078
USA (1986)	14363	3842	2682	673	3704	3462	15433	4547	3157	752	3392	3585
USSR (1987-88)	23881	5576	3612	2998	6017	5678	25737	7509	4565	2816	5750	5097
RSFSR	23754	6281	4130	1701	6837	4806	25687	7891	4929	1843	6403	4620
Ukraine	21129	6097	4207	1453	5329	4043	22610	7093	4641	1604	5182	4092
Belorussia	19362	5856	3702	1427	5084	3293	21645	7420	4415	1636	4930	3243
Estonia	20794	6706	3822	780	5690	3797	22433	7926	4374	842	5509	3782
Latvia	21189	6936	3967	797	5990	3499	22923	8187	4558	894	5772	3511
Lithuania	19226	5217	3512	939	6136	3421	21160	6426	4187	1090	6017	3440
Moldavia	23181	4528	3111	2903	5854	6784	25367	6472	4015	2780	5713	6387
Georgia	19078	6200	2210	2696	3356	4616	20460	7669	2574	2453	3274	4490
Armenia	24466	3056	2150	2408	11971	4881	24755	4990	3103	2166	10289	4207
Azerbaydzhan	22526	4308	2138	6575	3078	6428	24195	8200	3484	4450	2843	5218
Kazakh SSR	24429	4184	2989	4256	6138	6862	26544	6947	4689	3587	5675	5647
Kirgiz SSR	28679	3201	1907	9557	5123	8892	27120	6437	3343	6212	4897	6230
Tadzhik SSR	34377	2111	1321	10977	3174	16795	24971	5005	2530	5582	2919	8935
Turkmen SSR	38054	4155	1666	13615	4406	14211	31906	8727	3307	7295	3942	8635
Uzbek SSR	30238	2772	1463	10123	4204	11676	25741	6509	2769	5469	3663	7330
Female												
Hungary (1988)	18899	7870	4748	587	1841	3853	16997	6188	4247	547	1772	4243
England (1987)	13542	4837	4530	875	695	2604	11526	3502	4112	687	693	2532
Spain (1985)	9799	3341	2676	571	736	2476	9239	2810	2632	506	741	2550
USA (1986)	11521	3368	3322	661	1345	2825	11825	3322	3574	658	1324	2947
USSR (1987-88)	19191	7249	3303	2352	2000	4287	18208	6563	3382	2169	2016	4078
RSFSR	18002	7911	3657	1141	1874	3419	16469	6499	3483	1096	1915	3476
Ukraine	18062	8811	3758	1048	1544	2902	15753	6691	3455	936	1594	3076
Belorussia	15296	7053	3179	1078	1409	2577	14498	6214	3167	1006	1457	2653
Estonia	17158	7805	3785	570	1868	3131	15130	5932	3494	564	1914	3226
Latvia	17347	8117	3839	557	1926	2907	15188	6241	3534	516	1955	2941
Lithuania	14457	5834	3418	640	1784	2779	13651	4966	3361	613	1827	2884
Moldavia	21106	7238	3019	2141	2591	6118	22295	8267	3398	1984	2550	6095
Georgia	15774	6967	2464	2173	1097	3073	15305	6507	2528	2127	1098	3045
Armenia	29191	3538	2120	2514	16731	4288	28902	4816	2744	2140	15334	3868
Azerbaydzhan	19553	4787	1920	6094	1487	5265	19977	7274	2708	4339	1306	4350
Kazakh SSR	18992	4821	2866	3661	2150	5495	19312	6015	3622	2961	2029	4686
Kirgiz SSR	24530	4298	1893	8394	2300	7645	22784	6711	2873	5543	2001	5657
Tadzhik SSR	32354	2946	1281	11001	1767	15359	24763	5786	2299	6140	1397	9142
Turkmen SSR	33372	4896	1877	12170	2090	12338	28556	8667	3234	6940	1688	8027
Uzbek SSR	27045	3723	1613	9299	2206	10203	23678	6965	2750	5317	1682	6965

Table 2. Years of Potential Life Lost per Death by Cause, USSR and Selected Industrialized Countries

Male	All Causes (Actual)	Circu-latory (Actual)	Neo-plasms (Actual)	Respir-atory (Actual)	Injur-ies (Actual)	Resid-ual (Actual)	All Causes (Stand.)	Circu-latory (Stand.)	Neo-plasms (Stand.)	Respir-atory (Stand.)	Injur-ies (Stand.)	Resid-ual (Stand.)
Hungary (1988)	15.421	10.711	14.491	11.688	27.834	26.275	14.908	10.093	14.274	11.379	26.430	26.982
England (1987)	11.043	8.747	10.569	6.344	34.619	17.808	11.722	9.255	11.342	6.348	34.308	19.391
Spain (1985)	13.229	8.646	13.228	8.220	35.807	17.314	12.534	8.133	13.127	7.756	33.757	16.791
USA (1986)	15.269	9.434	12.409	8.331	40.006	24.066	14.326	9.488	12.644	7.986	36.907	22.088
USSR (1987-88)	23.661	12.265	19.214	32.136	41.011	44.804	16.781	9.242	16.384	20.901	36.031	34.398
RSFSR	22.400	13.056	19.045	22.485	40.052	41.356	16.173	9.339	16.076	15.751	35.677	32.963
Ukraine	18.373	10.589	18.797	15.004	38.056	35.617	14.852	8.433	17.054	12.109	35.323	31.472
Belorussia	19.037	11.523	19.275	14.395	39.582	36.940	14.911	9.294	16.973	10.791	35.768	31.423
Estonia	18.117	10.716	17.087	20.555	37.064	35.569	14.709	8.760	15.342	17.460	33.896	30.440
Latvia	17.371	10.415	16.887	15.028	38.122	32.179	14.837	9.156	15.585	13.093	35.129	27.928
Lithuania	17.698	9.580	16.800	13.015	37.761	34.832	15.625	9.011	15.796	11.837	34.930	30.724
Moldavia	23.212	10.371	21.120	30.035	41.175	38.563	14.347	6.453	18.142	18.247	34.497	28.284
Georgia	20.409	11.444	19.330	40.609	40.164	35.835	15.643	9.226	16.920	30.362	36.241	29.278
Armenia	29.864	11.330	20.964	34.394	47.793	44.606	19.032	8.774	16.971	18.989	38.123	28.813
Azerbaydzhan	31.533	13.541	21.809	61.116	47.859	50.820	16.865	9.632	16.089	36.727	36.999	30.892
Kazakh SSR	30.157	14.394	20.359	41.989	45.880	49.916	18.519	10.488	16.143	22.562	37.989	32.793
Kirgiz SSR	36.774	12.801	22.128	52.615	48.070	57.147	18.911	9.480	17.022	24.728	37.534	35.295
Tadzhik SSR	46.725	11.539	22.108	62.661	51.263	65.626	22.480	10.023	17.024	32.783	38.352	41.332
Turkmen SSR	45.141	16.065	22.347	67.027	51.803	64.116	21.183	10.939	16.662	38.325	39.078	39.486
Uzbek SSR	41.704	11.865	22.628	63.722	52.624	62.075	19.994	9.671	16.581	35.501	38.985	36.737
Female												
Hungary (1988)	15.541	11.115	19.504	14.550	21.092	28.142	18.446	12.184	22.068	17.908	25.091	35.382
England (1987)	12.158	8.996	17.124	8.237	26.207	14.564	17.070	11.753	21.789	11.691	34.091	23.136
Spain (1985)	13.000	8.711	19.176	9.657	35.101	16.431	15.320	9.591	21.829	11.083	38.054	20.500
USA (1986)	14.236	8.420	18.478	10.749	39.265	21.119	18.351	11.328	21.968	14.101	42.085	26.721
USSR (1987-88)	19.274	11.099	23.891	35.536	41.719	47.507	20.766	11.836	25.663	37.210	42.606	47.983
RSFSR	16.997	10.977	23.116	23.136	37.592	42.183	19.213	11.684	25.289	26.965	40.401	46.227
Ukraine	15.499	10.653	24.098	15.689	37.259	39.237	17.766	11.152	26.672	18.783	41.194	44.901
Belorussia	15.467	10.389	24.316	13.604	39.092	40.298	17.798	11.629	26.272	16.037	41.270	43.095
Estonia	14.326	9.017	21.993	27.396	33.808	37.349	17.189	9.926	24.647	33.063	38.776	43.322
Latvia	14.321	9.390	22.260	18.591	32.435	34.173	17.445	10.735	25.067	23.225	37.737	39.612
Lithuania	15.202	8.973	23.489	17.644	36.714	39.479	17.993	10.213	25.733	20.964	39.536	43.386
Moldavia	22.824	13.103	28.734	37.296	44.516	40.297	19.019	10.962	27.854	29.945	40.191	36.631
Georgia	18.562	11.504	25.990	43.854	43.136	41.249	19.787	12.102	27.276	45.843	43.834	42.491
Armenia	33.487	11.963	28.292	45.456	53.953	49.117	28.497	12.250	27.084	35.757	47.650	40.475
Azerbaydzhan	30.763	13.430	27.909	67.530	56.448	56.109	24.411	14.225	26.199	55.684	47.039	44.377
Kazakh SSR	26.761	12.898	25.434	47.367	51.173	52.846	24.417	14.077	25.520	39.745	46.118	45.393
Kirgiz SSR	35.133	13.773	27.530	55.133	55.794	61.632	26.123	14.645	26.560	38.714	44.928	47.859
Tadzhik SSR	49.786	14.746	28.518	67.824	61.769	71.648	30.728	15.304	26.370	44.932	46.448	52.559
Turkmen SSR	46.054	17.620	28.544	72.182	61.591	69.052	27.970	15.458	25.620	50.737	46.671	49.790
Uzbek SSR	41.616	13.621	28.985	69.040	63.592	67.385	26.422	13.819	26.430	47.361	48.647	49.337

DATA FOR INTERNATIONAL COMPARISONS
(Discussion)

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The papers in this session have touched on many problems affecting the analysis of international vital and health statistics. I would like to go backwards and start off with Mr. Kingkade's interesting presentation of regional mortality data by various diseases for the Soviet Union. First, he discussed the question of which summary figures he should present. Because the USSR population is made up of widely diverse cultural groups with quite different age structures, the selection of a suitable standardized index becomes a difficult problem. Also, there is bound to be differences in such factors such as completeness of registration and quality of medical certifications which affect the comparability of data. However, this is the traditional approach in the study of a particular problem. A person may start, as Mr. Kingkade has done, by choosing an appropriate index and compare data, depending on the purpose of the study, for the country as a whole and for its geographic subdivision to see if more light can be shed on the problem. Then, one may want to see how the country is faring in comparison with other countries. Similarly, a person interested in a State program may look at State, county and possibly city data as well as data for other States. The validity of inferences that can be made depends on how much we know about the accuracy and quality of data.

Sam Notzon's paper reviews a number of recent studies of international data conducted by the National Center for Health Statistics. He first raised the question of why we should conduct studies on an international basis. In addition to identifying health problems, he would like to know where we stand with respective to other countries, thereby generating domestic interest on a particular health issue. This was vividly demonstrated when the National Office of Vital Statistics first published a ranking of infant mortality rates by countries. This brought a scathing editorial in a medical journal accusing statisticians of playing the numbers game because the U.S. with the best medical care system in the world couldn't possibly rank so low. The editorial suggested that some kind of an artifact in the data was responsible for the unfavorable ranking. This brings up the important question of comparability of data.

Because differences may arise from the way we do things, there are many possible pitfalls in international comparisons as Notzon points out. These artifactual differences cannot usually be detected by examing tabular data. It takes a special inquiry to uncover them. I might cite an unusual example of this. Many years ago someone noticed that the diabetes death rate was approaching epidemic proportions in The Netherlands. An inquiry showed that a Dr. Salomonson, who was in charge of nosology coding, had a special interest in diabetes as a health problem. He started an intensive query program on diabetes which significantly increased the reporting of the disease, thus creating what later became known as Salomonson's epidemic.

One of the interesting developments in recent years is exemplified by the collaboration between countries in the ICE program. Perhaps the first collaborative NCHS study of this kind was that on infant mortality trends some years ago when we observed the leveling off of the infant mortality rate in the United States after years of constant decline. Because the same phenomenon seemed to be occurring in a number of other countries, we thought an in-depth study might get at the cause of the deceleration in the infant mortality rate. We persuaded colleagues in 5 or 6 other countries to conduct an analysis of infant mortality trends following the same study protocol to see if we could isolate the factors responsible for the deceleration of the infant mortality trend. At the conclusion of the studies, we met in Washington to discuss our findings. This resulted in more hypotheses but no conclusive evidence on cause. This was not surprising because descriptive analysis, no matter how intensive, cannot demonstrate cause and effect.

The ICE perinatal and infant mortality had somewhat the same kind of a beginning but it has evolved into a long-term study. This has certain important benefits. Communication is always a problem, especially in international circles. Although English is now the universal language, the same words do not always convey the same meaning. Improved communication is certainly obtained by frequent meetings of the same group. Another important benefit is that all the collaborators are now participating in the planning of the program and making technical contributions as equal partners. They all have a stake in the success of the program.

Any statistical study requires relevant data compiled on a comparable basis. As I understand from Dr. Eberhardt's presentation, the Inter-Country Working Group is embarked on a program to develop methodology for promoting international comparability of health data so that meaningful international studies can be made. The first stage is to determine the availability of data from various sources, their quality and comparability. This will be done by a series of questionnaires. The check lists should identify data availability from various data sources and should show differences, if any, in definitions and classifications used in the different countries. On the other hand, the fact that the same data collection method was used, or that the same definitions and classifications were employed do not necessarily mean that the data are comparable or of equal completeness or quality. For example, the International Classification of Diseases was devised so that all diagnostic data can be presented on a comparable basis. However, the fact that the Ninth Revision of the ICD is being used for the classification of mortality data does not mean that the cause-of-death data are comparable.

At the time of the Sixth Revision of the International Classification of Diseases, we conducted a small study to test the uniformity with which cause-of-death coding rules were applied. We prepared a deck of 1000 medical certifications of causes of death and had coders of three countries, England and Wales, Canada and the United States coded these cases. The comparisons showed a number of differences in the application of the coding rules which provided a basis for clarifying the coding rules. Later, the Euro office of WHO conducted the same exercise with a group of European countries which provided some idea of the comparability of cause-of-death coding on the European continent.

Just on the question of comparability of cause-of-death statistics, there are many important problems other than uniformity of interpretation of coding rules. How far one can go just in the investigation of comparability of such factors as differences in medical concepts, diagnostic criteria, medical nomenclature and manner of reporting of diagnostic information is a question. Not all these issues are quantifiable, but they affect inferences that can be drawn.

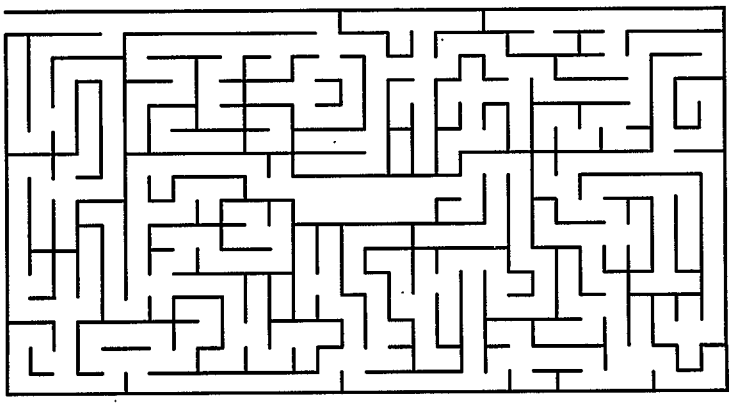
One question that occurs to me at this time is how the small group of collaborators in the Inter-Country Working Group will manage to address the numerous important but difficult questions of comparability in a number of major, but different, data collection systems. Also, how far will it go in developing methodology for studying the various issues of comparability, to say nothing about quality and completeness of data.

It seems to me that this is a very ambitious undertaking. It has the potential of obtaining far-reaching and permanent effects on the international comparability of vital and health statistics. If successful, it can do more than anything else to make health statistics more useful.

In conclusion, I might reiterate the point that Sam Notzon made about the accuracy, quality and comparability of health statistics not being peculiarly an international problem. It seems to me that a national working group, possibly under the auspices of the U.S. National Committee on Vital and Health Statistics, to improve the quality and comparability of vital and health statistics in the United States will be a worthwhile investment.

Session Q

Compression of Morbidity: Health Care for Elderly



LIFETIME MEDICARE COSTS BY TIME ON MEDICARE

James Lubitz, James Beebe, Edgar Peden, Alma McMillan,
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Introduction

There has been a concern that the projected increase in life expectancy at age 65 will increase Medicare program expenditures. However, little has been known about the relationship between longevity on the Medicare program and total lifetime per capita Medicare expenditures. Despite the fact that the Medicare Program has now been in existence for 25 years, studies of Medicare expenses have been confined to the last few years of life.[1,2] This presentation will describe the data available to estimate lifetime Medicare costs for persons enrolling in Medicare at age 65 and surviving to different ages, will outline some approaches to estimating lifetime costs, and will present some preliminary estimates of lifetime Medicare costs.

Data

The data source for this study is the Continuous Medicare History Sample (CMHS). The CMHS is a 5 percent sample of Medicare enrollees chosen on the basis of the ending digits of their Medicare identification numbers. New enrollees whose identification numbers place them in the CMHS are added to the sample, and the records of enrollees who die are retained in the file. The CMHS begins with data from 1974 and is presently current through 1989. The file contains calendar year totals of Medicare reimbursements for Medicare covered services for each enrollee in the sample.

The services covered by Medicare are:

1. Hospital inpatient and outpatient.
2. Physician.
3. Home health services.
4. Skilled nursing facility.
5. Hospice.

Services of importance to the aged which Medicare does not cover include prescription drugs and most nursing home services. Medicare covers nursing home services only at the skilled level. Only about 3 percent of all nursing home costs in the United States are paid by Medicare.[3] Thus, the pattern of total lifetime Medicare costs by age at death may be different from the pattern of total lifetime medical care costs for all services.

Methods

The basic problem in estimating lifetime Medicare costs was that currently the CMHS covers only the 16 calendar years from 1974 to 1989. Thus, complete data on lifetime Medicare costs beginning at age 65 are available only for enrollees surviving up to a maximum of 16 years on Medicare or to a maximum survival to age 80 (Figure 1). About 42 percent of the Medicare population survives up to age 80. For the remaining 58 percent, some portion of their lifetime Medicare costs must be estimated.

The data that we had to estimate lifetime costs consisted of annual per capita Medicare reimbursements for three cohorts. The first cohort were persons joining Medicare in 1974 at age 65 and followed for a maximum of 16 calendar years. (Again, see Figure 1). The second and third cohorts were persons age 75 in 1974 and age 85 in 1974. These cohorts were followed for a maximum of 16 calendar years or to maximum age at death of 90 or 100. As Figure 1 shows, we are missing the early Medicare history for enrollees who survived beyond age 80.

We are using three approaches to estimate total lifetime Medicare reimbursements for enrollees surviving beyond age 80.

1. We fit a curve relating total lifetime Medicare costs to length of time on Medicare and projected it to estimate lifetime costs beyond age 80.
2. We used actual data on costs in the last 16 years of life (that is, age 75 to 90) for persons dying at age 90 and added to this estimates of the costs from age 65 to 74 derived from other data. Specifically, we had data from the CMHS on the annual per capita costs of a group of Medicare enrollees surviving from age 65 to at least age 80 in 1989, the most recent year in the CMHS.
3. The third approach was to develop an econometric model relating annual per capita Medicare costs to calendar year, age, years before death and other factors. Then, the model could be used to "backcast" to estimate annual per capita costs for early unobserved years. This approach is still under development and results will not be presented here.

The per capita reimbursement data from the CMHS was inflated to 1989 by multiplying the annual per capita reimbursements of a cohort in year$_i$ by the ratio of 1989 average Medicare per capita costs for all enrollees to Medicare per capita costs in year$_i$ for all enrollees (Figure 2). This adjusts for program-wide trends in inflation and in the intensity

and volume of services. If effect, the estimates of lifetime costs that we will produce in 1989 dollars are estimates of what costs would be if prices and patterns of use in 1989 held throughout an enrollee's lifetime.

Results

The first approach began with a curve relating lifetime Medicare costs by length of time on Medicare before death (Figure 3). Medicare lifetime costs increase with years on Medicare before death, but the rate of increase slows as years on Medicare increase. When this curve is projected to age 90, the resulting figure is about $60 thousand, compared with observed lifetime costs of $35 thousand and $53 thousand for persons dying at age 70 and 80.

The second approach was to add to the observed data on the costs in the last 16 years of life for persons dying at age 90, estimates of costs for the first 10 years on Medicare which we could not observe. It also produced an estimate of $60 thousand for lifetime costs for persons dying at age 90.

Future Work

Future work will involve estimating lifetime Medicare costs up to age 100. We are hopeful that the econometric model will give us insight into the effects of age, time until death, and sex on the use of Medicare services. When the model is completed, we would like to model the effect on Medicare program costs of differing assumptions on future trends in longevity beyond age 65. We also plan to produce high and low estimated under varying assumptions. We feel the data will be useful for other researchers and policy analysts interested in estimating the effect on health care costs of efforts to increase life expectancy of the elderly through preventive or curative services.

References

1. Lubitz J, Prihoda R. The use and costs of Medicare services in the last 2 years of life. Health Care Financing Review. Spring 1984.

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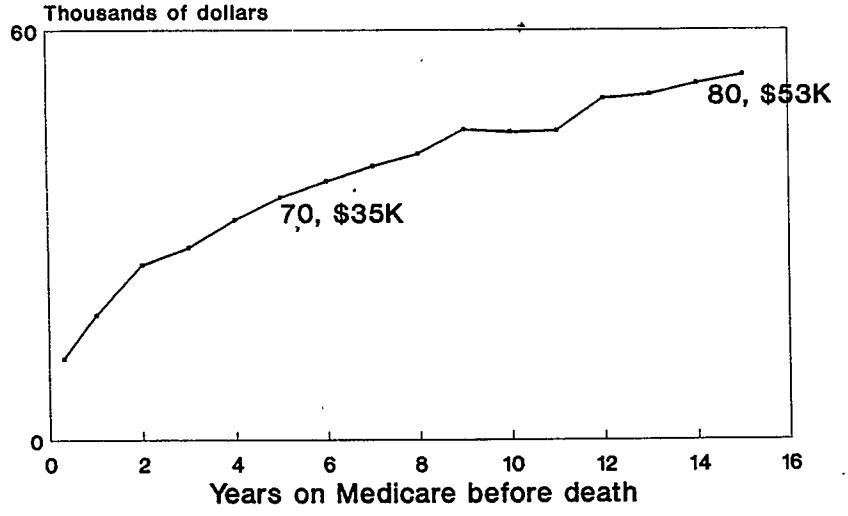
Figure 1. Three cohorts of Medicare enrollees used to estimate lifetime Medicare costs.

	Not observed	In CMHS file	
		1974----------	1989
Cohort and age:			
1.		65 ----------	80
2.	65 -------- 74	75 ----------	90
3.	65 ---------- 84	85 ----------	100

Figure 2. Adjustor used to inflate Medicare reimbursements to 1989.

$$\frac{\text{1989 Average Medicare per capita costs}}{\text{Average Medicare per capita costs in year}_i} \times \text{Annual per capita for cohort in year}_i$$

Figure 3. Total lifetime Medicare costs by time on Medicare before death



Costs are in 1989 dollars

POPULATION-BASED TRENDS IN ELDERLY HOSPITAL USE DURING THE LAST SIX MONTHS OF LIFE: 1970-1987

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Efforts to predict the impact of the aging population on future demands for hospital care are confounded by a number of observations. In 1987, the 12% of the total U.S. population that was ≥65 years of age accounted for 46% of hospital inpatient days[1]. The number of elderly persons in the population is increasing, due both to greater numbers of individuals entering the age group 65+ and to unprecedented declines in mortality after age 65 years. Based on the well demonstrated association between hospital utilization and age, it is expected that this growth in the elderly population will result in marked increases in inpatient utilization[2]. However, it has been demonstrated that approximately 25% of all hospitalizations among elderly individuals occurs among individuals in the last year of life[3,4]. It has also been shown that hospital utilization (measured as expenditures, days, or discharges) in the months prior to death is inversely related to age at death[4,5]. If mortality rates continue to decline at their current rate, these latter two observations will expectedly result in lower rates of utilization among decedents. It has been argued by some that, to the extent that recent increases in survival after age 65 are the result of disease prevention, reductions in hospital use prior to death may actually offset any increases in utilization brought about by greater numbers of elderly[6].

A test of the hypothesis that increased life expectancy has resulted in lower rates of utilization in the months prior to death requires longitudinal data on hospital use among persons who are near death. We are aware of only two other population-based studies of secular trends in utilization prior to death: a British study of trends 1976-1985[7] and a Health Care Financing Administration study of Medicare expenditures 1969-1982[8]. Because Medicare reimbursements increased nearly sevenfold over this time period, it is likely that any impact of age at death on utilization would have been masked. More recent data, at the level of utilization rather than reimbursements would be useful. Detailed data on utilization may also help address the question of whether increased age at death has affected the intensity of inpatient care in the months preceding death.

A valuable opportunity for such an investigation exists within Olmsted County, Minnesota. Declines in mortality among elderly Olmsted County residents over the past two decades have mirrored those reported at the national level[9]. This report addresses the issue of whether this increased survival has been accompanied by declines in hospitalization in the six months prior to death for the time period 1970-1987. Because utilization among decedents has been shown to vary markedly by cause of death[10], secular trends in underlying cause of death and cause-specific utilization rates are examined. Data on location of death, frequency of intensive care unit stays, and surgical procedures also provide information on trends in the intensity of care in the months prior to death.

METHODS

A detailed population-based study of this type is possible in Olmsted County because of a unique set of circumstances. Rochester, Minnesota, the county seat, is located 80 miles from the nearest metropolitan center and is the home of one of the world's largest medical centers, the Mayo Clinic. Consequently, more than 98% of all hospitalizations by county residents occur within the three area hospitals. All providers of medical care, including the Mayo Clinic, a second group practice (Olmsted Medical Group), and the three hospitals (Olmsted Community, Saint Marys, and Rochester Methodist), are linked by means of a patient-based medical records system. This system constitutes a single, readily available source that details all hospitalizations for each individual[11]. This data base has previously been employed to document population-based trends in hospitalization rates and hospital discharge outcomes among all elderly residents of Olmsted County, Minnesota, for 1970, 1980, 1985, and 1987[12,13].

The availability of utilization data for these calendar years afforded examination of inpatient activity in the six months prior to death among persons who died between July 1st and December 31st of each year (n = 160, 192, 216 for 1970, 1980, and 1987 respectively). Lists of decedents, ≥65 years of age and identified as Olmsted County residents on the death certificate, were obtained from tapes provided by the State of Minnesota Department of Health for 1970, 1980, and 1987. Location of death and underlying cause of death for each individual were obtained from the state data tapes. Because hospitalizations were limited to those occurring within Olmsted County, individuals whose death occurred outside Olmsted County were excluded (n = 11, 16, 8 in 1970, 1980, and 1987 respectively).

Name, birth date, death date, and social security number, when available, were used to match individuals on the state death tapes with those in the medical record data set. The numbers of decedents without a medical record on file were one in 1970, four in 1980, and none in 1987. These individuals were considered as having no inpatient activity in the six months prior to death. Individual medical records were examined, and information on hospitalizations ending within six months of date of death was abstracted by trained abstractors. Hospitalizations that ended in death were included. Information for each inpatient stay consisted of admission date, discharge date, principal diagnosis, principal surgical procedure, and intensive care unit admission and discharge dates. Surgical procedures were defined as Class 1 procedures using Eighth Revision ICDA[14] codes for 1970 discharges and ICD-9-CM[15,16] codes for 1980 and 1987 discharges. Direct transfers between the three hospitals were considered as a single hospitalization.

The analyses consisted of comparisons among time periods for age at death, location of death, underlying cause of death, and inpatient activity within six months of death assessed as decedents hospitalized, hospitalizations, and inpatient days. Rates were calculated using the number of decedents in each time period as the denominator. Tests for significant trends over time were based on logistic regression models for the proportion of hospi-

talizations and linear regression for the number of hospitalizations and inpatient days, where year of death was treated as a continuous variable.

RESULTS

Among Olmsted County residents ≥65 years of age, the proportion age ≥75 years increased from 42 to 47 percent between 1970 and 1987. This aging of the population was due in part to an 11% age- sex-adjusted decline in mortality rates (adjusted to 1970 population) among this age group over this time period.

Unadjusted hospitalization rates for all elderly residents of Olmsted County, both decedents and survivors, are presented in Table 1. The aging of the population, together with other factors, contributed to a 26% increase in hospitalizations/1000 residents over the time period 1970-1987. As a result of the 28% drop in mean length of stay, however, total hospital days declined 8%.

Table 1. UNADJUSTED HOSPITAL UTILIZATION RATES
OLMSTED COUNTY RESIDENTS AGE 65+

	1970	1980	1987
Hospitalizations per 1000 residents	244	291	307
Hospital days per 1000 residents	2834	2844	2597
Mean length of stay (days)	11.6	9.7	8.4

To investigate the possible contribution of increased age at death to the decline in hospital days observed for all Olmsted County residents, we examined the records of residents age ≥65 years who died in the county between July 1 and December 31 (n=149 in 1970, 176 in 1980, and 208 in 1987). These individuals exhibited a significant increase in age of death (p=.001), with median ages at death of 79 years in 1970, 82 years in 1980, and 83 years in 1987.

Table 2 provides data for all three time periods combined and reveals the expected association between hospital utilization in the six months prior to death and age at death, with individuals age ≥85 years at time of death being hospitalized less than individuals age 65-84 years

Table 2. UTILIZATION 6 MONTHS PRIOR TO DEATH
OLMSTED COUNTY RESIDENTS AGE 65+
JULY 1 THRU DECEMBER 31, BY AGE GROUP

	AGE (YEARS) 65-74	75-84	85+
# of Decedents	134	194	205
Decedents Hospitalized	61%	63%	56%
Hospitalizations per 1000 Decedents	978	1077	790
Hospital Days per 1000 Decedents	1260	1366	782

Secular trends for inpatient utilization for elderly decedents are provided in Table 3. There were no significant declines 1970-1987, despite the significant increase in age at death over this time period.

Table 3. UTILIZATION 6 MONTHS PRIOR TO DEATH
OLMSTED COUNTY RESIDENTS AGE 65+
JULY 1 THRU DECEMBER 31

	1970	1980	1987	p
# of Decedents	149	176	208	--
Decedents Hospitalized	60%	61%	59%	.741
# Hospitalizations per 1000 Decedents	986	915	933	.618
# Hospital Days per 1000 Decedents	12960	10890	10090	.103

Secular trends in hospital utilization by age group for 1970 through 1987 are presented in Tables 4-7. The significant decline over time in inpatient days/1000 among decedents 85 years of age and older is primarily the result of a decline in mean length of stay from 14.3 days in 1970 to 7.8 days in 1987. No other significant trends or consistent patterns were apparent across measures or among age groups.

Table 4. NUMBER OF DECEDENTS
OLMSTED COUNTY RESIDENTS AGE 65+
JULY 1 THRU DECEMBER 31, BY AGE GROUP

AGE (YRS)	1970	1980	1987
65-74	43	50	41
75-84	66	57	71
85+	40	69	96

Table 5. HOSPITAL DAYS/1000 DECEDENTS
OLMSTED COUNTY RESIDENTS AGE 65+
JULY 1 THRU DECEMBER 31, BY AGE GROUP

AGE (YRS)	1970	1980	1987	p
65-74	13770	11460	12760	.751
75-84	12920	14590	13620	.806
85+	12150	7370	6330	.010

Table 6. HOSPITALIZATIONS/1000 DECEDENTS
OLMSTED COUNTY RESIDENTS AGE 65+
JULY 1 THRU DECEMBER 31, BY AGE GROUP

AGE (YRS)	1970	1980	1987	p
65-74	1023	1020	878	.541
75-84	1045	1053	1127	.696
85+	850	725	812	.913

Table 7. PROPORTION OF DECEDENTS HOSPITALIZED
OLMSTED COUNTY RESIDENTS AGE 65+
JULY 1 THRU DECEMBER 31, BY AGE GROUP

AGE (YRS)	1970	1980	1987	p
65-74	58%	66%	58%	.886
75-84	62%	67%	60%	.893
85+	60%	52%	57%	.867

Olmsted County residents ≥65 years of age who died in the last half of the year accounted for 2% of the total elderly population in 1970, 1980, and 1987. In the six months prior to death, these individuals accounted for 9%, 6%, and 6% of all hospital discharges by elderly Olmsted County residents and 10%, 8%, and 8% of all inpatient days in 1970, 1980 and 1987 respectively.

Because utilization in the months prior to death has been associated with underlying cause of death[10], trends in cause of death and cause-specific hospitalization rates were examined. As shown in Table 8, the distributions by underlying cause of death were very similar for the three time periods under investigation. There was a shift over time from respiratory disease deaths in 1970 to "other" circulatory disease deaths in 1980 and deaths due to all "other" causes in 1987. Similar patterns were observed when these distributions for deaths in the last half of the year were compared with distributions for the entire year reported for Olmsted County, all ages, in U.S. Vital Statistics[17-19].

Table 8. PERCENT OF DEATHS BY UNDERLYING CAUSE
OLMSTED COUNTY RESIDENTS AGE 65+
JULY 1 THRU DECEMBER 31

CONDITION	1970	1980	1987
MALIGNANT NEOPLASMS 140-209[1] 140-208[2]	25% (37)[3]	24% (43)	24% (51)
CIRCULATORY DISEASES 390-458[1] 390-459[2]	49% (73)	54% (96)	49% (102)
VASCULAR DISEASE 401,403,430-458[1] 401,403,430-459[2]	14% (21)	14% (24)	14% (30)
ACUTE MI 410[1,2]	13% (19)	12% (21)	15% (32)
OTHER CIRCULATORY DISEASE	22% (33)	29% (51)	19% (40)
RESPIRATORY DISEASE 460-519[1,2]	11% (17)	8% (15)	6% (13)

Table 8. Cont.

OTHER	15% (22)	12% (22)	20% (42)
ALL CAUSE	100% (149)	100% (176)	100% (208)

[1]ICDA codes [2]ICD-9-CM codes [3]numbers of cases

Secular trends in hospital utilization by underlying cause of death are provided for the two leading causes of death, cancer and heart disease, in Table 9.

Table 9. SECULAR TRENDS IN HOSPITAL UTILIZATION
BY UNDERLYING CAUSE OF DEATH
OLMSTED COUNTY RESIDENTS AGE 65+
JULY 1 THRU DECEMBER 31

	1970	1980	1987
CANCER			
Number Decedents	37	42	51
Percent All Deaths	25%	24%	24%
Percent Hospitalized	78%	90%	80%
Median Length of Stay (Days)	15	12.5	15
HEART DISEASE			
Number Decedents	52	72	72
Percent All Deaths	35%	42%	35%
Percent Hospitalized	50%	49%	58%
Median Length of Stay (Days)	18.5	13.0	10.0

Among decedents, those who died of cancer were more likely to be hospitalized than those dying of heart disease. Rates of hospital utilization associated with cancer deaths did not differ 1970 vs 1987. Persons who died of heart disease were at slightly higher risk of being hospitalized in 1987 relative to 1970 or 1980, but for those who were hospitalized, the median length of stay dropped 46%.

The present study also addressed changes in the intensity of care delivered in the six months prior to death over this time period, with an examination of secular trends in location of death, frequency of intensive care unit (ICU) stays, and the proportion of hospitalizations that included a surgical procedure. As shown in Table 10, there was a significant shift in location of death, with a majority (54%) occurring in hospital in 1970 compared to a majority occurring outside of hospital in 1980 (62%) and 1987 (66%).

Table 10. SECULAR CHANGES IN LOCATION OF DEATH
OLMSTED COUNTY RESIDENTS AGE 65+
JULY 1 THRU DECEMBER 31

	1970	1980	1987
Hospital	54%	35%	33%
Long Term Care	29%	41%	37%
Home	17%	21%	29%
Other	<1%	3%	1%

The numbers of decedents admitted to an ICU at least once in the six months prior to death were 27, 53, and 42 in 1970, 1980, and 1987 respectively. For all three time periods combined, older decedents were significantly less likely than younger decedents to be admitted to an ICU (p=.001). There was no significant difference over time in the proportion admitted to an ICU, either among all decedents (p=.946) or among decedents who were hospitalized (p=.603). Although there was a large increase between 1980 and 1987 in the proportion of discharges among decedents that included a Class 1 surgical procedure, there was no significant trend across all three time periods (31/140 in 1970, 31/170 in 1980, 58/195 in 1987; p=.111).

DISCUSSION

There was an 11% decline in age- sex-adjusted mortality rates among elderly Olmsted County residents 1970-1987; and data for 1970, 1980, and 1987 combined support previous reports of decreasing utilization with increasing age at death. However, these two factors did not result in any significant declines over this time period in either the proportion of decedents hospitalized or the rate of hospitalizations per 1000 decedents in the six months prior to death (Table 3).

Although the trend did not reach significance, there was a tendency for fewer hospital days/1000 elderly decedents over the time period 1970-1987. The decline in days was due to shorter hospital stays rather than fewer hospitalizations. The decline in inpatient days among decedents contributed to a decline in total days for all elderly Olmsted County residents 1970-1987 (Table 1). Findings also suggest that the amount of total utilization accounted for by decedents was less in 1980 and 1987 than in 1970.

For certain comparisons in this study, the power to detect differences was limited by small sample sizes. Conversely, given the multiple number of comparisons employed, instances where significant differences were found should be interpreted with some caution. The data presented here are limited to utilization six months prior to death. Examination of longer time periods, e.g. 12 months or 36 months prior to death, may reveal different findings. It is also possible that the findings for persons who died in the last six months of the year are not representative of six months utilization for decedents throughout the year. We examined the six months of data by month and quarter of death for each year and all three years combined. We found no evidence to suggest bias, with the exception of fewer hospital days per 1000 decedents in the third quarter (8853/1000) compared to the fourth quarter (11274/1000) in 1987 (p=.037, Wilcoxan Rank Sum Test).

The conclusions of the present study do not differ substantially from those of two other studies of secular trends in utilization prior to death. Henderson et al.[7] linked nearly 142,000 death records to hospital discharge abstracts to examine utilization in the 12 months prior to death among elderly residents of Oxford England, 1976-1985 (number of decedents = 141,817). The authors reported no significant change in either hospital days per decedent or hospital days per total population, despite increases in life expectancy 1976-1985. Despite similarities in study design, differences between the U.S. and Britain in both definitions of care and in the variables affecting usage make direct comparisons difficult. A second study, by the Health Care Financing Administration[8], employed different Medicare data bases to examine secular trends in annual expenses among both Part A and Part B enrollees who died during the year. They reported a 14.5 percent increase in per capita reimbursements among decedents between 1967 and 1982. However, because this was similar to the 14.3 percent increase observed for survivors over this time period, the authors concluded that high cost, life prolonging efforts for persons near death were not the source of increasing Medicare program costs. These Medicare findings appear to refute the argument that increases in life expectancy have been associated with declines in utilization among decedents. However, any impact of increasing age at death on reimbursement may have been masked by the dramatic increases in Medicare expenditures during the time period under investigation. Utilization rates at the national level fluctuated dramatically in response to both Medicare, 1965-1983, and Prospective Payment, post 1983. Hospitalization rates in Olmsted County have traditionally been well below U.S. rates[11], and the fluctuations in utilization following changes in reimbursement have been less in Olmsted County than nationally[13]. Therefore, the opportunity may exist in Olmsted County for a closer examination of determinants of utilization other than those related to reimbursement.

Both Henderson et al.[7] and Riley et al.[8] suggested that data on admissions and expenditure did not provide any evidence of a secular trend toward increased intensity of care in the period prior to death. Specific information about events during hospitalization was not available in either of these studies. Information from Olmsted County revealed that a greater proportion of deaths occurred outside the hospital in 1987 vs 1970. No significant trends were apparent in either intensive care unit admissions or surgical procedures. This data, together with the significant decline 1970-1987 in the number of hospital days in the months prior to death among persons $\geq$85 years of age, argue against any increase in life prolonging efforts over time. Interpretation of these findings, however, depends in part on whether reduced inpatient activity is viewed as a more humanistic approach to death and dying or as evidence of rationing.

In a previous publication[13], we reported population-based trends in hospital use among all elderly residents of Olmsted County. Age-adjusted comparisons demonstrated that aging of the population did not completely account for the observed increases in hospital discharge rates over time. We discussed the multiple determinants of inpatient utilization, including levels of morbidity, access to care, availability of alternative sources of care, practice styles, methods of reimbursement, societal norms and attitudes, etc. The findings presented here suggest that the associ-

ation between utilization prior to death and age at death is similarly discretionary. While increased age at death 1970-1987 may have contributed to fewer total inpatient days, there were no significant declines in either the proportion of decedents hospitalized or the number of hospitalizations six months prior to death. The absence of any such declines may be interpreted to suggest that recent increases in life expectancy have been accompanied by changing attitudes about the age at which death should be considered premature.

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TRENDS IN CARDIOVASCULAR DISEASE IN THE ELDERLY AND THE COMPRESSION OF MORBIDITY

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It is well-known by now that the US is experiencing a dramatic increase in the numbers and proportions of people aged 65 and over. The population aged 65 and over is projected to grow to over 17.3% by the year 2020. In 1990, there were an estimated 31.8 million people aged 65 and over. The potential impact of these changes on health care and social services for future elderly have sparked intense debate. Alternative future scenarios have been proposed: one predicts a growing crisis in medical care as an unprepared health care system struggles to provide services to larger and larger numbers of ill and disabled elderly. Another view suggests that, due to reductions in risk factors such as smoking and improvements in medical treatments, the onset of chronic disease will be postponed to later ages, closer to death. If risk factor reduction and improved medical treatment is leading to a 'compression of morbidity', this trend should be evident for cardiovascular disease which has been the target of significant intervention efforts over the past 20-30 years.

Cardiovascular disease accounts for a significant proportion of morbidity, disability and mortality among the elderly. Diseases of the heart are the leading cause of hospitalization among people aged 65 and over. While the decline in coronary heart disease mortality (CHD) in the past two decades seems indisputable, the direction and existence of changes over time in the incidence of CHD remains controversial. Assessment of such changes is difficult and complex: changes over time in diagnostic procedures may influence case-detection; risk factor reductions and medical treatment may reduce severity without eliminating disease, leading to development of symptomatic disease at a later stage and age. As survival with cardiovascular disease improves, the influence of comorbid conditions on progression becomes more important.

According to Fries' hypothesis, a 'compression of morbidity' will occur if there is a fixed limit to the life span and if the age at onset of disease shifts over time to later ages, thus 'compressing' the period of morbidity. This analysis focuses on an examination of the evidence for a compression of morbidity in people with four cardiovascular diagnoses: angina pectoris (AP), myocardial infarction (MI), congestive heart failure (CHF) and stroke (CVD). Stroke in these analyses is restricted to atherothrombotic, intracerebral, cerebral embolism, and stroke indeterminate.

Study Design. At Kaiser Permanente's Northern California Regional Division of Research, a study of two cohorts of Kaiser members aged 65 and over in 1971 and 1980 is being done. Each cohort will include 3,000 people randomly selected within age-sex strata. Medical chart review is done for each subject for a 9-year period forward from baseline. Data on 32 chronic conditions, and on all outpatient and inpatient services utilization are being collected. All subjects have taken the Multiphasic Health Checkup (MHC), a standardized screening examination that includes an extensive array of risk factor information gathered by questionnaire and physical examination. The diagnoses examined in these analyses are derived from physician diagnoses found in the medical chart review. Standardized diagnostic criteria have been applied for both cohorts in an effort to reduce biases resulting from changes in medical practice. At present, data collection is not complete, so the analyses presented here are based on a total of 2,308 in the 1971 cohort and 2,595 in the 1980 cohort. A condition was prevalent if it was present at or before 1971 or 1980. Incidence was estimated as the ratio of the number of cases to the number of person-years of follow-up in nine years. Age-specific incidence rates are calculated using age at diagnosis. Comparison of the cohorts for both prevalence and incidence rates was done using the ratio of the 1980 measure over the 1971 measure. Confidence intervals for the prevalence ratios and for the incidence density ratios (IDRs) were calculated using a test-based approximation of the Taylor series approach.

Analysis of the compression of morbidity hypothesis requires comparisons of cohorts for incidence rates and prevalence. Lower prevalence in the 1980 cohort may support the compression hypothesis. Comparison of age-specific prevalence in 1980 to prevalence in 1971 for females for the four conditions revealed that AP was higher in the 1980 cohort across all age-groups, CHF was lower at younger ages and higher at older ages, MI and CVD were lower across all age groups. None of these differences were statistically significant. Analyses of differences between cohorts in age-specific prevalence among males for the four diagnoses for both cohorts revealed no statistically significant differences. Table 1 shows the incidence density ratios comparing the two cohorts for females by age for the four conditions. The IDR represents the sex-age specific incidence rate for 1980-88 divided by the same rate for 1971-79. No consistent age-related pattern of differences between cohorts was seen for stroke. All age-specific differences between the cohorts are statistically significant at the 5% level except CVD at ages 75-79 and 80+. Table 2 shows the incidence density ratios (IDRs) for males. Diagnoses of all four conditions are consistently higher in the 1980 cohort except for CVD and CHF at age 65-69 which are lower. All age-specific comparisons are statistically significant at the 5% level. The compression of morbidity hypothesis was further examined by comparing differences between cohorts in time from baseline to diagnosis and from diagnosis to death.

Table 1. Incidence Density Ratios among Females by Age at Diagnosis[1]

Diagnosis	65-69	70-74	75-79	80+
Angina Pectoris	0.42	1.14	1.55	0.79
Congestive Heart	0.21	1.87	0.83	0.96
Stroke	0*	0.67	1.03	1.01
Myocardial Infarc.	0.43	1.61	3.19	0.84

* no cases in 1980.

Table 2. Incidence Density Ratios among Males by Age at Diagnosis[1]

Diagnosis	65-69	70-74	75-79	80+
Angina	1.74	1.25	1.12	1.78
Congestive Heart	0.54	1.47	1.47	1.24
Stroke	0.26	1.57	1.92	1.02
Myocardial Infarc.	2.13	1.46	1.40	1.27

[1] Ratios of 1980-88/1971-79 incidence density rates.

If a compression of morbidity is occurring, time to diagnosis should be longer and post-diagnostic survival should be shorter in the 1980 cohort. The first step in analyzing time to diagnosis and post-diagnostic survival utilized the Kaplan-Meier method to estimate the survival distributions for each cohort within sex-age groups and by sex, across all ages. Differences between cohorts in time to diagnosis or in survival were examined using the log-rank test. A proportional hazards model was then employed to further examine sex-age specific differences between cohorts in time to diagnosis and post-diagnostic survival for each condition.

Table 3 shows the age-adjusted relative risks and 95% confidence intervals comparing the 1980 to the 1971 cohort for each diagnosis obtained from the proportional hazards models for females. There were no significant differences between the cohorts for either time to diagnosis or post-diagnostic survival for any of the diagnoses. Age-specific comparisons were also performed with similar results.

Table 3. Relative Risks for 1980 Cohort Compared to 1971 Cohort in Time to Diagnosis and Post-Diagnostic Survival.

Females	Time to Dx		Post-Dx	
Diagnosis	RR[1]	95% CI	RR[1]	95% CI
Angina (69,75)	0.85	0.62-1.17	0.77	0.42-1.42
CHF (143,160)	0.88	0.70-1.10	0.97	0.70-1.35
Stroke (73,82)	0.84	0.62-1.12	0.78	0.52-1.16
MI (34,82)	0.99	0.70-1.43	0.96	0.62-1.48

(N cases 1971-79, N cases 1980-88); [1] Age-Adjusted.

Table 4 shows the age-adjusted relative risk and 95% confidence limits comparing the 1980 to the 1971 cohort from the proportional hazards models for males. These models examined differences between cohorts in time to diagnosis and post-diagnostic survival for each condition. Time to diagnosis for angina was significantly later in the 1980 cohort. No other differences were statistically significant. Age-specific comparisons were also performed with similar results.

Conclusions. This examination of differences between cohorts in four CVD diagnoses has revealed an increase in nine-year incidence among males and little change among females.

Table 4. Relative Risks for 1980 Cohort compared to 1971 Cohort in Time to Diagnosis and Post-Diagnostic Survival.

Males	Time to Dx		Post-Dx	
Diagnosis	RR[1]	95% CI	RR[1]	95% CI
Angina (61.98)	0.70	0.52-0.96	0.84	0.54-1.31
CHF (137,202)	0.83	0.66-1.03	0.97	0.75-1.26
Stroke (72,97)	0.89	0.67-1.18	0.77	0.56-1.08
MI (43,67)	1.11	0.80 - 1.55	1.01	0.68-1.50

(N cases 1971-79, N cases 1980-88); [1] Age-Adjusted.

These analyses have not found any statistically significant differences between cohorts in time to diagnosis or post-diagnostic survival for females. Among males, angina pectoris appears to be diagnosed later in the 1980 cohort but is not accompanied by an increase or decrease in post-diagnostic survival. Among males, we also found some evidence supporting an increase in post-stroke survival in the 1980 cohort. Overall, there was no consistent support in these analyses for the existence of a compression of morbidity. These analyses are based upon preliminary data and do not take into account the influence of comorbid conditions or risk factor changes on differences between cohorts in time to diagnosis or post-diagnostic survival. The number of cases of stroke, MI and Angina are relatively small and may contribute to the non-significant findings. Future analyses will examine the influence of comorbidity and risk factor changes on these differences between cohorts.

TRADING OFF LONGER LIFE FOR WORSENING HEALTH: THE EXPANSION OF MORBIDITY HYPOTHESIS

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Abstract

In the 20th century the United States experienced a mortality transition which resulted in a trade-off of death in younger ages from infectious and parasitic diseases, for death in older ages from degenerative and age-dependent diseases. Today the medical community is focused on reducing death rates from the diseases that were traded for earlier in this century. How do declines in the risk of death from fatal diseases influence both the length and quality of life?

In this paper it is explained why future declines in mortality will have a diminishing effect on the metric of life expectancy, but a large impact on the size of future elderly cohorts. Additionally, the compression of morbidity hypothesis developed by Fries is addressed. While studies have already demonstrated that declining mortality can lead to worsening health, what is missing from the literature is a formal mechanistic hypothesis which describes why this phenomenon takes place. Two primary mechanisms are identified. One is based on arguments previously set forth by Greunberg in which medical technology is identified to improve the survival of those with disabling conditions. The second mechanism is that declining mortality from fatal diseases leads to a shift in the distribution of causes of disability from fatal to nonfatal diseases of aging. To test this hypothesis new data will need to be collected on age-at-onset of fatal and nonfatal diseases of aging.

INTRODUCTION

As recently as 50 years ago the world was plagued with what appeared at the time to be immutable diseases--including among others, polio and tuberculosis. As a consequence of improved lifestyles, better sanitation and living conditions, and medical technology, most infectious and parasitic diseases have nearly been eradicated in developed nations. Those saved from early death survived for decades before facing the higher and apparently inevitable risks of old age mortality. In effect, the mortality transition that occurred in this century redistributed the majority of all deaths to older ages.

As a result of this transition, life expectancy at birth increased by 28 years in the United States since the turn of this century--a remarkable achievement within an extremely short time period. In terms of health, the acute pain and suffering associated with death in early ages was traded for the diseases of old age. These diseases include the fatal diseases from which most people die (e.g., heart disease, stroke, and cancer) and the nonfatal diseases which are responsible for a substantial portion of all disability and frailty (e.g., arthritis, dementia, sensory impairments, and osteoporosis, to mention a few). In effect, we made the worthwhile trade-off of an additional 28 years of life for a higher incidence of chronic diseases in older ages.

As one might expect, the medical community has focused on reducing the risk of death from the very causes that were traded for earlier in this century--coronary heart disease, stroke, and cancer. The consequence of this focus in the developed nations of the world has been a remarkable success in reducing the risk of death from the major cardiovascular diseases (Pisa and Uemura, 1982, Uemura and Pisa, 1985). For example, the age-adjusted death rate from heart disease declined by over 34 percent from 1965 to 1985. The exact contribution from modern medicine to these declines has yet to be established (Beaglehole, 1986; Stallones, 1980).

Taeuber (1976,6) noted several years ago that "there is a good deal of appeal in the thought that resources might be available to eliminate cancer and thus to alleviate the human suffering of its victims. But in terms of health policy it would be necessary to ask the question, what diseases and causes of death would be substituted in its stead?" The same question is appropriate today. What do we get in return for reducing the risk of old age mortality from the major fatal diseases? More specifically, how do declines in the death rates from fatal diseases influence both the length and quality of life?

These are not new questions. Since the late 1970s, researchers have been attempting to determine whether declining mortality leads to additional years of health or additional years of disability. The focus of research on these questions has appropriately been on the calculation of what is now commonly referred to as active and disabled life expectancy, and on defining and understanding the term 'disability' (Johansson, 1990; Verbrugge and Balaban, 1989; Rogers, Rogers, and Belanger, 1990). Most of these studies indicate that declining mortality (particularly old age mortality) may result in worsening health (for example, see Bebbington, 1988; Brody and Miles, 1990; Colvez and Blanchet, 1981; Crimmins, Saito, and Ingegneri, 1989; Rice and LaPlante, 1988; Schneider and Guralnik, 1990; Verbrugge, 1984). What is missing from the debate, however, is a formal hypothesis which describes the mechanism by which lower mortality leads to increasing morbidity and disability at the individual and population level. In this paper we enumerate several plausible hypotheses and describe how they might be tested.

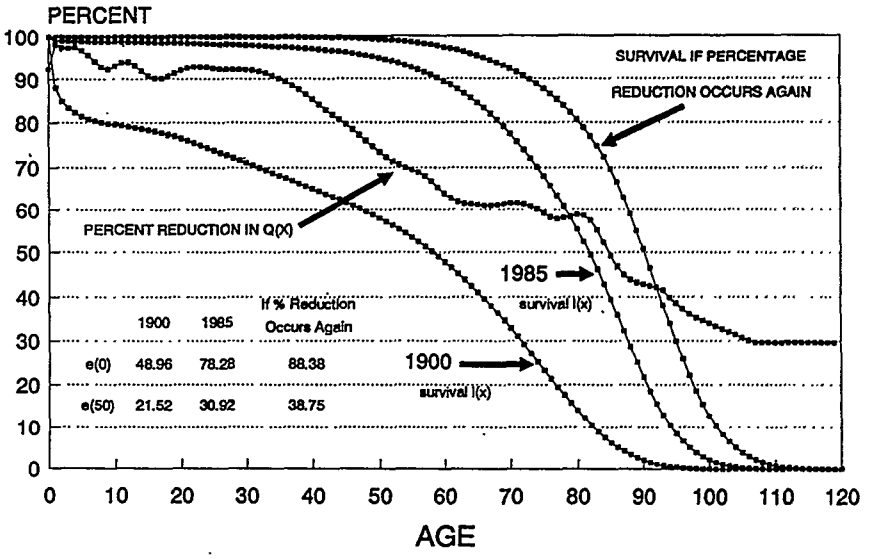

Figure 1

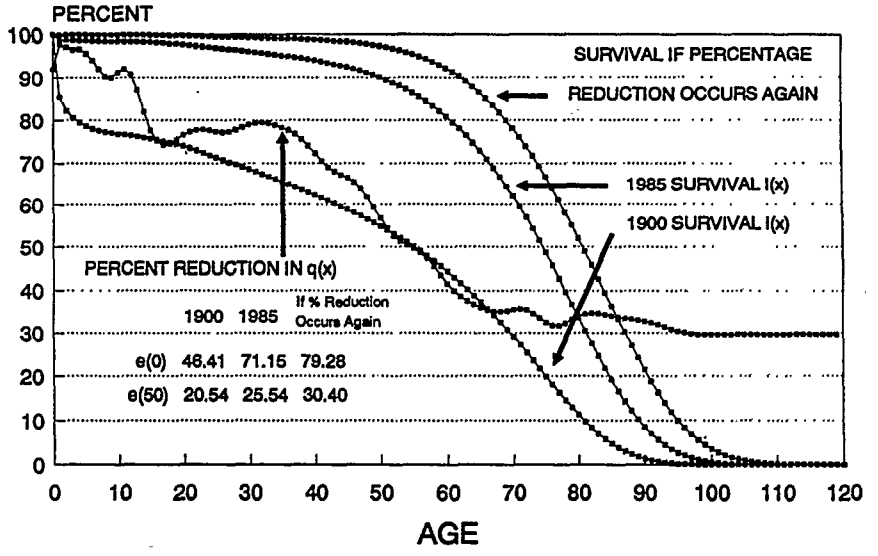

Figure 2

MORTALITY DECLINES AND LENGTH OF LIFE

The relationship between declines in mortality rates and life expectancy has changed considerably during this century. From 1900 to 1985, most declines in mortality occurred among infants, children, and women of childbearing ages (see Figs. 1 and 2). During this period in the United States, the conditional probabilities of death for males and females under age 50 declined by over 70 percent while 30 to 70 percent reductions occurred for the population aged 50 and older (mostly since 1968). In fact, today mortality rates are so low in younger and middle ages that if all deaths prior to the age of 50 were eliminated, life expectancy at birth would increase only 3.5 years. Thus, any additional gains in life expectancy will rely on reductions in death rates among the population aged 65 and older.

The Public Health Service in the U.S. has set forth targets for mortality rates from the major fatal diseases for the year 2000 (Public Health Service, 1990; Sullivan, 1990). It was suggested that these targets will be achieved by programs directed at middle age and older adults to improve risk factors for fatal diseases, and the development and use of new life-extending technologies. Comparable policies are present in most countries throughout the world, although the target population may vary.

What do public health experts expect to get in return for reducing the risk of death in older ages? If large or rapid increases in life expectancy is the goal, it has already been demonstrated that this is unlikely to occur (Schoen, 1986; Keyfitz, 1977; Olshansky, Carnes, and Cassel, 1990; Alho, 1990; Vaupel, 1986). For example, Keyfitz (1977) developed an index of mortality entropy (called H) that becomes smaller as equivalent proportional reductions in mortality produce smaller increases in life expectancy. When applied to mortality schedules that yield life expectancies between 75 and 85 years, H rapidly approaches zero. This indicates that

mortality declines that occur after life expectancy at birth has approached 80 years, will have little impact on the measure of life expectancy. It should be noted that most developed nations have already reached this point of diminishing returns.

Olshansky, Carnes, and Cassel (1990) demonstrated that, in order for life expectancy at birth to increase from present levels to 85 years, mortality rates from all causes of death would need to decline at all ages by 55 percent, and at ages 50 and over by 60 percent. Since the hypothetical elimination of all deaths from ischemic heart disease and cancer (an unlikely event) would decrease death rates by less then 50 percent, it was concluded that life expectancy at birth is not likely to exceed 85 years unless major breakthroughs occur in controlling the fundamental rate of aging. In short, the metric of period life expectancy is no longer a sensitive measure of mortality declines--especially when such declines are concentrated in older ages (Keyfitz, 1977; Olshansky, Carnes, and Cassel, 1990).

Another way of illustrating this phenomenon of diminishing returns is to consider what the effect on life expectancy would be if the age-specific reductions in the conditional probabilities of death that have already occurred in the United States during this century, were to occur again from present levels (Fig. 1). Declines in mortality from 1900 to 1985 combine all of the gains made in reducing infant and child mortality earlier in this century with gains made in reducing mortality rates for middle and older age groups in the last 25 years. Reductions of this magnitude are remote, but if they did occur again, an entire century's worth of progress in reducing death rates would be represented.

Life expectancy at birth increased by just under 30 years for females and 25 years for males in the United States from 1900 to 1985 (Figs. 1 and 2). If identical reductions in mortality occurred again, the gains in life expectancy would be only 10.11 and 8.13 years, respectively. The changes in the survival curves between 1900 and 1985 are much larger than the differences between the hypothetical and 1985 curves (Figs. 1 and 2). If the goal of public health programs is to extend life, then they are likely to be marginally successful because future gains in life expectancy will be small and difficult to achieve.

Why do declines in old age mortality have a diminishing effect on life expectancy? Being saved from death in older ages does not have the same effect on life expectancy as being saved from death in younger ages. This occurs for several reasons. Because the risk of death doubles about every 8 years past age 30, reducing the risk of death from any single cause in older ages still exposes the survivors to the remaining high mortality risks from other competing causes. Eliminating mortality late in life has much less effect than eliminating mortality early in life because the expected remaining years of life for older persons is relatively short. It is important to remember that even if all major fatal diseases are eliminated, people will still grow old and die. This occurs because major fatal diseases are symptoms of aging, not causes of aging. The fundamental rate of aging is believed to remain unaltered by declines in cause-specific death rates. This means that for many people who die after the age of 85, instead of dying from a specific disease, death will result from old age (probably multiple organ failure). It is this fundamental rate of aging that is revealed by continued reductions in death rates from fatal diseases.

Another reason for the phenomenon of diminishing returns is that the proportion of the total population that currently benefits from declining old age mortality is relatively small. For example, reducing the risk of death to one-half of its present level for females aged 85 and older in the United States results in a gain in life expectancy at birth of only 1.6 years. This occurs because the longevity benefits are concentrated among the relatively small proportion of the entire population that is currently aged 85 and older (0.8 percent). Thus, the cumulative person years of life gained by reducing old age mortality rapidly approaches a point of diminishing returns.

While declining old age mortality has a diminishing effect on the metric of life expectancy, it does result in substantial increases in the size of the older population. This occurs because the largest gains in survival are occurring at the declining phase of the survival curve where the greatest numerical increases in the size of the older population are possible. For example, if life expectancy at age 50 for females in the U.S. increased from its present level of just under 31 years to 35 years, the proportion of the life table population surviving to ages 85 and older would increase from its present level of 39.4 percent to 53.0 percent (Fig. 3). Under these same conditions, the proportion of the life table population surviving to be centenarians would increase from its present level of 2.1 percent to 7.9 percent. Each year of life expectancy gained for females at age 50 (from its 1985 level of 30.92 years to 40 years) results in an average increase of 2.5 percent of the life table population surviving to ages 85 and older. The proportion of the population surviving to be centenarians would increase at an even more rapid pace with each year of life expectancy gained.

MORTALITY DECLINES AND QUALITY OF LIFE

If the goal of public health programs is to improve quality of life (and not quantity of life) as suggested by Fries, Green, and Levine (1990), then there is some question as to whether declining mortality leads to better health. For example, Greunberg (1977) argued that an unintended effect of technical improvements stemming from health research was the increased survival of those with disabling conditions (e.g., dementia, heart disease, diabetes, stroke, etc.). The mechanisms linking declining mortality to increased disability in this case were the development and use of antibiotics, insulin, and

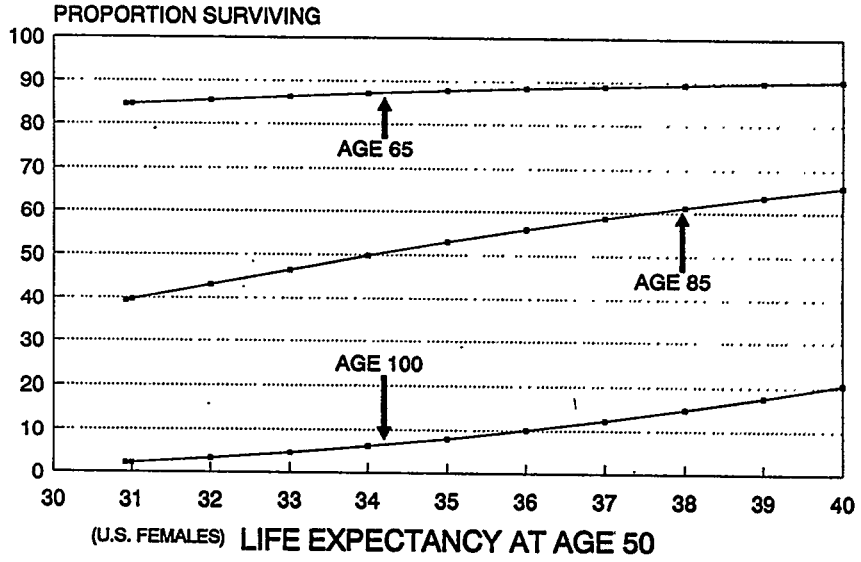

Figure 3

anti-hypertensive medication, and more recently beta blockers, anti-platelet agents, and cancer chemotherapy, among others. Each of these technological developments resulted in a prolongation of the lives of those who already had disabling conditions by reducing the risk of death from the complications that normally accompany these diseases. Since it is the complications that accompany these disabling conditions that often leads to death, the normal progression of the disabling conditions themselves were thought to remain unaffected by advances in medical technology. This same argument was later made by Kramer (1980) who forecasted for the United States large increases in the absolute number of people with disabling conditions.

The Greunberg and Kramer arguments are factually accurate because they demonstrate that an absolute increase in population morbidity and disability appears inevitable as a result of a combination of improved survival among those with normally disabling conditions, and as a result of population aging. However, these studies considered only the survival benefits that accrued to the frail population and failed to consider the possible contributions of these same technologies to the extension of healthy years of life. A thorough understanding of the effects of declining mortality on the health status of the population requires a determination of what portion of the gains in longevity represent an extension of healthy years of life (e.g., active life expectancy), and what portion is an extension of unhealthy years of life.

The partitioning of life into healthy and unhealthy years first appeared in the literature recently as the calculation of the expected duration of functional well-being, termed "active life expectancy" (Katz et al., 1983). Since then a number of other studies have addressed the calculation of active life expectancy or related measures (Crimmins, Saito, and Ingegneri, 1989; Rice and LaPlante, 1986,1988; Colvez and Blanchet, 1983; Rogers, Rogers, and Belanger, 1989; Bebbington, 1988; Schneider and Guralnik, 1987; Gerontologica Perspecta, 1987; Palmore, 1986; Verbrugge, 1984). Also, attention has been drawn to studies published before the Katz et al. (1983) article which addressed similar issues (Colvez and Blanchet, 1981; Manton, 1982; Wilkins and Adams, 1983; Kovar, 1977; Shanas, 1982).

There are three problems with the way in which active life expectancy is considered. First, the measures used to define active life expectancy (e.g., morbidity, disability, and functional well being), are not operationally defined in the same way by all researchers. For example, Katz et al. (1983) used four activities of daily living (ADLs) as a measure of functional well being while Rogers, Rogers, and Belanger (1989) used six. Second, different analytic techniques have been used to analyze data on morbidity and disability (for example, see Crimmins, Saito, and Ingegneri, 1989 and Rogers, Rogers, and Belanger, 1990). Finally, a more accurate measure of health status in the population is an observation of secular trends in the age-at-onset of fatal and nonfatal diseases of aging. To date these data have not been collected.

In spite of these limitations, the evidence published to date tends to support the hypothesis that lower mortality leads to increases in morbidity and disability. There is little evidence to support the hypothesis developed by Fries (1980) that morbidity and disability are declining and compressing into a shorter duration of time before death. In fact, recently published studies indicate that mortality compression has not yet begun (Rothenberg, Lentzner, and Parker, 1991), a phenomenon that is likely to occur before morbidity compression could begin. This lends additional support to the hypothesis that declining old age mortality is related to the expansion of morbidity and disability among the older population (Crimmins, Saito, and Ingegneri, 1989; Rice and LaPlante, 1988; Rogers, Rogers, and Belanger, 1989).

FORTHCOMING MEDICAL TECHNOLOGIES

It has been argued that with existing medical technology and assuming ideal lifestyles are adhered to by the entire population, life expectancy at birth is not likely to exceed 85 years. To extend life expectancy beyond 85 years, it will be necessary for medical science to alter the fundamental rate of aging by manipulating 'aging' genes through techniques developed in molecular biology. It may also be possible to simulate a change in the fundamental rate of aging by 1) developing anti-aging drugs that supplant the lost functionality or products of aging genes, 2) manipulating the physical environment and nutritional status of individuals, and 3) developing new life-extending technologies. The improvement of existing life-sustaining and life-extending technologies is not likely to have much of an effect on life expectancy (Olshansky, Carnes, and Cassel, 1990), although these technologies would certainly result in substantial increases in the absolute size of the older population. Research is already underway into directly and indirectly altering the fundamental rate of aging, and we believe it is only a matter of time before one or more technological breakthroughs occur. Breakthroughs in any one of these areas of research could result in substantial increases in both life expectancy at birth and the size of future older cohorts. However, research is proceeding in the absence of established methods of determining how such technologies might influence the length and quality of life, and the size of the older population. Some have raised questions about whether it is worthwhile to continue to develop high-tech medicine that is designed to prolong life (Ginsberg, 1990).

The major areas of medical technology that have the potential to significantly influence both the length and quality of life include new imaging devices, surgical techniques, and anti-aging drugs, artificial organs and transplants, and monoclonal antibody testing, among others (The Futures Group, Inc. 1988). Medical experts believe there is a high probability that these technologies will be improved in the coming years to the extent that they will make earlier diagnosis possible for fatal conditions such as coronary heart disease, cerebrovascular disease, and peripheral artery disease (The Futures Group, Inc., 1988). Although less certain, it is conceivable that new technological developments may also make it possible to diagnose the nonfatal diseases of aging (e.g., macular degeneration, dementias, diabetic retinopathy, osteoarthritis, hearing loss, etc.) at earlier stages in their development.

While early detection may improve survival in some cases for those with certain fatal diseases (Gomez-Marin, 1987; Fleischer et al., 1989; Bailar and Smith, 1986; Beaglehole, 1986; Bonita and Beaglehole, 1986), the same relationship does not hold in the case of most nonfatal diseases of aging. Consider the most common nonfatal diseases of aging such as osteoarthritis, Alzheimer's disease, and sensory impairments. Over 50 percent of the population of the United States aged 75 and older report having arthritis (Verbrugge, 1989), and in one community up to 47 percent of the population aged 85 and older had Alzheimer's disease (Evans et al., 1989). With regard to sensory impairments, eye disorders are the third leading cause of activity limitation among those aged 65 and older, and among the 85 and older population it is estimated that over 50 percent suffer from hearing impairment (Public Health Service, 1990). The exact etiology of these diseases is not known at this time. More significantly, only palliative therapies (rather than cures) exist for these diseases, and some forms of treatment can result in a worsening of the condition itself. The effect may be an extension of life in a disabled state. As an example, the medical treatment of behavioral problems in some patients with Alzheimer's disease can result in a worsening of their cognitive functioning (Raskind and Risse, 1986). In short, based on our present knowledge it is not possible to delay the progression of osteoarthritis and Alzheimer's disease; they are considered irreversible conditions; and their progression cannot be altered even if they are detected at early stages in their development (Cassel et al., 1990).

Hearing loss increases with age and affects the majority of the older population. It occurs as a result of a combination of environmental and genetic factors (Cassel et al., 1990). If environmentally caused, it may be possible to reduce the rate of subsequent hearing loss by limiting exposure to noise, although this has not been proven conclusively. It is not possible at this time to alter the course of hearing loss caused by genetic factors. In either case, the use of hearing aid devices can restore some hearing loss, although it is less than completely effective. Diminished vision is most often caused by glaucoma, macular degeneration, and diabetic retinopathy--all of which are age-dependent diseases (Cassel et al., 1990). Risk factors for blindness (with the exception of poor glucose control for diabetic retinopathy), are either not known or are not amenable to modification. Although it is possible to treat retinopathy and glaucoma, the consequence may be a reduction in the rate of visual loss, but vision itself may not be improved substantially. In the case of macular degeneration its cause is unknown; it is progressive and irreversible; treatment is helpful only for a small percentage of those with the disease; and knowledge of its existence does not alter its course for most people (Cassel et al., 1990).

Anticipated advances in medical technology are therefore likely to be used to detect the progression of fatal diseases and alert individuals and their physicians to the need to slow the progression of these diseases. They may also be used to extend the lives of those who have already exhibited clinical manifestations of fatal diseases. The 'saved' population would therefore survive longer as a result of earlier detection by slowing the progression of the diseases, or by removing the diseased tissue before it reaches advanced stages when surgery and therapeutic interventions become less effective. If the progression of these normally fatal diseases

pre-disposes those with the diseases to experience related complications, then medical advances might also serve to postpone both disease onset and their complications.

In contrast, the progression of nonfatal diseases of aging is not likely to be affected by anticipated medical advances--even if such advances allow for the earlier detection of these diseases. An advanced warning of the presence of most nonfatal diseases of aging will allow for changes in lifestyles that may limit the disabilities and handicaps associated with having these diseases, but it will not alter the underlying disease processes.

THE EXPANSION OF MORBIDITY HYPOTHESIS

Fries (1980; 1988) hypothesized that morbidity will be prevented and postponed, becoming compressed into a shorter duration of time as a result of improved lifestyles. Most of the studies that have been published on this issue in the past 15 years have not supported this hypothesis and in fact indicate that declining mortality leads to increases in age-specific disability rates (i.e., an expansion of morbidity and disability). Furthermore, at present there is no clinical evidence to support the hypothesis that the nonfatal diseases of aging may be prevented or postponed (Rudberg and Cassel, 1990), a phenomenon that is critical to the compression of morbidity hypothesis.

There are two physiological/epidemiological mechanisms that may link lower mortality to worsening health. Improvements in the medical management of the complications associated with disabling diseases have permitted longer survival with the disease than was the case for previous cohorts (Greunberg, 1977). The duration of disability therefore increases as case-fatality rates decline. The surviving population, which is already frail, lives longer with a disability that tends to worsen as a function of age.

Anticipated advances in medical technology are likely to postpone the onset of fatal diseases and improve survival for those with symptoms of these diseases. However, at present, there is no evidence to suggest that these advances will influence either the onset or progression of nonfatal diseases of aging. Increases in survival resulting from the use of medical technology therefore provides additional theoretical support to predictions made by Greunberg. One implication of this hypothesis is that the absolute size of the disabled population in developed nations will increase dramatically in the coming decades as a result of improved survival and population aging.

To test Greunberg's original hypothesis one need only multiply age-specific disability rates observed in the past by the current population, and compare the absolute size of the disabled populations. Additionally, one may test this hypothesis by observing secular trends in survival rates for those with disabling conditions. Greunberg's original argument that increases in the absolute size of the disabled population was inevitable--even with declining disability rates, has been confirmed (Rice and Feldman, 1983; Brody, 1985; Schneider and Guralnik, 1990). However, research has yet to be conducted on the extension of active and disabled life expectancy in relation to improved survival for selected fatal diseases. To determine precisely how medical technology influences active and disabled life expectancy, it is necessary to calculate the person-years-of-life that are attributable to a particular treatment, and then partition those additional years of life into healthy and unhealthy years.

A second potential mechanism linking lower mortality to increases in disability is a hypothetical shift in the distribution of the causes of disability. The disability experienced by a population may be partitioned into that attributable to fatal diseases, nonfatal diseases of aging, and the coexistence of both kinds of diseases (Brody and Schneider, 1986). Reductions in the risk of death from fatal diseases could 1) shift the distribution of disability away from fatal diseases to nonfatal diseases of aging, and 2) force the saved population further into the oldest-old ages where the risks of nonfatal diseases of aging are extremely high and currently immutable.

There is some evidence to indicate that a shift is occurring in the distribution of disability. For example, Crimmins, Saito, and Ingegneri (1989) found that while recent gains in longevity are dominated by an extension of unhealthy years of life, these additional years are not the kind requiring confinement to a bed. Prior to death, people with fatal diseases have a higher probability of requiring confinement to a bed than those with nonfatal diseases of aging (Crimmins, Saito, and Ingegneri, 1989). Also, Manton (1988) attributed a higher incidence of impairments among females than males before the age of 85 to lower mortality from fatal diseases for females. Additionally, Manton (1991) found female disability to be attributable to less lethal conditions (e.g., arthritis and diabetes) while disability among males was associated with more lethal conditions (e.g., cancer and heart disease). This gender difference leads to shorter periods of acute care for males and longer but less acute periods of care for females (Manton, 1991). Finally, Jacobson et al. (1990) found increases in the age-specific incidence rate for hip fractures in the U.S. over the past ten years. If death rates from fatal diseases continue to decline for both sexes, it is then reasonable to hypothesize a shift in the distribution of disability from those associated with fatal conditions toward those associated with nonfatal diseases of aging during the period of improved survival.

Support for the expansion of morbidity hypothesis is currently based on quantitative measures of the consequences of a trade-off between longer life (measured by mortality rates and life expectancy) and worsening health (measured by disability statistics). A more direct and rigorous test of the expansion of morbidity hypothesis requires an examination of cohort trends in the duration of time between age-at-onset of fatal and nonfatal diseases of aging, and death. The difficulty

with measuring disease onset is that it is defined as the moment an individual experiences the physical manifestations of a disease--such as myocardial infarction or a stroke. Yet most fatal diseases are known to progress steadily for years before their physical manifestations are recorded or diagnosed. Individuals can be pre-symptomatic for years while the diseases advance at rates that may be modulated by personal habits or environmental factors.

The data required to test this hypothesis include age-at-onset of fatal diseases and nonfatal diseases of aging; the interrelationships among morbidity, disability, and mortality; and an understanding of the causes of declining old-age mortality. That is, we need to know whether declines in old age mortality are caused by changes in the age-at-onset of fatal diseases, or improved survival with these diseases. If the causes of declining mortality are disassociated from the possible causes of declining morbidity and disability, then it is likely that further declines in old age mortality will result in an expansion of morbidity and disability in the population. To address the problem of a lack of data for age-at-onset of nonfatal diseases, Brody and Miles (1990) have suggested that it will be necessary to a) embark on cross-national studies of the point prevalence of nonfatal conditions, b) direct research efforts to determine what factors might postpone the age-at-onset of these conditions, c) estimate the maximum years that active life expectancy can be preserved, and d) perhaps initiate a set of new prospective longitudinal studies that address issues specific to nonfatal diseases of aging.

If an expansion of morbidity is occurring, the following would be hypothesized: 1) a postponement in age-at-onset, a decrease in the age-specific incidence rate, and a decline in the age-specific death rate from fatal diseases, 2) an increase in the duration of time between age-at-onset and death for those with fatal diseases (that is, fatal diseases will tend to become chronic conditions), and 3) an increase in the age-specific disability rate exclusively from nonfatal diseases of aging (i.e., an increase in the proportion of total disability attributable to nonfatal diseases). In more general terms, one would hypothesize a trade-off between lower mortality and morbidity from fatal diseases, for a small increase in life expectancy and an accompanying increase in the duration of time for the expression of non-fatal diseases of aging. These changes are anticipated because disability among those who survive with fatal conditions is more likely to restrict daily activities but be of a shorter duration (because of higher subsequent mortality risks) than is the case for those with nonfatal diseases of aging.

Therefore, reducing the death rate from fatal diseases in middle and older ages is hypothesized to result in the desired effect of a longer life, but it may have the unintended effect of extending life into the oldest-old ages where the nonfatal diseases of aging are currently immutable. With increasing age the oldest-old will tend to accumulate nonfatal diseases of aging (i.e., the presence of co-morbidities), thus making the prospect for dealing with these problems much more difficult. Declining mortality would therefore be hypothesized to accelerate the growth in that segment of the population most likely to experience co-morbidities, and extend the lives of individuals with co-morbidities. Both phenomenon would add substantially to the prevalence of morbidity in the population. To this end Brody and Miles (1990) noted that "the specter of not being able to postpone or prevent Alzheimer's disease and related disorders with 2.5 million to 4 million current cases and an aging population is sobering." Add to that sobering thought the prospect of surviving much larger proportions of subsequent cohorts into their 8th, 9th, and 10th decades of life without the ability to postpone osteoarthritis, osteoporosis, and hearing and visual impairments, and the trade-off now underway appears less desirable.

CONCLUSIONS

The mortality transition that occurred earlier in this century resulted in a substitution of death in younger ages from infectious and parasitic diseases, by death in older ages from what is referred to here as fatal diseases. The consequence of this transition was an increase in life expectancy at birth of 28 years. As would be expected, the medical community has since focused its efforts on reducing the risk of death from those diseases that resulted from the mortality transition earlier in the century. The central issue now becomes, "what will be the consequence of postponing or eliminating the diseases that tend to kill in older ages"?

If rapid increases in life expectancy is the desired effect, it has already been demonstrated that this goal becomes less achievable as the expectation of life approaches 80 years--something that has already occurred in developed nations. The fundamental question remains, will declining old-age mortality lead to a compression or an expansion of morbidity and disability? What has been missing from the debate on this question is an enumeration of the quantifiable effects that would discriminate between these competing hypotheses.

The hypothesis for an expansion of morbidity rests on two lines of reasoning. First, medical technology will improve survival for those with disabling conditions associated with fatal diseases, but the progression of the diseases themselves will remain unchanged. As a result, the duration of disability for this segment of the population will be increased. In this scenario, medical technology has improved survival by postponing death, but has not had an appreciable impact on the disabling conditions associated with the nonfatal diseases of aging. It has already been demonstrated that existing technology has extended life for individuals who have contracted fatal diseases (Goldman and Cook, 1984). However, the impact on the quality of the extended life is not known. An evaluation of this will require estimating the extension of life that can be attributed to a specific

medical technology, and identifying the duration of this time that is spent in either a healthy or disabled state.

The second component of a morbidity expansion involves a shift in the causes of disability from fatal diseases to the nonfatal diseases of aging. As mortality from fatal diseases in older ages is reduced, the morbidity associated with the fundamental aging process itself will have a greater opportunity for expression. It is assumed that advances in medical technology are likely to postpone and/or reduce case-fatality rates for those with fatal diseases, but have little or no impact on the nonfatal diseases of aging. In this scenario, there is a trade-off of lower mortality in middle and older ages for a redistribution of the causes of disability and an expansion of morbidity. As previously hypothesized, the expansion of morbidity would lead to very specific and quantifiable changes in disability statistics. To test this hypothesis, an accurate measure of the change in the age-at-onset of fatal diseases and nonfatal diseases of aging, and the time between the age-at-onset of these diseases and death, is needed. At present, valid estimates of secular trends in age-at-onset for fatal and nonfatal diseases do not exist.

If in the current mortality transition, we are unavoidably trading off a lower risk of death from fatal diseases at older ages for an extension of disabled years, then more attention must be given to ameliorating the nonfatal diseases of aging. Given the profound societal impact of an expansion of morbidity, it is essential that this hypothesis be rigorously tested. A test of this hypothesis will require measurements of the age-at-onset of fatal diseases and nonfatal diseases of aging, as well as better monitoring, quantification, documentation, and dissemination of data on morbidity and disability. It is also suggested that researchers seek out ways to improve the quantification and broaden the availability of modeling software for studies of interrelated disease processes. Basic research into the molecular basis of the fundamental aging process should also be supported as this work may lead to methods of slowing the progression of age-dependent diseases. Since it may eventually be possible to modify (e.g., with genetic engineering) or ameliorate (for example, with anti-aging drugs) the aging process itself, the ethical problems associated with the development and use of these technologies should be addressed now. Finally, efforts at identifying behavioral and environmental risk factors that affect fatal and nonfatal diseases should continue in order to provide continued longevity gains and to help clarify the heritable component of aging. In sum, we suggest that the public health community begin to place the quantity of life into perspective with the quality of life.

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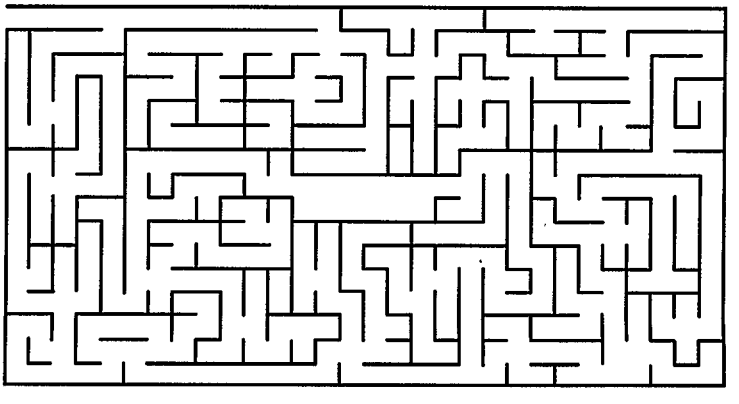
Session R

Health Risk Assessment



From basic BRFSS to special surveys:
The collection, analysis and use of state, area and local data

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I. Introduction

Quality data on the health status and current attitudes, beliefs and practices of Missouri residents are needed to strengthen planning, education, research and legislation aimed at promoting healthier lifestyles and reducing morbidity and mortality among Missouri citizens. The Behavioral Risk Factor Surveillance System (BRFSS) provides one of the best means of obtaining current data on lifestyle risk factors such as seat belt use, tobacco use, alcohol consumption, dietary habits, cancer screening behavior, etc., and of measuring changes in health status, attitudes, beliefs and practices.

The Missouri Department of Health (MDOH) has been collecting BRFSS data since 1985 and has been part of the Centers for Disease Control's (CDC) surveillance system since 1986. A paper and pencil format was initially used for data collection but a computer-assisted telephone interviewing (CATI) system was initiated in June 1987. MDOH staff developed the system, using dBASE applications loaded on IBM-compatible personal computers for presenting the survey screen and storing the data[1].

Since 1989, MDOH has completed 126 BRFSS random digit dialed telephone interviews per month for a yearly total of 1,512 questionnaires. Interviews are conducted by hourly staff trained for the task. A sampling frame of all Missouri telephone numbers, published and unpublished, is utilized. Selection of any given number to call is purely random and is based on the Waksberg three-stage cluster design[2]. All residential numbers throughout the state are eligible for inclusion in the sample but, once a number is selected, only one household member, 18 years of age or older, is eligible to complete the survey.

II. Modification of Missouri BRFSS

In late 1989, MDOH upgraded the existing CATI system to better serve state needs. A combination of Clipper, FoxBase, Norton and Pascal software was used to create compiled, executable modules for data entry, data management and editing[1]. Using this modular format, questions can be added or deleted as needed. For example, a state-added module on pesticide use might be added one quarter and replaced with an optional CDC module on radon the next quarter.

Prior to beginning 1990 BRFSS interviews, a pilot test was conducted to determine the optimum way of presenting an expanded survey instrument containing nearly twice the number of questions as the 1990 CDC core instrument. It was determined that question flow was more important than number of questions. Respondents did not want to answer additional questions on a topic covered earlier in the interview but did not object to the same questions or to the length of the interview, if the questions were logically sequenced. After consultation with CDC staff, the decision was made to integrate related state-added questions into the 1990 CDC core questionnaire.[3] Thus, a smooth flowing, menu driven instrument that avoids redundancies was created. This modular instrument became the foundation for two special surveys conducted in 1990 and for Missouri's 1991 BRFSS Questionnaire.

III. Uses and Limitations of BRFSS Data

A major use of BRFSS data is to determine the prevalence of health risk factors which increase a person's risk of death, illness or injury. Since county of residence is obtained for each respondent, data can be analyzed on a statewide basis, by county or by region within the state. BRFSS data can also be used to examine differences in the reported health status, attitudes, beliefs and/or practices of subpopulations within the state, such as rural/urban, Black/White, women 50 and over/women under 50 years of age, etc.

One dilemma that MDOH, in common with other state health departments, has faced concerns obtaining sufficient data on subpopulations within a defined geographic area to assess objectives targeting special populations (i.e., people with low incomes, older adults, minorities, etc.). Traditional solutions include increasing the survey sample size and/or aggregating data from several years. To assess objectives targeting special populations in specific locales, such solutions are not always feasible. A special survey based on BRFSS methodology may be a better alternative.

IV. Special Surveys: Need, Problems and Solutions

Two intervention projects were funded in late 1989. The first, a cardiovascular risk reduction project (CVD Project) funded by CDC, targeted residents of an economically depressed, medically underserved six-county region in the extreme southeast corner of the state. This region (known as the "Bootheel") also has a substantial minority population.

The second project, a smoking cessation project (SCBA Project) funded by the National Heart, Lung, and Blood Institute (NHLBI), was a collaborative project between MDOH and Washington University. This project targeted residents of four inner city neighborhoods with a predominately African American population in St. Louis. Four neighborhoods in Kansas City, matched on ethnicity and income, served as controls.

Both projects required baseline data on the targeted populations, preferably point-in-time surveys, so that later follow-up surveys could assess change. Since Missouri has 114 counties plus the City of St. Louis, it was not feasible to expand the regular BRFSS survey and obtain a large enough sample for the CVD project. Moreover, study neighborhoods in the SCBA Project were defined by census tract, a much smaller unit than available with BRFSS data. The decision was made to conduct two special surveys.

The CVD Project survey was relatively straightforward. Surveying began on January 4, 1990 and was completed two months later. Direct labor costs per completed interview were approximately the same as for BRFSS interviews for the first half of 1990. Other than modifying the 1990 Missouri BRFSS questionnaire to delete two modules (and thus reduce the instrument from 121 to 96 questions), only minimal changes were made. The sampling frame was switched to a simple random rather than a cluster sample. A new final disposition code of "wrong county" was added to exclude Missouri residents who resided outside the six-county area. Additional telephone surveyors and survey supervisors were hired so that survey work could be carried out seven days a week on three shifts (day, evening and weekend). To avoid confusion, since multiple surveys were to be conducted simultaneously, the decision was made to color code all printed materials (except computer print outs) associated with each project. Pink was the color assigned this project.

Telephone services in the survey area were provided by a number of small, independent companies. Therefore, it was anticipated that more random numbers would be required than if one company had provided coverage to the area. Consequently, 10,000 random telephone numbers were generated for a projected sample size of 1,000. Over 8,700 of these numbers were used. Only 13% (1,143 of 8,737) of the numbers dialed were potentially productive, i.e., were working residential numbers.[4] Of the non-productive numbers, 93% (7,050) were non-working. Three percent (227) were nonresidential (business) numbers. The remainder were either residential numbers in an unknown location or outside the survey area (24) or were residential numbers that did not qualify for some reason (293; child's phone, non-English speaker, respondent unable to communicate due to physical or mental disability, etc.).

Of the potentially productive numbers, approximately 88% (1,006) resulted in a completed survey and less than 1% (7), in a partial interview. The refusal rate was about 10% (111). Few problems were experienced with this project and a quality assurance review revealed a high degree of accuracy in coding final dispositions and recording responses.

The second special survey, the SCBA Project, was considerably more complex. Printed materials associated with study and control neighborhoods were assigned different color codes, blue for the former and green for the latter. Since study and control neighborhoods had different telephone area codes, these were preprinted on telephone call sheets.

Surveying began in mid-March 1990 but was not completed until September 1990. Simple random sampling was also used for this project and the questionnaire was the same length (97 questions). However, a number of core questions were dropped in order to add additional questions on attitudes and behaviors related to tobacco and a section on social isolation. This led to numerous complaints from respondents and may have had some impact on the completion rate (see Charts 4 and 8), since a slightly higher percentage of respondents started but did not complete an interview compared with the CVD Project.

The final disposition code of "wrong county" was changed to "wrong neighborhood" to exclude residents who lived outside study or control neighborhoods. Unlike the CVD Project, this accounted for a substantial portion of the nonproductive numbers in each group (see Charts 3 and 7).

As the survey progressed, two additional final disposition codes were added, one to indicate that the wrong respondent had been interviewed and another, that someone not in a study/control neighborhood had been interviewed. These dispositions, resulting from surveyor errors, were discovered during quality assurance reviews. They accounted for less than 1% of potentially productive numbers in each group (see Charts 7 and 8).

Finally, another code was added to indicate that after multiple attempts, neighborhood remained unknown. In the CVD Project, essentially no one refused to give their county of residence but "unknown neighborhood" was the final disposition for over one-third of all non-productive SCBA Project study and control group numbers (see Charts 3 and 7).

Given that only small declines in smoking rates were anticipated as a result of interventions in the four study neighborhoods, tight boundaries were set for baseline data collection. Study neighborhoods in St. Louis were defined by census tract, information that could not be obtained directly from most respondents. Control neighborhoods in Kansas City were identified by zip code.

A common question was asked of all respondents, "What street do you live on and what is your zip code?" Surveyors recorded both street name and zip code on paper but entered only one or the other in the computer.

For control neighborhoods, after a zip code was entered, a menu showing each zip code designating a control neighborhood appeared on the screen. The surveyor had to make a selection in order to advance the screen. If the potential respondent's zip code was not listed, the interview was terminated.

For study neighborhoods, a census tract data base was indexed to the survey instrument. By keying into the computer only the first two letters of a street name, surveyors could bring up a screen menu of all streets beginning with those letters. Rather than asking for a specific address, the surveyor asked if a respondent lived within a range of blocks, those blocks being the ones included in a particular census tract. This was originally proposed to maintain confidentiality and anonymity; it also proved helpful in overcoming respondents' suspicions regarding our purpose in asking the question. As we discovered, there had been widespread publicity about telephone fraud in St. Louis.

Potential problems related to determining place of residence had surfaced during piloting of the survey instrument. This coupled with the large volume of paper generated during the CVD Project led to a decision to separate screening and surveying into two separate stages. The screening stage was designed to eliminate the majority of nonworking, business and wrong neighborhood numbers. Charts 1 and 5 show the number and percent of phone numbers rejected at this stage in St. Louis and Kansas City, respectively.

Charts 2 and 6 demonstrate that screening was more effective in Kansas City than in St. Louis. Over half the Kansas City numbers accepted for the survey stage were potentially productive numbers compared with just under one quarter of St. Louis numbers. Completion rates were similar in the two cities (Charts 4 and 8); refusal rates were virtually identical. Refusals and partial interviews were more common in this study than in the CVD Project.

By the end of the survey period (when 1,000 or more interviews had been completed in both study and control neighborhoods), nearly 15,000 telephone numbers had been used in St. Louis, compared with about 7,800 in Kansas City. This difference was due to a number of factors, including:

- the way telephone prefixes were assigned by the telephone company;
- necessity of obtaining a street name in St. Louis; and
- greater suspicion from St. Louis residents.

Media publicity about telephone fraud undoubtedly contributed to St. Louisans' suspicion toward a telephone survey project. St. Louis is frequently characterized as "eastern, metropolitan" whereas Kansas City is said to have a "western, small town" atmosphere, so a more urban attitude may also have been a factor. For whatever reason, more than 1,500 people in St. Louis ultimately refused to disclose their place of residence compared with only slightly over 400 people in Kansas City (Charts 3 and 7, respectively). However, nearly 2,000 people in St. Louis who had initially refused to name the street on which they lived ultimately did so and were found to be in the wrong neighborhood (Chart 3). Likewise, over 300 residents of Kansas City who refused to give their zip code when contacted during the screening phase ultimately responded and were found to live outside the control neighborhoods (Chart 7).

An attempt was made to characterize the people who lived in one of the study or control neighborhoods but who would not complete an interview. These individuals would be asked to complete an eight-question mini-survey. The majority (labeled "Refusal" on Charts 4 and 8) refused to answer even one question. A minority (labeled "Partial Interview" on the same charts) answered some or all of the eight questions but this group was not large enough to characterize the non-responders/non-completers.

Individuals who did complete the interview were representative of the population targeted, based on the two major criteria of ethnic origin (Black/African American) and income (low). Approximately 78% of St. Louis and 71% of Kansas City respondents were Black.[5] Statewide, less than 11% of the population is Black.[6] Approximately 58% of St. Louis and 56% of Kansas City respondents had household incomes under $20,000; about 45% and 46%, respectively, had household incomes under $15,000.[5] Comparable figures for the state as a whole, based on 1990 Missouri BRFSS data, are 36% of respondents with incomes under $20,000 and 26%, with incomes under $15,000. Although female respondents comprised 65% of the total in both St. Louis and Kansas City, this represents only a slightly higher percentage of females than on the statewide BRFSS (61% during 1990) and could not account for the disparity in income between representatives of these neighborhoods and a statewide sample.

SCBA Project direct labor costs per completed interview greatly exceeded costs for the CVD Project. There was also a significant difference between interview costs for SCBA study neighborhoods and control neighborhoods. A final breakdown of costs has yet to be completed, but it is estimated that each interview with a respondent in a SCBA control neighborhood was obtained at nearly double the cost of a CVD or BRFSS interview. An interview with a respondent in a SCBA study neighborhood may had a cost approximately 4.5 times that of a BRFSS or CVD interview. The difference in

costs between study and control neighborhoods in the SCBA Project can largely be explained by the higher number of non-productive numbers coded as "wrong neighborhood" or "unknown location" in St. Louis than in Kansas City (see Charts 3 and 7). All of the "unknown location" and most of the "wrong neighborhood" dispositions were only made after multiple attempts over a number of calling periods.

Another factor contributing to differences in direct labor costs was the number of calling periods required to obtain a completed interview or a refusal. An average of 1.2 calling periods per interview was required to obtain the first 50 CVD interviews. Comparable figures for the SCBA Project were 1.8 and 2.1 calling periods for each Kansas City and St. Louis interview, respectively.[5] A quality assurance review of refusals revealed that the average CVD refusal[7] required 2.9 calling periods. The average number of calling periods required to obtain a final refusal for the SCBA Project was 4.0 in Kansas City and 4.1 in St. Louis.

V. Summary

Missouri's CATI system, originally developed for collecting BRFSS data, was successfully modified in 1989 so that it could more easily serve multiple functions. The modular format utilized by MDOH has facilitated the conduct of a number of special surveys, two of which were discussed in the preceding section. These surveys have provided baseline data on subpopulations in defined geographic areas when needed data could not be obtained from the BRFSS.

Important uses, current and proposed, of Missouri BRFSS and special survey data include:

- monitoring and measuring progress toward Year 2000 goals and objectives;
- supporting legislative issues (e.g., successful passage of mandated mammography insurance coverage during the 1990 legislative session);
- identifying target populations or special populations at risk;
- supporting legislative requests for program funding;
- planning community health promotion projects;
- assessing public knowledge, attitudes and/or self-reported behavior concerning specific topics (AIDS, tobacco use, preventive health measures, etc.)
- supporting public and professional education programs and training courses;
- providing baseline information for grant applications and program planning; and
- through cooperative efforts with other state health departments, developing regional databases on special populations.

Data obtained through special surveys are an important supplement to regular BRFSS data. Direct labor costs per special survey interview may be similar to BRFSS costs or may be considerably higher. Based on MDOH's experience with two special surveys in 1990, the geographic size of the calling area is inversely related to the cost per interview. Other factors which can impact interview costs include assignment of telephone prefixes, media publicity about telephone fraud, general attitude of residents, definition of survey area, etc.

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[1]Since the computers are not currently networked, at the end of each survey period data from all computers are transferred to floppy disks and consolidated in one file for editing and transmittal to CDC. Although this system requires some paperwork, it functions quite well.

[2]Waksberg, J. Sampling Methods for Random Digit Dialing. J. Am. Stat. Assn, 73:40-46, March 1978.

[3]BRFSS data sent to CDC each month are formatted according to CDC specifications. Responses to CDC core questions appear first, in the columns specified by CDC. If any CDC optional modules are included, these responses appear next, also in CDC specified columns. Responses to state-added questions appear last, in columns set aside for such questions.

[4]In order to meet publication page limits, some of the pie charts, tables and figures displayed in a conference handout have been eliminated. Much of the information contained therein has been incorporated into the text, with percentages rounded to the nearest whole number. Copies of the handout are available upon request from the author.

[5]Missouri Department of Health, unpublished data, 1991.

[6]United States Census Bureau, 1990 Census of Population and Housing, Summary Tape, file 1, table P-6.

[7]A final disposition of "refused interview" was coded only after someone in the household had refused on two separate occasions.

Chart 1. SCBA, St. Louis
Stage 1: Screening Calls

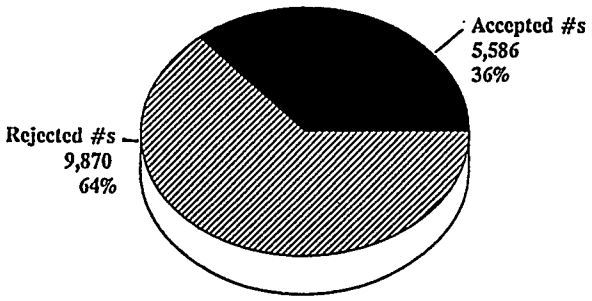


Chart 5. SCBA, Kansas City
Stage 1: Screening Calls

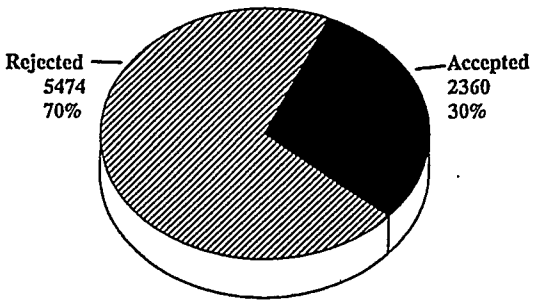


Chart 2. SCBA, St. Louis
Stage 2: Survey Calls

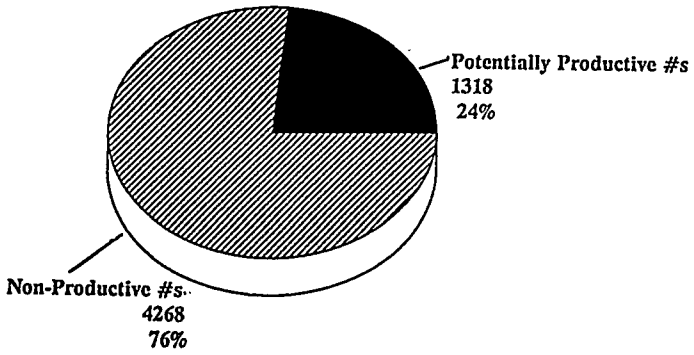


Chart 6. SCBA Kansas City
Stage 2: Survey Calls

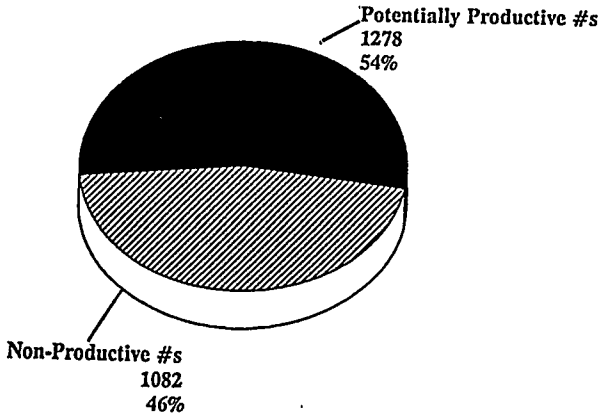


Chart 3. SCBA, St. Louis
Breakdown of Non-Productive Numbers
by Final Disposition

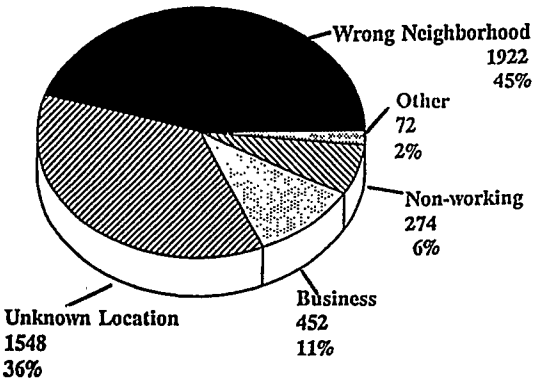


Chart 7. SCBA Kansas City
Breakdown of Non-Productive Numbers
by Final Disposition

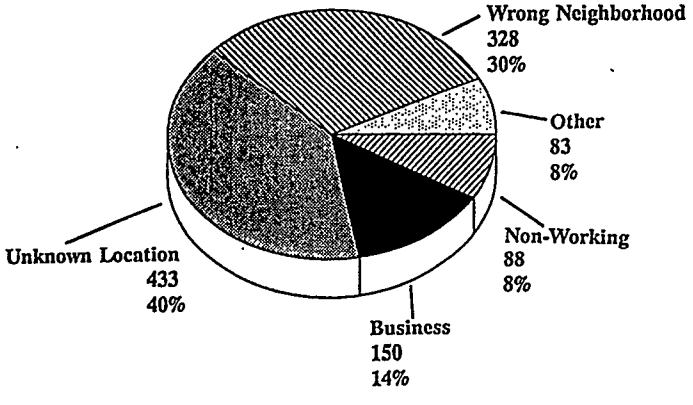


Chart 4. SCBA, St. Louis
Breakdown of Potentially Productive Numbers
by Final Disposition

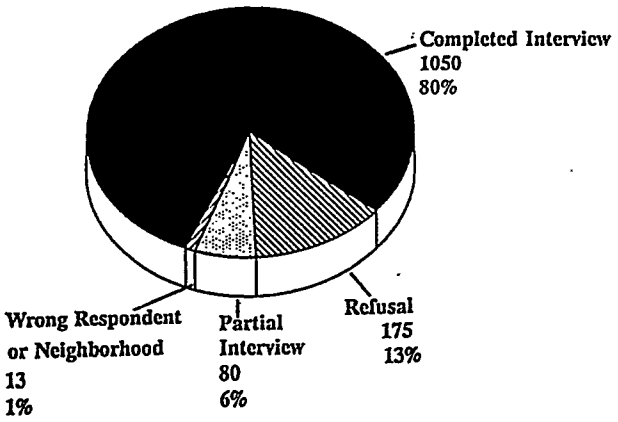
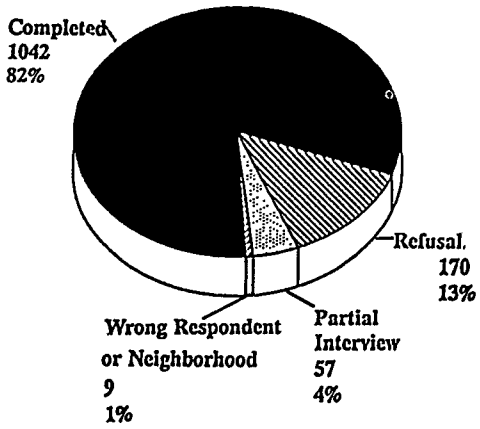


Chart 8. SCBA, Kansas City
Breakdown of Potentially Productive Numbers
by Final Disposition



CONDUCTING A MODIFIED BEHAVIORAL RISK FACTOR SURVEILLANCE SURVEY IN A HISPANIC COMMUNITY

D Littlefield, Monterey County Health Department, California
JP Snider, RJ Melton, LF Folkers, B Marquez, E Gentry, K Wilson

Introduction

In California, the four leading causes of death for Hispanics are heart disease, cancer, unintentional injuries, and stroke (1). Premature deaths and disabilities resulting from these conditions are largely preventable through the adoption of healthy lifestyles and other preventive health practices. Behaviors, such as avoiding tobacco, eating low fat and high fiber foods, exercising regularly, maintaining normal weight, wearing seatbelts and limiting alcohol can contribute significantly to improved health status and longer life. Early diagnosis and treatment are also important to reduce deaths from chronic diseases.

National, state, and local data on the health status and health practices of Hispanic Americans, one of the largest ethnic groups in the United States, are limited. According to the Secretary's Task Force on Black and Minority Health, it is a difficult and complex challenge to present an accurate picture of the health status and needs of Hispanic Americans due to the lack of data (2). This gap in information limits the ability of policy makers, health planners, and community leaders to plan appropriate interventions to promote the well-being of Hispanics.

Local health departments, which are responsible for protecting and improving the public's health, need accurate data in order to plan and develop appropriate public health strategies and interventions. When the community is comprised of a large ethnic group, it becomes even more critical to obtain local data and to do so in a culturally sensitive manner. In Monterey County, California, where 34 percent of the population is Hispanic, the need for local data to plan appropriate and culturally sensitive programs was recognized (3).

In 1988, the Monterey County Health Department was awarded funds from the California Department of Health Services as part of a cooperative agreement with the Centers for Disease Control to conduct a modified version of a Behavior Risk Factor Survey among the adult Hispanic population in Monterey County. The purpose of the survey was to assess the prevalence of risk factors related to chronic diseases and injury control among Hispanic adults in Monterey County.

The purpose of this paper is to briefly describe the survey components and the survey questionnaire. Preliminary findings from the telephone survey for hypertension, diabetes, smoking, obesity, weight control, cancer detection practices, and health insurance will also be presented. A final report will include the results of all of the health practices assessed and will also include nutrition, exercise, weight control, alcohol use, seat belt use, and other cancer detection practices for the three survey components.

Methods

For survey design and implementation, the project maintained high research standards by relying on a partnership of technical expertise from the Centers for Disease Control, the California Department of Health Services, Stanford University, the American Institutes for Research, and the California Public Health Foundation. In addition, the Health Department formed a local community task force to provide input into the survey design and to make recommendations for survey questions.

The questionnaire was adapted from the Centers for Disease Control Behavior Risk Factor Survey instrument. Topics include tobacco use, alcohol use, car seatbelt use, exercise, weight control, hypertension, diabetes, routine check ups, cancer detection practices and demographics. Nutrition questions from a California Department of Health Services statewide survey to assess fruit and vegetable intake were also included as were questions to determine sources of dietary fat.

Acculturation has been defined as the cultural and behavioral adaptation that takes place when individuals are exposed to a new culture. The process of acculturation may affect health practices so a five question acculturation scale based on language was added. Hispanics who primarily think, read, and speak Spanish were classified as less acculturated. Hispanics who primarily think, read, and speak English were classified as more acculturated (4).

Questions regarding health insurance status, financial ability to see a physician or purchase prescriptions, and media sources of information were also added to the questionnaire.

Using the 131 question instrument, over 1000 Hispanic adults were interviewed. Only Hispanic adults 18 years and older were eligible to participate in the survey. The survey was conducted county-wide with the exception of the western coastal area of the county, where only 5 percent of the residents in that area are Hispanic. The interview period was from July through December 1989.

800 Hispanic adults were interviewed by telephone. Participants were selected using the Waksberg method, a three stage cluster sampling technique (5). The sampling methodology was designed to generate a random sample of all telephone numbers in the survey area, including unlisted and new subscribers. Standard procedures were followed for recontacting refusals, busy numbers and numbers for which there were no answer.

Since 16 percent of the local Hispanic population do not have telephones, additional funding from the Northern California Cancer Center was obtained to expand the survey to include 108 face-to-face interviews in Hispanic households without telephones and 113 interviews of Hispanics living in migrant camps in the agricultural Salinas Valley.

Hispanic households without telephones were included through a door-to-door survey of housing units without a telephone. Information regarding Hispanic housing units with no telephone was obtained from the 1980 Census data for tracts having 400 or more persons of Hispanic origin. The census tracts in the survey area contained 83 percent of all such units in the county. The survey was restricted to census tracts with the following characteristics: (a) at least 20% of the occupied housing units in the tract had a Hispanic household member; (b) at least 15% of the housing units occupied by Hispanics were units without a telephone; and, (c) at least 100 housing units within the tract should be without a telephone. All of the census tracts that met the criteria described above were included in the sample.

Hispanic agricultural workers residing in registered camps in Monterey County were also included to complement the telephone survey and the door-to-door survey. A listing of the forty registered camps was obtained. These camps were classified as either single camps for single men or as mixed camps for families and single men. A systematic random sampling strategy was used to select the camps for conducting the survey. The number of separate housing units was determined for each camp and the units were randomly selected.

For the telephone, household, and camp survey, a list was obtained of all adult Hispanics occupying the eligible individual residential unit. A respondent was randomly selected from this list. At least three attempts were made to interview the designated respondent.

Results

The major risk factors for heart disease, cancer, stroke, diabetes, and injury were assessed by demographic variables including sex, education, occupation, and language. The prevalence of health practices, such as smoking, nutrition, exercise, weight control, alcohol use, and seatbelt use varied widely among the Hispanic population when examined by these demographic variables. The prevalence of self-reported blood pressure, cholesterol, and cancer screening practices and self-reported hypertension and diabetes were also determined. In addition to demographic variables, risk factors were analyzed by level of acculturation, health insurance status and media sources of information. The findings from the survey indicate both positive health practices and areas of concern when the results are compared to the Year 2000 Health Objectives.

Demographic results from the survey indicate the Hispanic population in Monterey County is young; over half of all adults are between the ages of 18 to 34 years of age. Over 70 percent of Hispanic adults are employed. Men are more likely to be employed (85%) than women (56%). 43 percent of Monterey County Hispanics are employed in agricultural-related jobs. 66 percent of adults have not completed high school. 46 percent have an eighth grade education or less. For agricultural workers, 85 percent have not completed high school. 42 percent of Hispanic adults have a family income of less than $15,000 per year. 68 percent of Hispanics and 91 percent of Hispanic agricultural workers are less acculturated (primarily Spanish speaking). 63 percent were born in Mexico and 36 percent were born in the U.S.A. 59 percent of Hispanics and 87 percent of Hispanic agricultural workers responded to the survey in Spanish.

Smoking is the chief preventable cause of death and disease in our society. The Year 2000 Tobacco Objective for smoking among Hispanics is a prevalence of no more than 18 percent (6). The smoking prevalence among Hispanics in Monterey County is lower than the prevalence for Hispanics in California (7). This is due to the low prevalence of smoking among Hispanic women in Monterey County (5.6%) compared to Hispanic women in California (17.6%). The prevalence of smoking among Hispanic men in Monterey County (24.5%) is similar to the prevalence of smoking among Hispanic men in California (26%).

Hispanic men with less than a high school education have a higher smoking prevalence (28%) than Hispanic men with a high school education (18%). It is important to note that 66 percent of all Hispanic men and 85 percent of agricultural workers have less than a high school education. There was no significant difference in the prevalence of smoking among Hispanic women by education level.

Figure 1

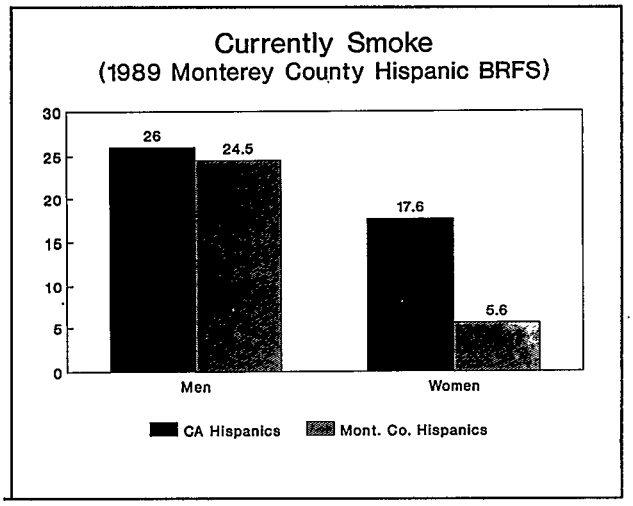
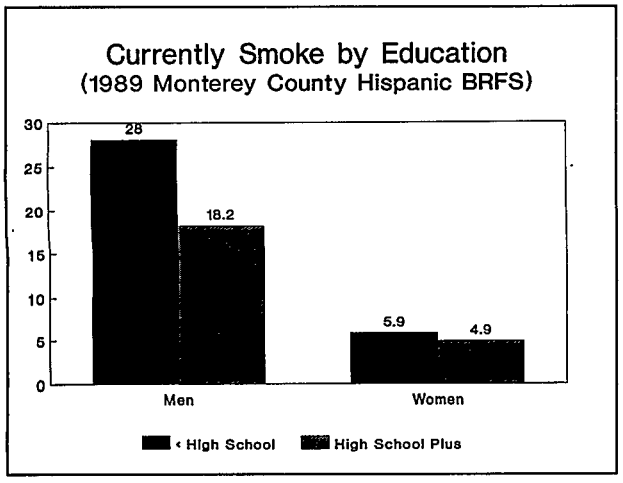
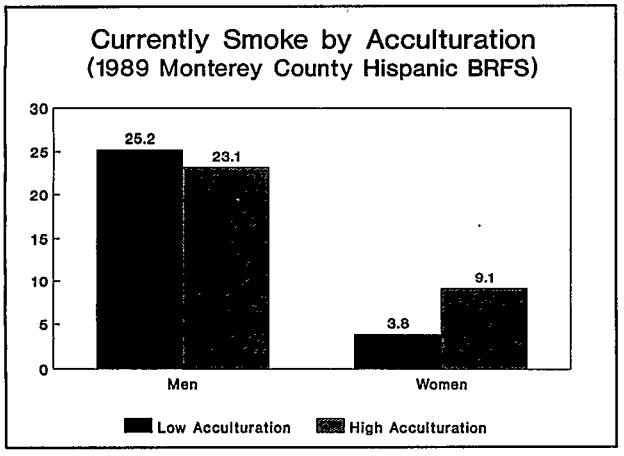


Figure 2



Less acculturated Hispanic women were significantly less likely to smoke (4%) than more acculturated Hispanic women (9%).

Figure 3



Hispanic men employed in agricultural-related jobs were more likely to smoke (30%) than Hispanic men employed in non-agricultural jobs (22%). Again, it is important to note that 44 percent of Hispanic men are employed in agricultural-related jobs.

Prevalence of Hypertension

Hispanic adults in Monterey County (88%) have almost achieved the Year 2000 Hypertension goal of 90 percent of adults having their blood pressure measured in the preceding 24 months (6). The prevalence of self-reported hypertension in Hispanic men in Monterey County (16.1%) is similar to the rate for Hispanic men in California (15.6%), but the prevalence for Hispanic women in Monterey County is higher (23.2%) than for Hispanic women in California (18.0%) (7).

Figure 4

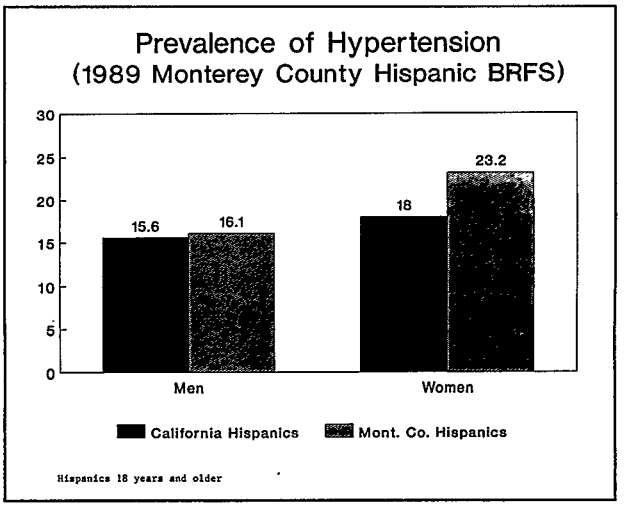


Table 1

Hypertension: Percent Responses

	Last Time B.P. Was Taken ≤ 2 Yrs %		Ever Been Told of High B.P. %	
	M	F	M	F
			Yes	
Education				
< High School	86	88	15	25
≥ High School	86	95	18	20
Income				
< $15,000	84	89	12	27
$15,000-25,000	87	90	15	28
> $25,000	91	98	24	09
Acculturation				
Less	86	88	15	26
More	87	95	20	18

The prevalence of hypertension varied significantly by education level, income and level of acculturation. Hispanic women with less education, less income, or less acculturation were more likely to have been told they have high blood pressure. However, for Hispanic men the opposite was true. Hispanic men with more education, higher income or more acculturation were more likely to have been told they have high blood pressure.

Prevalence of Diabetes

The prevalence of diabetes among Hispanics in Monterey County (7.1%) is higher than the Year 2000 Diabetes Objective of 4.9 percent for Hispanics (6). The rate was higher among Hispanic women (8.3%) than Hispanic men (5.8%). The prevalence of diabetes increases with age. 17.2 percent of Hispanic men age 45 and older and 18.9 percent of Hispanic women age 45 and older report they have diabetes. The prevalence of diabetes did not differ by education level, income, or acculturation.

Prevalence of Obesity and Weight Control

Hispanic women in Monterey County had higher rates of obesity (30%) based on body mass index than Hispanic women in California (20%). 48 percent of Hispanic women and 32 percent of Hispanic men want to lose weight. Hispanic men and women were twice as likely to try to lose weight by eating fewer calories than by increasing physical activity.

Table 2

Weight Control

	Men %	Women %
Trying to lose weight	32	48
Eating fewer calories to lose weight	85	79
Increased activity to lose weight	46	43
Consider yourself overweight	23	44

Cervical Cancer Screening

The Year 2000 Cancer Objective of at least 95 percent of women 18 and older with uterine cervix who have ever received a Pap test has not been achieved for Hispanic women in Monterey County. 29 percent of Hispanic women have never heard of a Pap test and 25 percent have never had a Pap test. The Pap test procedure was explained to women who responded that they had never heard of a Pap test. After the explanation, these women were then asked if they have ever had a Pap test. According to the California BRFS protocol, women who had never heard of a Pap test are not asked if they have ever had the test. This difference in protocol may limit data comparisons between state and local data.

Hispanic women with less than a high school education, less acculturated, and without health insurance were even less likely to have ever had a Pap test. In addition, of those women who have had a Pap test, those with less education, less income, or less acculturation were more likely to have had their last Pap test because of a health problem rather than as part of a routine visit.

Table 3

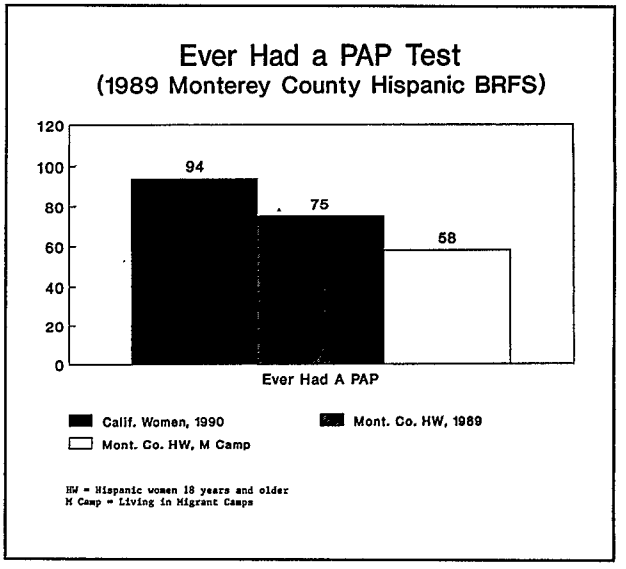
Pap Test: Percent Response by Variables (Hispanic Women 18 years and older)

	Ever Heard	Ever Had	Reason	
	YES(%)	YES(%)	HP	RV
Education				
<High School	60	70	20	80
≥High School	94	85	10	90
Income				
<$15,000	61	74	22	78
$15,000-$25,000	79	85	15	85
>$25,000	92	84	5	95
Acculturation				
Less	59	66	18	82
More	95	92	14	86

HP = Health Problem
RV = Routine Visit

Hispanic women who work in agricultural jobs are as likely (74%) to have ever had a Pap test as Hispanic women working in non-agricultural jobs (78%). However, of Hispanic women surveyed in migrant camps, only 58 percent reported ever having had a Pap test.

Figure 5



Health Insurance

Among adult Hispanics in Monterey County, 32 percent do not have health insurance. Of the 68 percent Hispanics who do have health insurance, 23 percent did not have any health insurance at some time during the previous 12 months. In addition, during the past year, 23 percent of Hispanic adults did not see a doctor nor fill a prescription when they needed to due to cost.

Table 4

Health Insurance: Percent Response Hispanic Men and Women 18 years and older

	Have Ins. %Yes	Time No Ins %Yes	No M.D. 2° Cost %Yes	No RX 2° Cost %Yes
Education				
<High Sch.	62	29	29	21
≥High Sch.	78	14	15	12
Income				
<$15,000	51	29	33	24
$15-$25,000	76	31	25	21
>$25,000	89	9	8	6
Acculturation				
Less	60	29	28	20
More	82	14	17	14

Have Ins. = Have Insurance

Time No Ins = Time during the past year when did not have health insurance.

No M.D. 2° Cost = Time during the past year when did not see a doctor due to cost.

No Rx 2° Cost = Time during the past year when did not fill a prescription due to cost.

Discussion

The Monterey County Hispanic Behavior Risk Factor Survey provides baseline data which will be helpful in planning appropriate health promotion programs to reduce chronic diseases and injury among the local adult Hispanic population in Monterey County. This data may also be helpful to other Hispanic communities in their program planning efforts.

Conducting the survey at the local level also produced valuable outcomes in addition to the local data. For example, the process of involving the community in determining the survey design and the questions to be asked was invaluable in raising community sensitivity in planning Hispanic health promotion programs. There is also increased interest in the survey results among the agencies involved in planning the survey to use the results in their own efforts to provide culturally appropriate Hispanic health promotion programs.

As with all studies, it is important to note that there are limitations to the data which need to be considered when interpreting the findings. However, the data are most useful when considering program planning applications.

The high prevalence of smoking among Hispanic men employed in agricultural related jobs is important to note since most Hispanics in Monterey County work in agricultural jobs. Analyzing the data by occupation is useful in planning intervention strategies. Delivering tobacco education programs through agricultural worksites might be considered.

Positive health practices based on actual data, such as the low prevalence of smoking among Hispanic women, can be emphasized and reinforced. The major media sources of information for Hispanic women can be identified from the survey findings and used for mass Spanish language media campaigns.

The high prevalence of overweight among Hispanic women is of concern since the prevalence of hypertension and diabetes was also high. Obesity is linked to hypertension, Type II diabetes mellitus and certain cancers. Language and culturally appropriate programs for weight reduction among Hispanics are lacking in Monterey County. The findings indicate, however, that 48 percent of Hispanic women want to lose weight.

The survey found inadequate levels of cancer detection practices. One out of four Hispanic women had never had a Pap test. Although the survey did not explore the barriers to having Pap tests, the baseline prevalence estimate helps to identify the high risk groups for follow-up assessments. Less acculturated women and women with less than a high school education were at increased risk of never having a Pap test; Hispanic women living in migrant camps were most at risk.

Preventive health practices which require a visit to a health care provider are unavailable to many Hispanics due to limited health insurance and low income. Health access is a critical issue which needs to be addressed at a national level. However, many premature disabilities and premature deaths can be prevented through the adoption and maintainance of healthy lifestyles, such as avoiding tobacco, eating low fat diets rich in fruits and vegetables, limiting alcohol, and always wearing seatbelts when riding in a car.

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CONDUCTING A CULTURALLY-SENSITIVE HEALTH SURVEY IN THE CHINESE COMMUNITY

Rod Lew, Asian Health Services
Art Chen

In 1989, Asian Health Services conducted a behavioral risk factor survey of 296 Chinese residents living in Oakland Chinatown. This paper reveals some of the initial results and describes the significance of the Chinese community survey.

Asian Health Services (AHS) is a non-profit, community clinic which provides medical and health education services to low-income, non-English speaking Asian population in Alameda County. Currently, bilingual staff provide services in seven Asian languages.

Background

The Asian Pacific Islander[1] population is growing faster than any other ethnic group. In the eight year span from 1980-1988, Asians grew by more than 85 percent in the U.S. In Alameda County, the Asian population more than doubled from 1970-1980; according to the 1990 Census, the Asian population now numbers 192,554 or 15 percent of the County's overall population.[2] It should be noted that Asian Pacific Islanders are an extremely diverse population with more than 30 racial and ethnic groups represented. In Alameda County, the Chinese are the largest of the Asian subgroups, comprising 36 percent of the Asian population.

Certainly, with the growth of the Asian population has come many valuable contributions to America's economic and cultural growth. However, as the Asian population continues to grow, it becomes increasingly important to understand the health profile of the specific ethnic Asian subgroups.

Few health studies have focused on collecting information from a specific Asian American subgroup in a culturally-sensitive manner. Notable exceptions include University of California at San Francisco's Vietnamese Community Cancer Prevention Survey[3] and Indochinese Health and Adaptation Research Project (IHARP) study in San Diego[4]. For this reason, through funding by the California Department of Health Services Health Promotion Section and Centers for Disease Control (CDC), Asian Health Services took the first step to reducing the gap in health data by conducting a health study of Chinese Americans living in Oakland Chinatown.

The goal of the AHS project, named the Gin Hong Si Fook (Health is Wealth) Program, was to assess the individual health risk behavior among Chinese and to develop a community-wide intervention to reduce smoking among Chinese. The program consisted of five main objectives: to conduct a local survey, to conduct a community resource inventory, to convene a community coalition, to launch a community campaign to address chronic disease issues and to establish smoke-free policies at the workplace.

This paper will focus on Asian Health Services' survey which studied a variety of health risk factors including smoking, alcohol, hypertension, diet and women's health. Local surveys, like this one, are significant in that they 1) contribute to the field of research, 2) establish a baseline of information for Asian and Pacific Islander health, 3) place special emphasis on community-sensitive research (CSR) and 4) identify priorities for program interventions, and 5) assist in program planning and implementation.

Community-sensitive research is an extremely important concept in conducting studies in ethnic specific populations such as the Chinese. In the AHS survey, community-sensitive research included using bilingual interviewers, adding culturally appropriate questions and conducting face-to-face interviews. Its importance lies in the emphasis placed on community participation in the planning, implementation and presentation stages of the survey. The AHS approach was to engage Chinese residents in generating their own community health profile and to stimulate interest in developing solutions to defined problems.

Methodology

The Chinese community survey used a two-stage systematic random sampling method. Based on the 1980 Census, the two census tracts in Oakland with the largest percentages of Chinese residents were selected as the sampling frame. (In 1980, the Chinese population for these two census tracts was 1852). Using a reverse directory, Chinese households (identified by Chinese surnames) were identified in this 6-by-8 block sampling frame. For those households not listed in the directory, bilingual interviewers went door-to-door to identify missing addresses.

Every second Chinese household was selected within these two census tracts. After approaching a selected households in-person, the interviewer asked the initial contact person to enumerate all of the household members who were Chinese and at least 18 years old. Then through a random grid selection process, the respondent was selected to complete the survey.

The interviews were conducted in the home, and some questions (such as on diet) involved the use of props to ensure accuracy and consistency. Almost all of

the surveys were conducted in Cantonese by bilingual workers.

The survey instrument was modified from CDC's Behavioral Risk Factor Survey and then translated into Chinese. Audio tapes of the questions were made to ensure accuracy and consistency in the translation.

As with other household survey projects, the AHS interviewers encountered many barriers such as the usual "No solicitors" signs. Additionally, unexpected and unfortunate events, such as the Tiananmen Square massacre in China and the Loma Prieta earthquake in California, had tremendous impact on the Chinese community in Oakland Chinatown. The interviewer training and cultural background of the interviewers helped to reinforce the need for sensitivity to the community residents during these times.

Despite these difficult situations, the AHS survey had a high response rate of 76 percent. Of the 388 Chinese households approached by our interviewers, 296 surveys were completed. Sixteen percent of those households approached refused to participate in the survey and another seven percent could not be reached.

Results

The age distribution of the surveyed population revealed a wide age range. This tended to be an older population with the mean age equalling 53.3 years.

Other demographic characteristics appear in Table 1. 57 percent of those interviewed were female. A very important variable when studying Asians is nativity, or country of birth. Almost 80 percent of the respondents were born in China versus only seven percent who were American born. More than half of the respondents had an 8th grade education or less. And more than half were below the poverty level of $10,000 for household income.

Table 1 **DEMOGRAPHICS**

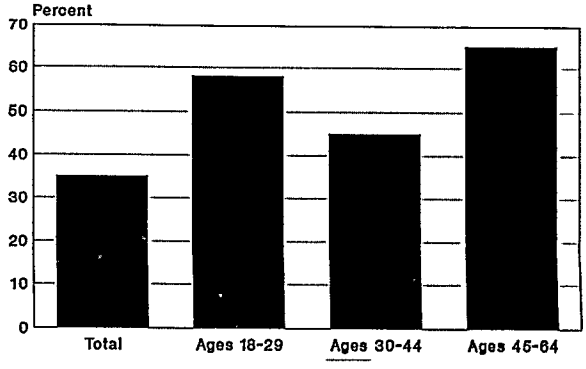
Nativity (country of birth):	
China	78%
Hong Kong	7%
Vietnam	4%
U.S.A.	7%
Educational Level:	
8th grade or less	52%
High school	31%
College	17%
Household Income Level:	
< $10,000	53%
$10,000-25,000	36%
> $25,000	11%

Another important variable which has great impact on Asian American populations is fluency in English. 87 percent of the respondents were not fluent in English. Even more revealing, 38 percent of the non-English speakers were also illiterate in Chinese, their primary language. This has tremendous implications when developing health education programs and materials for this Chinese population.

Health insurance status is another important variable. Of those surveyed, 18 percent had private insurance but 35 percent of those surveyed had no form of health insurance. When cross- tabbed by age, there was an even higher percent uninsured in the younger age brackets. For example, of those Chinese between the ages of 45 and 64, 65 percent were uninsured. (Table 2)

Table 2

WITHOUT HEALTH INSURANCE
By Age



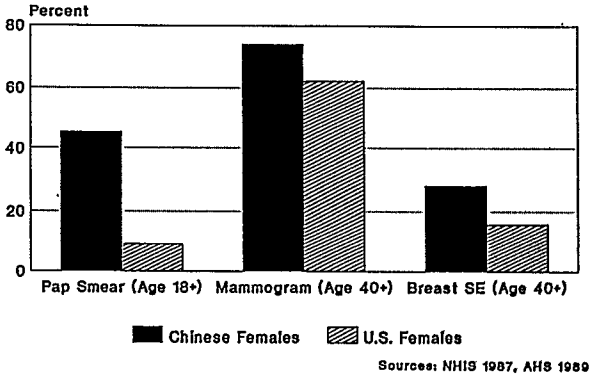
Prevalence

In the AHS study, smoking prevalence rates for Chinese males was 28 percent and for Chinese females was one percent compared to 1987 NHIS figures of 32 percent and 27 percent for U.S. males and females respectively.[5] This indicates that smoking still is a very important problem for Chinese males.

Knowledge and Access

For Chinese females, screenings for cervical and breast cancer are highly important. When asked if they had ever had a Pap Smear test, 45 percent of those age 18 and older reported they never had one compared to 1987 NHIS statistics which found that nine percent of U.S. females age 18 and older never had a Pap Smear.[6] (Table 3)

Table 3 NEVER HAD
Cancer Screenings



Sources: NHIS 1987, AHS 1989

The low level of knowledge about and behavior toward these important cancer screening procedures reveals a gap in access to preventive procedures for Chinese females.

For Asians, access to health care is often impeded by two main barriers: language/cultural and financial barriers.

When asked when they had their last mammogram and Pap test, those who were non-English speaking were more likely to have delayed getting the screening than those who were English fluent. For example, half of English-fluent Chinese females age 40 and older had their last mammogram within the past 2 years, whereas only 21 percent of those non-English fluent Chinese females had a mammogram in the past 2 years. Due to the low numbers of English fluent subjects, this comparison was not statistically significant. However, the fact that 79 percent of non-English fluent Chinese women did not get mammograms suggests that language still represents an important barrier to getting access to preventive cancer screening procedures.

Household income appears to play a role in the impact on knowledge of mammograms and Pap smear tests. Higher-income Chinese females age 40 and older were significantly more likely to have knowledge of a mammogram than those who have household income of less than $10,000 year. The same is true for knowledge of Pap smear for Chinese females age 18 and older. 44 percent of the higher income bracket knew what a Pap smear was versus only 22 percent of those women below the poverty line.

Discussion

Public opinion has often been swayed by the belief that Asian Americans have few problems-health, social or educational- and are thus the "model minority". When seen as one homogenous group, which Asians are not, statistics may also seem to indicate that Asians have no health problems when compared to other racial groups.

National studies such as the National Health Interview Survey and the Report of the Secretary's Task Force on Black and Minority Health are prime examples of this. Criticisms of such surveys are directed toward their methodology which involved no translators and was not carried out in a culturally sensitive manner. For example, the National Health Interview Survey (1987) shows low smoking prevalence rates for Asians as a whole, in this case, 12 percent for Asian males.[7]

But when specific ethnic Asian subgroups such as the Chinese are studied, the data reveals much higher prevalence rates than indicated for Asians as a whole.

It is clear that language, cultural and financial variables are important for adequate access to health care for Chinese. It should be made clear that the Chinese interviewed in this survey may not necessarily be representative of all the Chinese living in Alameda County. But, these results provide insight into the health profile of a population that is primarily immigrant and non-English speaking. This is especially significant since many of these health risks are highly preventable. But, what makes prevention much more difficult are the many barriers that the Asian population faces: in particular, language, cultural and financial barriers.

Conclusion

In conclusion, the Chinese community survey has made great impact in several areas. First, it stresses the need for community sensitive research. As more studies are done in recently arrived immigrant communities, it is imperative to provide a culturally appropriate method to doing research that involves the community and therefore, yields more accurate results than those obtained through national surveys.

This information on Asian health is extremely important in helping to fill the gap in data on Asian health. In particular,it provides key information on nativity, English fluency and baseline data on many risk factors.

Thirdly, it provides an appropriate needs assessment on general health risk for the community of focus. Community health organizations can better understand the population that they will be outreaching and planning health promotion programs for. Already, Asian Health Services has developed a comprehensive smoking and a hypertension programs based on the preliminary data from the Chinese community survey.

Finally, this study dispels the image of all Asian Americans as the model minority and that indeed subgroups like the Chinese do have serious health problems and needs. It also shows that culturally appropriate steps must be taken to address the concerns of health access. Much more needs to be done to develop multicultural, multilingual programs for the diverse Asian Pacific Islander community.

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PUBLIC LAW 99-457 AND EARLY INTERVENTION: WHO IS 'AT RISK' AND HOW SHOULD WE FIND THEM?

Mark E. Swanson, University of Arkansas University Affiliated Program, Russell S. Kirby

P.L. 99-457 mandates states to establish a statewide, comprehensive, coordinated, multidisicplinary, interagency system of intervention services for eligible children. Children under 3 years are eligible if they are experiencing developmental delay in one or more of the following areas: cognitive, physical, speech and language, psychosocial or self-help or have a physical or mental condition with a high probability of resulting in delay. States have the discretion of including children who are 'at risk' for medical or environmental reasons.

There are many medical diagnoses associated with risk for developmental delay. These include:

Down syndrome
Other chromosomal abnormalities
Syndromes involving multiple congenital anomalies
Cerebral palsy
Brain tumors and other malignancies which involve the brain
Meningomyelecele (spina bifida)
Phenylketonuria (PKU) and other metabolic disorders
Fetal alcohol syndrome
'Crack' cocaine babies
AIDS
Microcephaly
Failure to thrive
Significant hearing loss
Significant vision loss

Other medical events that children experience may also make them at risk for developmental delay. These include:

Birthweight less than 1500 (or 1250) grams
Neonatal asphyxia
Prolonged mechanical ventilation
Prolonged nursery stay
Neonatal seizures
Intracranial hemorrhage (Grade III or IV)
Meningitis
Encephalitis

Environmental risk factors that may predispose a child to developmental delay include:

Teenage mother
Multiple children in family
Low maternal education
Unmarried mother
Poverty
Isolated family
Unstable home environment

The comprehensive system of state services consists of multiple components. Direct services to the child include multidisciplinary assessment, physical therapy, occupational therapy, speech therapy, and daycare. Services to the family include an Individualized Family Service Plan (IFSP) and case management (service coordination). Other components of the system include a Child Find and tracking system, a central directory and a comprehensive system of personnel development.

Central directory and the Child Find/tracking system are 'data-oriented' components. The Child Find/tracking system consists of children identified by a variety of means as meeting the state's definition of developmental delay or 'at risk'. Children are identified by health professionals (pediatricians, various therapists, nurses), parents, families and other human service professionals and then referred for multidisciplinary assessment to see if they meet the state's eligibility requirements.

Other potential sources of information on children who may be eligible are various birth certificate records (which contain much information about prenatal and perinatal risk factors) and Medicaid/insurance files (whose diagnostic codes would identify other children at-risk).

Some experts have proposed that a combination of risk factors, medical and environmental, be used to determine eligibility for early intervention services. They point out that a single risk factor (e.g., birth weight less than 1250 grams) has low sensitivity and specificity in the prediction of such important outcomes as mental retardation and cerebral palsy. If a child has both low birth weight and neonatal asphyxia, however, there is a much increased sensitivity and specificity. When one adds in factors such as low maternal education and poverty indicators to low birth weight, a more powerful set of predictors has been established.

A number of researchers have looked at the relationship between medical factors known at birth or in the first months of life and incidence of specific developmental disabilities, such as cerebral palsy and mental retardation.

STUDIES OF CEREBRAL PALSY

Ellenberg and Nelson (1988) followed more than 39,000 children with birthweights over 2.5 kilograms in the Comprehensive Perinatal Project in the U.S. for the occurrence of three risk factors: 1) clinically recognized neonatal seizures (occurring in the nursery before 3 days of age); 2) 5-minute Apgar scores less than five; 3) at least one of five signs compatible with neonatal encephalopathy (decreased activity after first day of age, incubator care more than 3 days, feeding problems, poor suck or respiratory difficulty). Survivors who had all three risk factors had a 55% risk of cerebral palsy. Even so, this group contributed only 16% of the cases of cerebral palsy. 63% of children with cerebral palsy had no risk factors at all.

When Nelson and Ellenberg (1986) looked at all 54,000 births in the Comprehensive Perinatal Project, they identified a number of risk factors through multivariate analysis. Mother-child pairs who were in the highest 5% of risk (considering risk factors identifiable before labor) contributed 34% of cases of cerebral palsy. The 5% at highest risk when prenatal and perinatal risk factors were considered contributed only 37% of cases of cerebral palsy. Thus inclusion of intrapartum factors made only a modest contribution to the detection of cerebral palsy. Risk factors identified in this study included maternal mental retardation, severe proteinuria late in pregnancy, prematurity, low birth weight, breech presentation, delay in first cry and neonatal seizures. Even so, only a minority of cases of cerebral palsy could be predicted from this high-risk group.

In a case control study of very-low-birth-weight infants, Cooke (1990) matched 81 survivors with controls on the basis of gender, gestational age, and place of birth. He found that cases of diplegic cerebral palsy (a type characterized by greater involvement of the legs) differed from controls in terms of prenatal variables, such as duration of labor, presence of amnionitis, maternal smoking and low Apgar scores at 5 minutes.

A population-based study in northern Finland of 12,058 births (Rantakallio and Von Wendt, 1986) found a prenatal risk factor present in 28% and a perinatal risk factor in 53% of children with cerebral palsy. Relative risk of developing cerebral palsy was 63 with congenital infection, 167 with brain malformation, 71 with multiple anomalies and chromosomal aberrations and 51 with neonatal asphyxia, yet only 16 of 128 children with neonatal asphyxia developed cerebral palsy.

In a California-based HMO birth cohort of 19,044, Torfs and colleagues (1990) found multiple significant predictors on univariate analysis. Maternal predictors included unusually long or short intervals between pregnancies and unusually long menstrual cycles. Prenatal predictors included birth defects, low birth weight, low placental weight, abnormal fetal position, and premature separation of the placenta. Perinatal factors included delayed crying (a measure of asphyxia) and abnormal delivery. On multivariate analysis, only birth defects, abnormal pregnancy intervals and long menstrual cycles remained significant of the prenatal variables. All the perinatal variables remained significant. 78% of children with cerebral palsy did not experience birth asphyxia.

Stanley and English (1986) studied a cohort of 551 babies with a birth weight less than 2.0 kilograms in Australia. Cerebral palsy prevalence was 3.6% for those less than 1.5 kilograms and 4.3% for those weighing between 1.5 and 2.0 kilograms. The main factors predicting cerebral palsy were indicators of birth asphyxia (taking longer to breathe, need for resuscitation). The majority of children with cerebral palsy had no extra risk factors, were not aspyhxiated and did not require intensive care.

STUDIES OF MENTAL RETARDATION

The Finnish researchers Rantakallio and Von Wendt (1985) prospectively studied the risk factors for mental retardation in 12,058 children born in northern Finland. They found that a risk diagnosis could be found in 70% of children with IQs below 70 (the standard cutoff score for mental retardation). Prenatal conditions (chromosomal abnormalities, malformations, other inherited disorders, congenital infection) were associated with 63% of cases of children with IQ scores below 50. Overall, 87% of this latter group had a known risk factor. For those children with IQ scores between 50 and 70, only 30% had a known risk factor.

When Ramey and colleagues (1978) looked at a cross-section of 1000 1st graders in North Carolina, they found that birth certificate information was useful in predicting the developmental status of the children. Risk factors for low functioning in school included: birth order, race, educational status of mother, month prenatal care began, survivorship of older siblings and mother's marital status.

A prospective study of 24,498 births in an urban area of Sweden was conducted by Hagberg and colleagues (1981). 91, or 0.4%, of the population was found to have mild mental retardation (IQ between 50 and 70). 73 children had IQ scores below 50. In 72% of the children with mild retardation, a putative cause was identified. The cause was prenatal (including fetal alcohol syndrome, chromosomal abnormalities, other syndromes with fetal malformations) in 23%. In 18%, the cause was perinatal (asphyxia,/hypoxia, infection of the central nervous system). Postnatal causes made up 2% of cases, and another 29% had close family members with sub-normal intelligence.

Smith and colleagues (1972) prospectively studied 301 black children from a Southern urban population, looking for risk factors that would predict developmental outcome. They found that maternal intelligence, maternal age, maternal education, maternal infection, low Apgar scores, high bilirubin levels and delayed cry seemed to predict which children would end up in the 'abnormal' group at age 7 years. Their study was not large enough to measure the independent contribution of each of these factors.

CONCLUSIONS

1. Birth certificate data and other health databases contain information relevant to identification of young children with cerebral palsy and mental retardation.

2. Individual parameters tend to have low sensitivity and specificity in predicting cerebral palsy and mental retardation. Most children with cerebral palsy and the milder forms of mental retardation have no risk factors.

3. Combinations of individual risk factors may prove to be better predictors of cerebral palsy and mental retardation than individual risk factors.

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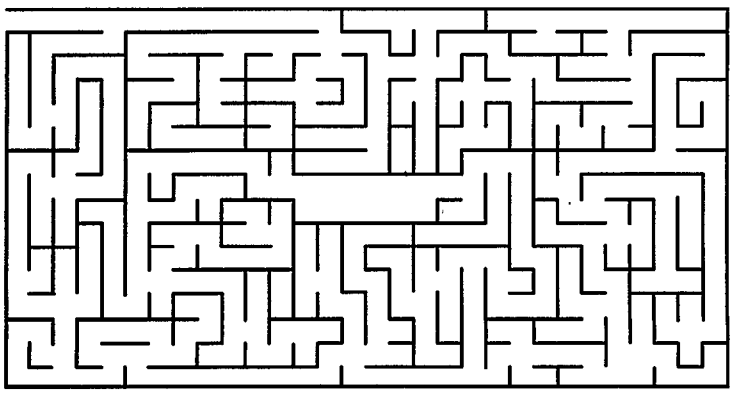
DISCUSSANT

Ashley Files
Office of Disease Prevention and Health Promotion

(Not available for publication)

Session S

Minority Health



CLINICAL PREVENTIVE SERVICES IN FEDERALLY FUNDED COMMUNITY AND MIGRANT HEALTH CENTERS

Deborah Parham, Health Resources and Services Administration
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Introduction

The Department of Health and Human Services has plotted an ambitious course to reach the year 2000 national health promotion and disease prevention objectives. However, these objectives will remain elusive unless clinical preventive services are provided to underserved populations. At present, significant numbers of people throughout this country do not receive preventive and primary care health services due to a variety of financial, geographic or cultural barriers. To bridge some of these barriers, the Federal community and migrant health center (C/MHC) programs fund preventive and primary health services systems around the Nation designed to improve health status of the patients and the greater communities they serve.

Many C/MHCs provide preventive health services as part of the package of comprehensive primary care services. The purposes of this study were as follows: 1) to gather specific information on the extent to which C/MHCs have incorporated clinical preventive services in their individual programs and on the uniformity of those services between programs; 2) to determine the range of clinical preventive health services offered in C/MHCs; 3) to determine the types of providers who are delivering these services; and 4) to assess the barriers which limit the provision of clinical preventive health services.

Methods

A survey instrument was sent to the medical director in all community and migrant health centers which received Federal funding in fiscal year 1990. Approximately two-thirds of the C/MHCs are located in rural areas of the country; the remaining one-third are located in urban areas. During calendar year 1990, over six million individuals received primary and preventive health services at C/MHCs. Eighty-five (85) percent of C/MHC clients had incomes below 200 percent of poverty; 64 percent of C/MHC clients were members of racial and ethnic minority groups.

The survey instruments were based on the age-specific recommendations for clinical preventive services established by the U.S. Preventive Services Task Force.[1] In an effort to balance completeness with length, some categories from the Task Force recommendations were condensed and some services for high risk group services were omitted. Two similar survey instruments were developed. One instrument included questions on preventive screening practices for pediatric and adolescent age groups; the other listed screening items for adult age groups. Three lifecycles were included in the pediatric instrument - birth to 23 months, ages 2-12, and ages 13-18. The lifecycles included on the adult instrument included ages 19-39, ages 40-64 and ages 65 and over.

Both instruments contained sections on pregnant women and counseling services for all age groups. Counseling services were addressed separately because of their importance but not easily definable place in a patient encounter. Finally, the survey included several open-ended questions to encourage elaboration on various items and identification of barriers by the respondent.

Division of the instruments was made feasible by the fact that the survey items, as with preventive services, were grouped by lifecycle. It was, therefore, possible to separately and randomly distribute the adult screening and the pediatric screening sections; thus reducing the instrument length and burden of response for an individual respondent, without jeopardizing instrument clarity or the validity and generalizability of the aggregate data.

Within the 10 PHS regions, the two versions of the survey instrument were randomly distributed in equal proportions to 538 C/MHCs. A total of 270 pediatric and 268 adult survey instruments were distributed. Each C/MHC received only one survey instrument. The surveys were mailed in November, 1990 and collected through February, 1991. A total of 357 medical directors completed and returned the survey. (see Table 1)

Analysis of the survey data consisted primarily of cross tabulations with chi-square significance tests were used where appropriate to assess differences among responses by specific variables. Tables displaying frequency counts and percentages for the values of individual questions were also generated. The number of variables on the survey instrument (almost 900) and the required analyses necessitated the use of a mainframe-based data base management and statistical software package.

Table 1 - Description of Sample

	Pediatric Instrument	Adult Instrument	Total Sample	C/MHC Universe
Response Rate	n = 186 68.9%	n = 171 63.8%	n = 357 66.4%	N = 538
Location (%)				
Rural/Frontier	55.2	57.9	56.5	63.6
Urban	34.0	35.1	34.5	36.4
Both	10.8	7.0	9.0	na
Funding (%)				
329	4.8	2.9	3.9	4.9
330	76.5	83.0	79.6	79.8
Both	18.8	14.0	16.5	15.3
Region (%)				
I	5.9	8.8	7.3	6.6
II	11.8	10.5	11.2	9.9
III	16.7	12.3	14.6	13.1
IV	19.9	22.2	21.0	25.0
V	12.4	12.9	12.6	11.2
VI	10.2	8.8	9.5	9.4
VII	3.8	2.9	3.4	3.9
VIII	7.5	7.6	7.6	5.9
IX	8.1	9.4	8.7	10.3
X	3.8	4.7	4.2	4.8
Race/Ethnicity (%)				
African American	26.0	23.0	24.6	30.0
White	44.7	49.8	47.1	44.0
Hispanic	23.7	23.2	23.5	23.0
Asian American	2.3	2.3	2.3	2.0
Native American/ Alaska Native	0.7	2.3	1.5	2.0
Other	2.6	1.2	1.9	na

Note: Section 329 of the PHS Act authorizes migrant health centers; section 330 authorizes community health centers.

Results

In order to establish a baseline of reported preventive services, a large number of items were included on the survey instruments. Selected results, by preventive service, are presented here along with the rural-urban variations which were found to be significant for most preventive services offered. A description of the type of providers who most often deliver a preventive service and barriers which limit the provision of these services are also identified.

Lead Screening

A large percentage of responding centers indicated that lead screening is not performed on any asymptomatic infants or children (46 percent and 50 percent of responding centers, respectively). Urban centers were significantly more likely to perform lead screening than rural centers, although over 20 percent of the urban centers responded that lead screening is not performed on any asymptomatic infant.

Tuberculosis Screening

More than 40 percent of the responding centers indicated that they periodically screen children for tuberculosis. Some screen children once at age 4 or 5 while others indicated screening once in infancy and again at school age. Some centers indicated screening infants for tuberculosis, but not asymptomatic patients in the older age group.

Over 80 percent of the urban centers that responded indicated that tuberculosis screening is provided to all asymptomatic individuals compared to only about 60 percent of the rural centers. Close to 20 percent of the rural centers reported that

tuberculosis screening is not provided to any asymptomatic child. The U.S. Preventive Services Task Force recommended limiting such screening to individuals considered to be high risk.

Sexually Transmitted Disease Screening

About one-fourth of responding centers indicated that chlamydia or "other STD" screening were not performed on any asymptomatic teens that are sexually active. Another 19 percent (for chlamydia) and 16 percent (for other STDs) indicated that screening is focused on those teens considered at high risk which was generally defined as pregnancy, being a family planning client, or as indicated by sexual history. About one-half of the responding centers are screening all asymptomatic, sexually active teens for sexually transmitted diseases. In contrast, nearly 80 percent of the respondents indicated that they perform pap smears for all sexually active teens; another 11 percent perform pap smears on high risk teens.

Seventy-five percent of urban centers provided screening for sexually transmitted diseases to all asymptomatic teens compared with only 44 percent of rural centers.

Smoking and Substance Use History

Over 80 percent of all responding health centers noted that they obtain a smoking and substance use history on all clients over age 12 at the frequency recommended by the U. S. Preventive Services Task Force. However, there was an urban/rural difference with 95 percent of urban centers inquiring about smoking and substance use history compared with only 81 percent of rural centers.

Breast Cancer Screening - Mammography

A relatively high percentage of responding centers reported providing mammograms to asymptomatic women. For women over age 35, 69 percent of centers provide baseline mammograms to all women and another 15 percent focus screening on those at elevated risk (for example, family history of breast cancer). For women between ages 40 and 49, the number of respondents providing a mammogram to all women every 2 years increased to about 71 percent. Another 13 percent indicated that they provide the exam at a different frequency. About 95 percent of the centers reported providing mammograms every 1 or 2 years or as indicated to all asymptomatic women over age 50. The percentage is essentially stable for women over age 65; about 77 percent of centers indicated routinely screening women every 1 or 2 years or as indicated.

Ninety-seven (97) percent of all responding rural centers reported that they provide mammograms compared to 91.5 percent of responding urban centers.

Who Provides Preventive Services?

The results indicated a broad division of labor across different types of providers for delivering preventive services. At many centers, physicians appeared to concentrate on items associated with history taking and physical examination. Many of the services provided in the youngest two age groups were delivered by nurses. In the older age groups, physicians were the most common providers of most items except for services such as height, weight, blood pressure and immunizations. Nurse practitioners (NP), certified nurse midwives (CNM), physicians assistants (PA) and nurses were more involved relative to physicians in service delivery to pregnant women. Physicians, NPs, CNMs, PAs and nurses all offered counseling services.

Why Aren't More Preventive Services Offered?

Two open-ended questions were included which asked the respondents to identify barriers to delivery of preventive services experienced by their centers. Those results are presented in Table 2. Lack of ancillary staff to provide clinical preventive services was the most prevalent barrier cited.

Discussion

The results of this baseline survey indicated that a broad range of age-, gender-, and risk-appropriate services for screening, immunizations, and counseling are available to most C/MHC clients. There were some variations in practice by location of the health center (rural or urban) and health care provider staffing patterns.

Rural centers were less likely to routinely perform screening for lead exposure and tuberculosis in children, sexual histories and sexually transmitted disease screening in teens, smoking and substance use history in teens and adults, and counseling on a variety of issues. Rural centers were more likely to report providing mammography for women under age 50. Respondents from rural health centers were also more likely to cite the perception that lack of patient interest in health promotion and disease prevention was a major barrier to service delivery.

The findings on breast cancer screening are of particular interest because these data compare favorably to the number of women in the general population who have received a mammogram. A number of respondents clarified a distinction between their intended practice and the eventual compliance rate for mammography.

Many centers do not have on-site mammography capability and must refer patients for the exam. Those patients who are referred often face prohibitive cost

barriers to routinely accessing mammogram. Thus, many C/MHC patients do not or cannot follow through with a recommended schedule for breast cancer screening by mammogram.

In some instances such as tuberculosis screening, the C/MHCs reported providing preventive services at a different, often higher, frequency than recommended by the U.S. Preventive Services Task Force. Given the socially and medically high risk population that uses C/MHCs, these variations from the recommendations are appropriate.

The respondents identified several structural, patient, provider, and financial barriers that hinder the provision of preventive health services in community and migrant health centers. Foremost among the barriers were a lack of ancillary health care staff, large patient loads and time demands of acute care needs.

There are some limitations of this study which make it difficult to make a definitive statement regarding the provision of preventive services in C/MHCs. A number of studies have demonstrated that physicians may tend to overestimate their actual performance of preventive services.[2] Despite the expressed intention of this study to solicit information on actual clinical practices, it is probable that the survey data are skewed by optimism toward an ideal perception of practice.

The data do not distinguish between attempted provider practices and the actual percentage of patients that receive appropriate and timely preventive services. Finally, information was collected only from medical directors to establish a baseline of service delivery practices for each center. Such a format did not allow for individual variations among physicians or among various other health care providers at the same site.

Despite the limitations, in the aggregate, the results of this baseline survey suggest that the practices of most C/MHCs on a core set of preventive services are congruent with many of the recommendations of the U.S. Preventive Services Task Force.

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Table 2 - Reported Barriers to Preventive Health Service Delivery

Reported Barrier	% of all centers (n = 321)
Lack of ancillary health care staff	27.7
Large patient loads/time demands of meeting acute care needs	27.1
Lack of patient interest/resistance to lifestyle change	25.5
Limited program finances/funding resources	24.9
Transportation barriers	17.1
Preventive services not reimbursable	14.0
Low patient compliance with appointments or preventive care protocols	12.1
Physician shortages/turnover/discontinuity	11.2
Limited patient financial resources/poverty	10.3
Lack of facility space	7.5
Language and literacy barriers	7.2
Customs/cultural barriers	5.6
Rural area/rural population	3.4
Provider disinterest	3.4
Lack of child care	1.9
Other	5.9

LIPID RESULTS FOR MONOLINGUAL FEMALE HISPANICS FROM A WORKSITE HEALTH SCREENING

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Worksite wellness programs have begun to demonstrate their efficacy in lowering risk for chronic disease (1,2). Most evaluative data on worksite programs, however, are gathered from predominantly white, non-Hispanic populations of workers. Since worksite wellness programs may provide local health departments with a vehicle for promoting health to hard-to-reach populations, more data are needed to assess the unique health risks of Hispanic workers.

A study was done by a local health department to compare the health screening results of two small groups of Hispanic and non-Hispanic white women.

Specifically, the lipids and body mass index (BMI) of a group of monolingual Hispanic women, employed by a local produce packing company were compared to a group of non-Hispanic white women who work for the County and had previously participated in a health screening. Dietary information related to fat consumption was also gathered from the Hispanic women in order to explore ethnic differences in obesity and lipids.

Description of Populations

Participation in the worksite health screening was voluntary. All of the monolingual Hispanic women who participated in the health screening at the packing company were included in this study and then matched by age with 51 non-Hispanic white County employees. Ages ranged from 20 to 62 years, with an average age of 35.8 years for both groups.

Most all of the non-Hispanic white women had sedentary jobs. Nearly half were clerical, one third professional and the remainder listed their occupation as paraprofessional, technician or failed to answer the questionnaire item.

In contrast most all of the Hispanic women had more active jobs. Some stood, trimming cauliflower or broccoli, and others had very physically active jobs moving boxes or sweeping.

Methods

A t-test for paired samples was used to compare the lipids and BMI's of the two groups of women. Correlation coefficients were calculated to determine whether an association existed between the Hispanic women's dietary practices and their lipids.

The source of some dietary questions was the American Cancer Society's Cancer Risk Factor Prevalence Study (3). Other items were taken from the Monterey County Hispanic Behavioral Risk Factor Survey (4). Body mass index was calculated by dividing weight (Kg) by height (m) squared. All data was analyzed on a personal computer, using a spreadsheet program.

Results

The BMI and lipid comparisons between the Hispanic and non-Hispanic white women are first described, as shown in Table 1.

Table 1. Average BMI and lipid comparisons for Hispanic and non-Hispanic white women

	Hispanic women	non-Hispanic white women
Body mass index (kg/m^2)	26.72	26.17
Total cholesterol (mg/dl)	188.61	196.41
LDL (mg/dl)	107.22	125.12*
HDL (mg/dl)	57.18	52.37*
Triglycerides (mg/dl)	120.98	94.67*

*$p<.05$

In terms of obesity, the Hispanic women were slightly heavier, but the difference was not significant. The mean BMI for both groups was close to 27, usually considered obese.

The mean total cholesterol of the non-Hispanic whites was about 8 mg/dl higher, although the difference was not significant. The mean for both groups was below the National Cholesterol Education Program's desirable level of 200 mg/dl (5).

A significant difference in LDL was observed. The Hispanic women had an average LDL of 107.2 mg/dl compared to 125.1 mg/dl for the non-Hispanic whites.

The Hispanic women also had a higher mean high density lipoprotein (HDL) of 57.2 mg/dl than their non-Hispanic white counterparts with a mean of 52.4 mg/dl.

Hispanic women had a significantly higher mean triglyceride level of 120.9 mg/dl, compared to the non-Hispanic white women at 94.7 mg/dl.

Next, prevalence data on fat consumption for Hispanic women are described. Comparable data for non-Hispanic whites from the American Cancer Society study is also listed, although no dietary information was taken from the non-Hispanic white participants.

In selecting a fat to cook with, most Hispanic women reported choosing vegetable oil (84%) over lard (6%) and meat fat (8%). The majority of women reported always trimming the fat from meats (90%) and always removing chicken skin (86%).

37% reported eating fried foods daily and 47% reported eating fried foods several times each week. The American Cancer Society's Cancer Risk Factor Prevalence Study found that Hispanics reported consuming more than twice as much fried foods as whites.

67% of the Hispanic women reported eating red meat several times each week and 18% ate red meat daily. 53% said they ate eggs several times each week and 6% ate eggs daily. Red meat and egg consumption was similar for both Hispanic and non-Hispanic whites.

About one third of the Hispanic women reported drinking whole milk, with almost 60% choosing lowfat milk. In contrast, the American Cancer Society study found that 65% of the Hispanics surveyed drank whole milk, compared to 30% of the whites.

The third step of the analysis, examined the association of the Hispanic women's dietary habits to their mean lipid levels (Table 2). The total fat score was a crude index, which simply added responses to diet questions: the higher the score, the lower the reported fat consumption.

Table 2. Correlation coefficients between dietary habits and lipids for Hispanic women

	LDL	Triglycerides
Fried foods	-.119	-.253
Red meat	.012	-.127
Chicken	.056	-.056
Type of milk	-.136	-.095
Eggs	-.160	.043
Total Fat score	-.040	-.060

No relationship was observed between LDL, triglycerides, BMI and selected dietary items. Many of the correlations were negative, including the total fat score. The correlation between the total fat score and BMI was insignificant at .009.

Finally, the relationship between the lipids and BMI was examined for both groups, since obesity has been linked to higher levels of LDL and triglycerides (6). As shown in Table 3, a much stronger relationship was found between the lipids and BMI for the non-Hispanic white women. Little or no relationship was observed between the lipids and BMI of the Hispanic women.

Table 3. Correlation coefficients between BMI and lipids for Hispanic and non-Hispanic white women

	Hispanic women	non-Hispanic white women
BMI and triglycerides	.039	.609
BMI and LDL	.075	.373

Conclusion

The Hispanic women had higher mean triglyceride and HDL levels and a lower mean LDL level than the non-Hispanic white women. Fat consumption reported by the Hispanic women did not correlate with their lipids nor with obesity as measured by B.M.I. Low fat cooking techniques and dietary habits were reported by the majority of the Hispanic women.

Discussion

Higher triglycerides among Hispanics and similar levels of total cholesterol have been previously reported. However the observed lower LDL, higher HDL and comparable BMI are inconsistent with the literature reviewed. Some possible explanations for these seeming inconsistencies are next explored.

Self-selection may have effected these results since participation in the health screening was voluntary. For example, unhealthy or obese women may not have participated. This bias has not been previously observed among County workers, but cannot be discounted with the Hispanic participants.

Another factor that may have influenced the results is that the participants were working women and perhaps different from other Hispanic women previously studied. The "healthy worker" effect suggests that healthier women are able to work while women in poor health are more likely to stay home (7). However, Hazuda, Haffner and Stern in the San Antonio Heart Study compared working non-Hispanic white and Hispanic women, and refuted this effect in a similar study (8).

Further study is required to see if alcohol or foods high in sugar, effected the Hispanic women's triglyceride levels. For example, Hazuda et al found that working Hispanic women tended to

drink two to three times as much alcohol as the full-time Hispanic homemakers that they studied (7,8).

As previously mentioned, the Hispanic women had a significantly lower LDL than their non-Hispanic white counterparts in this study. Several possible explanations for this difference are offered. First, higher fiber consumption, especially from dried beans which are common in the Hispanic diet, may contribute to lower LDL (9).

Second the prevalence of low fat eating and cooking techniques was also consistent with the Hispanic women's lower mean LDL, although not borne out in the correlational analysis. The San Antonio Heart Study also noted that working Hispanic women ate less atherogenic diets (8).

In general the lack of relationship between the dietary items and the lipids may also be a fault of the questions themselves or the use of a single instrument to gather dietary data.

The higher HDL observed among the Hispanic women may be related to their more active jobs. Few of the studies reviewed seemed to measure work related activity and tended to focus on minutes of aerobic exercise, outside of work.

Hazuda et al found that working Hispanic women had higher HDL than Hispanic homemakers, although the difference was not significant for blue collar workers (7,8).

Finally, the lack of relationship between BMI and lipids for Hispanic women, seemed unusual. Investigators of the San Antonio Heart study found that controlling for BMI reduced ethnic differences between non-Hispanic whites and Hispanics for triglycerides, however the difference between the two groups remained significant suggesting that genetic factors may account for the ethnic differences (10).

In summary, this study attempted to learn more about a population of Hispanic female workers in order to better adapt our worksite health promotion program. By offering programs like this to agribusiness, local health departments can more easily promote health to this sometimes hard-to-reach population. These data, suggesting some unique characteristics of working Hispanic women, may help accomplish this objective more effectively.

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EVALUATING THE UTILIZATION OF INDIAN HEALTH SERVICE FOR ALCOHOLISM AND ALCOHOL ABUSE HOSPITALIZATIONS

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INTRODUCTION

Our objective has been to evaluate the impact of alcoholism/alcohol abuse on IHS inpatient resources through an investigation of utilization rates and discharge rates for alcohol attributable diagnoses, (ARD). Alcohol abuse/alcoholism among American Indians and Alaska Natives,(AI/AN), is considered one of the most significant health problems facing this minority population. Considerable effort has gone into attempts to measure the impact of chronic and acute medical conditions associated with alcohol abuse/alcoholism. Specifically, previous work can be broadly categorized as either descriptions of alcohol consumption patterns and behaviors of specific AI/AN tribes(1,2), or mortality studies focusing on deaths due to alcoholism, alcohol abuse, chronic liver disease or cirrhosis(3,4). A different perspective can be obtained by considering the burden this problem has imposed upon the health care delivery system used by AI/AN, the Indian Health Service,(IHS).

METHODS

The taxonomy of ICD-9 codes that was used, (see Table 1), has been used extensively by the National Institute of Alcohol Abuse and Alcoholism. This choice of taxonomy was made so that comparisons could be made with published data for the U.S. general population(5). Furthermore, modifications of this taxonomy have been used in previous studies addressing the economic costs associated with ARD(6,7).

TABLE 1
Chronic Alcohol-Related Diagnoses
ICD-9-CM Diagnostic Categories and Codes for Chronic Conditions Often Associated With Alcohol Abuse

Title	ICD-9 Code
Alcoholic Psychoses	291.0 - 291.9
Alcohol Dependence Syndrome	303.0 - 303.9
Alcohol Abuse	305.0
Alcohol Polyneuropathy	357.5
Alcohol Cardiomyopathy	425.5
Alcohol Gastritis	535.3
Alcohol Fatty Liver	571.0
Acute Alcoholic Hepatitis	571.1
Alcoholic Cirrhosis of Liver	571.2
Alcoholic Liver Damage, Unspec.	571.3
Chronic Hepatitis	571.4
Cirrhosis of Liver w/o Mention of Alcohol	571.5
Biliary Cirrhosis	571.6
Other Chronic Non-alcoholic Liver Disease	571.8
Unspec. Chronic Liver Disease w/o Mention of Alcohol	571.9
Portal Hypertension	572.3
Hepatorenal Syndrome	572.4
Other Disorders of Liver	573.0 - 573.9
Chronic Pancreatitis	577.1
Cyst and Pseudocyst of Pancreas	577.2
Gastrointestinal Hemorrhage	578.0 - 578.9

The source of data for this study was the IHS inpatient database for direct and contract admissions. Our case definition was: (1) any direct inpatient admission, (2) for an individual 14 years or older, and (3) with any mention of an ARD condition during the time period January 1, 1980 through December 31, 1988. Direct care is care provided in an IHS facility; this is in contrast to contract care, which is provided in non-government operated facilities and paid for by the IHS. The following definitions were established for use in this study:

(a) IHS Hospital: An IHS inpatient facility that was operated by the government during the entire study period. Facilities that closed or whose management was assumed by tribal entities during the period were excluded.

(b) Adult Patient Days: Total patient days minus the sum of newborn patient days, obstetrical patient days and pediatric patient days.

(c) Utilization Rate: The ratio of the number of adult patient days for a specific condition to the total number of adult patient days within a given time period.

(d) Discharge Rate: The ratio of the number of discharges for a specific condition, relative to the estimated population for a specific age-sex group, converted to a rate per 10,000.

FINDINGS

Elimination of hospitals that were not continuously managed by the IHS during the study period resulted in a set of 43 hospitals. Capacity data on these hospitals were extracted; Table 2 summarizes these findings relative to facility size, in terms of average number of beds available annually. Overall, during nine years of the study, these 43 hospitals provided approximately 1.4 million adult patient days in an average of 1908 beds available per year. With the exception of the three major referral centers (100 or more beds), approximately 75% of the IHS facilities have 50 beds or less and these facilities accounted for slightly over half of the adult patient days over the nine year period.

TABLE 2
Number of Hospitals, Yearly Available Beds and Adult Patient Days Used For IHS Hospitals

Bed Size	Hospitals #	Hospitals % Total	Average Annual # Beds Available #	Average Annual # Beds Available % Total	Adult Patient Days Used, 1980-88 #	Adult Patient Days Used, 1980-88 % Total
All	43	100	1908	100	1394228	100
<25	11	26	200	11	139937	10
25 - 49	22	51	826	43	535973	38
50 - 99	7	16	429	22	240233	17
100 - 199	3	7	453	24	478085	35

During the period examined, a steady decline in adult patient days each year was observed. However, a similar trend in ARD adult patient days did not occur. Rather, the number of ARD adult patient days behaved in a cyclical fashion.

Table 3 displays the observed yearly utilization rates for the IHS hospitals investigated. Overall, there was a 13.7% ARD utilization rate, with the male ARD utilization rate of 18.6%, exceeding the observed female rate by a factor of two. In addition, the reported rates in Table 3 clearly demonstrate the previously mentioned cyclical nature of ARD patient days. This pattern is observed consistently both in total ARD utilization rates and sex specific ARD utilization rates.

TABLE 3
Inpatient ARD Utilization Rates, 1980-1988
For 43 IHS Hospitals

Year	Total ARD Utilization	ARD Male Utilization	ARD Female Utilization
Overall	13.73	18.64	9.02
1980	14.40	19.03	9.69
1981	3.39	17.94	8.79
1982	12.67	16.46	9.06
1983	15.98	21.52	10.50
1984	12.92	17.67	8.31
1985	12.83	18.09	7.75
1986	13.00	17.94	8.47
1987	13.31	18.55	8.52
1988	15.19	20.80	10.17

Note: ARD Utilization Rate -- refers to the Alcohol Related Discharge (ARD) Utilization Rate for adults, age >= 14, and represents the proportion of adult ARD beddays relative to the number of total adult beddays used.

Recalling that slightly over 75% of the IHS facilities had 50 beds or less, ARD utilization rates by hospital size were calculated. Table 4 presents these results, together with sex and age specific rates by hospital size. The findings for the nine year period under investigation demonstrate that the two groups of smaller hospitals have an ARD utilization rate of approximately 25%. Alcohol-related utilization varies inversely with hospital size in IHS facilities. Irrespective of hospital size there is a two to one difference between the male ARD utilization rate and that for females. For the total population, the 25-44 year old age group generally contributes about one half the overall ARD utilization.

TABLE 4
Utilization Rates For Alcohol-Related Conditions Total and Sex-Age Specific By IHS Hospital Size, 1980-1988

	≤ 24 Beds	25-49 Beds	50-99 Beds	100-199 Beds
Total	25.4	25.5	17.3	12.9
Males	17.2	17.1	11.8	7.5
14-24 yrs.	1.0	1.6	0.8	0.5
25-44 yrs.	8.0	8.3	6.0	3.9
45-64 yrs.	6.6	5.8	3.8	2.5
65 + yrs.	1.5	1.5	1.2	0.6
Females	8.2	8.3	5.5	4.6
14-24 yrs.	0.8	0.9	0.5	0.3
25-44 yrs.	4.5	4.3	2.4	2.4
45-64 yrs.	2.3	2.5	1.9	1.6
65 + yrs.	0.6	0.7	0.6	0.3

Note: Utilization rates represent the adult beddays used by category, relative to the total number of adult beddays used.

Considering utilization in terms of discharges or disease episodes, the same cyclical pattern noted earlier for total ARD patient days was observed, see Table 5. However within these cycles, consistency with respect to the distribution of discharges by age was demonstrated. That is, each year at least 50% of the ARD discharges were attributable to persons between the ages of 25 and 44 and overall about 80% of all ARD discharges were attributable to persons between 25 and 64 years of age.

TABLE 5
Percent Distribution of Alcohol-Related Discharges by Age Group Over Time

	#ARD	Age Group 14-24	25-44	45-64	65+
1980	5701	12	54	29	5
1981	5536	11	54	29	5
1982	4756	13	53	28	6
1983	6165	11	53	30	6
1984	5217	11	51	31	6
1985	5033	13	52	28	7
1986	5552	15	52	26	7
1987	5527	13	50	30	7
1988	5516	13	51	29	7

Population-based discharge rates per 10,000 population were calculated at three year intervals for comparison with published results for the U.S. In Table 6, one can observe that the discharge rate for males is generally twice that of females, but that for both sexes, there may be a declining ARD discharge rate. When ARD discharge rates are examined by age group, a declining trend in the two middle age groups, 25-44 years and 45-64 years can be observed, but there is an increasing trend in the youngest and eldest groups.

TABLE 6
Alcohol-Related Discharges (per 10,000) By Age Group and Sex for IHS Direct Care Facilities

Age Group	1980	1983	1986
14-24	59.1	54.4	60.2
25-44	256.5	252.4	211.7
45-64	278.3	290.0	224.8
65+	113.0	128.2	134.2
Males	252.3	256.8	211.6
Females	167.9	100.7	95.6

When ARD discharge rates for the IHS are compared with those reported for the U.S., at each time point and for all age categories, the IHS rate exceeded the all-U.S. rate by a factor of two to three. These findings are presented in Table 7. Further, the observed ARD discharge rates of the IHS males and females also exceeded their respective all-U.S. rates by a factor of two to three. In fact, the ARD discharge rate for females hospitalized in IHS facilities exceeded the ARD discharge rate for all-U.S. males. However, Table 8 demonstrates that when overall discharge rates are compared, the rate for the IHS population is very close to that of the all-U.S. rate. For both populations, the discharge rate is declining. A real difference exists between the IHS population and the all-U.S. population with respect to ARD. While the trend in ARD discharges in IHS appears to be declining, there is still an excess of IHS discharges for ARD conditions by a

factor slightly greater than two for each of the years considered.

TABLE 7
A Comparison of Alcohol-Related Discharge Rates at IHS Facilities with All-U.S. Rates by Age and Sex

	1980		1983		1986	
Age Group	IHS	All-U.S.	IHS	All-U.S.	IHS	All-U.S.
14-24	59.1	16.7	54.4	18.7	60.2	23.5
25-44	256.5	62.9	252.4	58.3	211.7	65.5
45-54	278.3	102.0	290.9	88.5	224.8	90.2
65+	113.0	66.5	128.2	57.2	134.2	68.2
Male	252.3	91.2	256.8	83.3	211.6	91.7
Female	103.9	33.6	100.7	33.1	95.6	35.4

TABLE 8
Alcohol-Related Discharges and All Discharges Based on Population - A Comparison of IHS and All-U.S. Rates

	1980		1983		1986	
	Dischg/ 10,000	ARD/ 10,000	Dischg/ 10,000	ARD/ 10,000	Dischg/ 10,000	ARD/ 10,000
IHS Hospitals	1498	176.0	1404	176.2	1395	152.2
All-U.S. Hospitals	1691	61.2	1670	57.2	1431	62.4
Ratio IHS/ All-U.S.	.93	2.9	.84	3.1	.97	2.4

CONCLUSIONS

The use of hospital discharges alone has limitations from an epidemiologic standpoint, in that large portions of morbidity data for a given disease or condition are not considered. This same limitation applies should the total economic costs of diseases or conditions be under examination. However, hospital discharge data has two advantages. First, hospital costs are the major component of health care costs; and second, hospital discharge data are more reliable than that based on ambulatory records. Using hospital discharge data over a period of nine years, we have demonstrated that the IHS is providing more hospital care for alcohol-related conditions than is provided in all-U.S. hospitals. This care is provided in small facilities (less than fifty beds), to a young to middle-aged group of individuals, relatively more male than female. These facts should raise several questions regarding the future of these facilities. The first question might be, "How can preventive techniques be applied so as to reduce the number of discharges for these conditions?" A second question might be the advisability of continuing to operate certain facilities as all-purpose hospitals. Perhaps these might better be converted to inpatient alcohol treatment centers. Third, if utilization for ARD should decline due to efforts to prevent the disease, closure of some small facilities should be planned together with the means for providing inpatient care for these people at other locations.

In summary, this study had two basic objectives; (1) identify resource usage at IHS facilities through adult patient day utilization for ARD and (2) examine ARD utilization patterns in IHS, by age and sex, as compared to the U.S. general population. The findings presented have lead us to conclude that while the overall actual adult patient days for the IHS has been declining, no similar pattern was observed for ARD adult patient days in IHS facilities. Rather we observed a cyclical pattern in ARD utilization numbers. In addition, while the overall structure of the IHS system is small by accepted standards, those hospitals with 50 beds or less are clearly expending considerable resources in providing care for ARD admissions for a population group that is generally not a high user of inpatient services.

Finally, while overall hospital discharge rates per 10,000 population for the IHS facilities are comparable to those in the U.S. population, the ARD population-based discharge rates for IHS hospitals are over twice that for the U.S. population. While ARD discharge rates over time appear to be declining, both age and sex specific rates are still two to three times that of the all U.S. population.

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* The opinions expressed in this study are those of the authors and in no way reflect those of the Indian Health Service or the U.S. Dept. of Health and Human Services. In addition, we would like to thank Lisa Preston,(IHS, OHPRD) for her suggestions, recommendations and efforts in the preparation of the text for publication.

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A REGISTER OF CHRONIC DISEASE INTERVENTIONS FOR HISPANICS: METHODS AND PRODUCT

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Background

The availability of complete national morbidity and mortality data on Hispanic populations in the United States is limited. But, there are clear indications of unmet needs in health education and health promotion interventions aimed toward Hispanics. Earlier this year, some of these unmet needs were described in the American Journal of Public Health and in the Journal of the American Medical Association. Articles in both journals used HHANES data collected from 1982-84 to make their points: Hispanics are dying from the nation's leading causes of death - heart disease, cancer, and stroke (Haynes et al., 1990; Marks et al., 1990); they suffer disproportionately from diabetes, kidney disease, and certain cancers (Fanelli-Kuczmarski, and Wotecki, 1990); and they are more likely not to have health insurance so are less likely to be exposed to health education messages or to seek medical care in the early stages of disease (Solis et al., 1990; Trevino et al., 1991). This lack of access to medical care underscores the need for effective community-based health promotion and education interventions for Hispanics. For the practitioner, locating health education and health promotion programs offered to Hispanics is not easy, and according to the literature, finding chronic disease programs developed specifically for Hispanics is even harder (Morris, 1989). This cooperative endeavor between COSSMHO and the Centers for Disease Control proposes to take a first step to making it easier to reach Hispanic populations with a culturally sensitive health education/health promotion message.

Purpose

There are three purposes of this project:

- To document gaps in Hispanic health status data
- To document effectiveness of existing chronic disease prevention and control programs for Hispanics
- To produce and disseminate a document that synthesizes the key elements of successful and replicable strategies and activities for Hispanics

The first purpose will be fulfilled by summarizing and referencing the existing documentation of health status gaps mentioned earlier in the project's final document.

However, the second and third purposes lend themselves to a descriptive study to gather information that does not now exist in one place. That is, to produce a document that provides some rating of effectiveness of existing chronic disease prevention and control programs for Hispanics; and that synthesizes key elements of successful and replicable strategies and activities for Hispanics.

This presentation will outline the methodology of and give preliminary results from year one of this two year project.

Methodology

To help guide us, an advisory task force was carefully selected. The task force represents four Hispanic subpopulations, Cuban, Mexican-American, South and Central American, and Puerto Rican. Members have wide geographic representation; they're from public and private sectors, have state and local perspectives, and access key dissemination channels.

Generally, the procedure was to (1) develop a list of national, state and local organizations and agencies with potential for chronic disease programs or initiatives for Hispanics, (2) send them a questionnaire to identify these programs, and to
(3) follow up - if permitted by respondent - with an in-depth program survey.

It was decided to use a convenience sample with high yield for program identification because of time and financial limitations. The nine states with the largest Hispanic population based on 1988 Census Data and Puerto Rico were chosen to be surveyed.

The nine states are listed with their corresponding percent of the United States Hispanic Population in Table 1.

Table 1
States with largest percentage of the U.S. Hispanic Population

California	33.7	Arizona	3.6
Texas	21.5	New Jersey	3.2
New York	9.9	New Mexico	2.7
Florida	7.9	Colorado	2.1
Illinois	4.3		

Though Puerto Rico is 100% Hispanic, the task force felt it important to document the programs conducted there as potential models for replication in the states or as sources for culturally appropriate materials. Puerto Rican responses will be kept separate throughout the study so as not to misrepresent states' activity.

Originally, we defined "a program for Hispanics" as a health education or health promotion program that has greater than or equal to 50% Hispanics in the audience. Later the task force decided to broaden the

definition to collect programs that had any percent Hispanic participants. The rationale was that programs designed specifically for and offered exclusively to Hispanics would be readily identified. However, those designed for many groups that just happen to have Hispanics in the audience may not be so easily identified especially if the percent of the community's population that is Hispanic is low. The task force felt it would benefit this study to be more inclusive than exclusive.

Our definition for chronic disease is limited to primary and secondary prevention efforts in cancer, cardiovascular disease including stroke, and diabetes.

Federal or national agencies, state, and voluntary agencies were surveyed at three levels to represent policy, administration and practice. The agencies surveyed are listed in Table 2.

Most of the federal and national, and voluntary agencies chosen have purposes or activities that closely match this project, and this is evident in their agency name. There is one exception: The Foundation Center. This organization was surveyed to identify programs for Hispanics funded by private foundations.

Table 2

Federal and National Agencies Surveyed
National Cancer Institute
National Heart, Lung, & Blood Institute
National Institute on Diabetes, Digestive, & Kidney Diseases
Office on Minority Health
National Institute on Aging
Office on Substance Abuse Prevention
Foundation Center

National Voluntaries Surveyed
American Cancer Society
American Heart Association
American Lung Association
American Diabetes Association

State Community-based Organizations Surveyed Through
ASTDPHE & ASTCDPD membership
COSSMHO network
National Community Health Centers
Migrant Health Centers
Research in Progress Database
National Technical Information Database

State and local health departments were surveyed through members of the Association of State and Territorial Directors of Public Health Education and the Association of State and Territorial Chronic Disease Program Directors. To identify programs unique to the community and not related to previously mentioned agencies, survey forms were sent to members of the COSSMHO network, National Community Health Centers and Migrant Health Centers. To access programs conducted through universities, staff of the Research in Progress Database and the National Technical Information Database were also contacted.

Results

An initial mailing to states and voluntaries of 452 program identification forms yielded a return of 225 or 49.8%. Of the 225 returned forms, 141 (31%) were from the nine states. The response rate for those with chronic disease programs for Hispanics from the initial 452 surveys sent was 15.9% (72).

It was interesting to note that while all nine states responded, several of the states with larger percentage of US Hispanics had lower return rates. Task force members have agreed to follow-up with phone calls or personal visits to those receiving program identification forms and encourage them to complete and submit the forms. Additionally, since the definition of "programs serving Hispanics" has changed, those respondents that answered "no" will be resurveyed.

Many of the organizations distributed the identification forms broadly, thus, programs outside the ten areas were identified. This incidental information will be entered into a database along with the other information, but will not be pursued in depth for this project.

Table 3: Chronic Disease (CD) Health Promotion or Health Education Programs for Hispanics

	In States	In PR
< 50% Participants Hispanic	52 (36.9%)	0
≥ 50% Participants Hispanic	89 (63.1%)	2 (100%)
CD related	72 (80.9%)	2 (100%)
Not CD related	17 (19.1%)	0
Total CD programs	89 (100%)	2 (100%)
Total programs	141 (100%)	2 (100%)

Somewhat surprising is that respondents listed most programming done for Hispanics as chronic diseases related. It will be interesting to see if this continues to be the trend in the final report. Perhaps the respondents who have chronic disease related programs were more likely to complete and mail the form, while those without chronic disease programs had no impetus to do so.

Nine choices of topics for chronic disease programs were given in a checklist. This was to make answering easier and to provide examples of what was meant by chronic disease. Respondents were asked to check all that apply. The "other" category included written in responses of AIDS/HIV (most frequent), asthma, arthritis, mental hygiene, epilepsy, tuberculosis, and parasites.

Table 4
Topics of Chronic Disease Programs Offered

	Offered in states		Offered in PR	
Smoking Cessation	44	(49.4%)	2	(100%)
Heart Disease	28	(31.4%)	1	(50%)
Diabetes	25	(28.1%)	1	(50%)
Breast/Cervical Cancer	24	(26.9%)	1	(50%)
Lung Cancer	22	(24.7%)	1	(50%)
Cholesterol Screening	19	(21.3%)	0	
Physical Activity	18	(20.2)	1	(50%)
Stroke	12	(13.4%)	0	
Nutrition	9	(10.1%)	1	(50%)
Other	34	(38.2%)	1	(50%)

Another question asked if the respondent would complete an in-depth survey of the program he or she identified. Majority of respondents (83.1%) said yes (Table 5). The 11 that had no answer will be recontacted.

Table 5
Complete in-depth program survey

	In State	In PR
Yes	74 (83.1%)	1 (50%)
No	4 (4.5%)	1 (50%)
No answer	11 (12.1%)	0
TOTAL	89 (100%)	2 (100%)

The last question asked respondent if he or she knew of other agencies offering programs for Hispanics and then requested a list of them. Seventy-nine of the 141 respondents returned lists which added 250 programs to be surveyed.

Next Step

The next step is sending the detailed program survey to all who agreed to complete it. One program survey is to be completed for each program.

Questions in the detailed survey were developed with the practitioner in mind. The task force wants to gather enough detail about a program to allow users of the product to be able to pinpoint existing programs most like what they need and to know how to contact the appropriate person. The task force also wants to gather enough information to develop guidelines for conducting programs for Hispanics with regard to setting, delivery, and participation.

The in-depth program survey has five sections in the survey: responder identifying information, program identification information, Hispanic program setting information, Hispanic program description, and strategies for targeting Hispanics.

Conclusion

Second year activities will include ongoing collection of program identification and program survey information, data entry, and data analysis. From these data a final document will be produced. This document will summarize the existing health status data gaps, catalogue the chronic disease programs serving Hispanics; and identify their contacts. It will display the elements of these programs in a format that allows comparison between and among programs, and synthesize individual responses to suggest guidelines for chronic disease programming for Hispanics with regard to setting, delivery methods, and participation. Lastly, it will recommend uses for this information in future research and program development toward reaching the health objectives for the nation and for Hispanic in the Year 2000.

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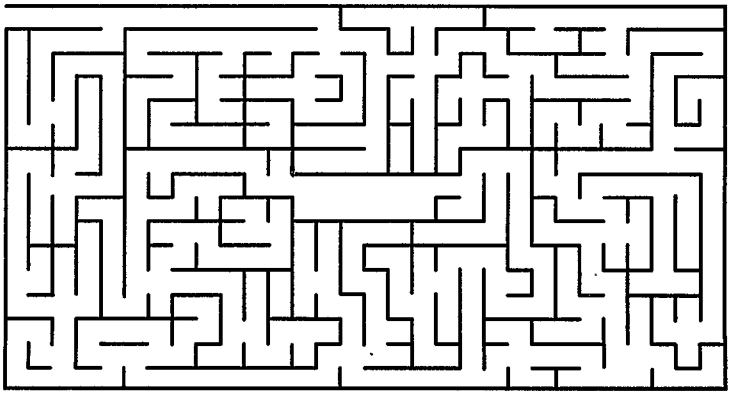
Session T

Family Health



HEALTHY FAMILIES 2000
THE ROLE OF THE FAMILY IN MEETING THE NATION'S HEALTH OBJECTIVES

Thomas L. Campbell, University of Rochester School of Medicine

It is time to stop thinking of health from only an individual or a public health perspective, but to consider health and illness, and therefore health statistics, within the context of the family. To use the words of the report of the health objectives for the year 2000[1], we should be thinking not just about Healthy People, but about Healthy Families, and examine the role of the family in meeting the Nation's health objectives.

We are social beings and our health is strongly influenced by our social context, especially our social relationships. The family is our most intimate current and past social environment. The family has a powerful influence on our health beliefs and behaviors, as well as our overall mental and physical health[2]. In turn, illness in the family impacts on family relationships and the health of other family members.

This paper will briefly review some of the research that demonstrates linkages between healthy family relationships (that is family health) and individual mental health, physical health and health related behaviors. This paper will serve as an introduction to the other papers on Family Health.

Social Relationships and Health

The most powerful evidence that families influence health comes from the social support literature. This research has shown a strong and consistant relationship between social relationship, especially the perception of social support, and overall morbidity and mortality[3].

In a recent article in the journal Science, sociologist James House reviews this research, including six large prospective studies of social support and health and makes the following statement.

> The evidence regarding social relationships and health increasingly approximates the evidence in the 1964 Surgeon General's report that established cigarette smoking as a cause or risk factor for mortality and morbidity from a range of diseases. The age-adjusted relative risk ratios are stronger than the relative risks for all cause mortality reported for cigarette smoking.[4]

Thus, social relationships deserve some of the same attention and study by public health specialists and policy makers as smoking now has.

Family members, particularly the spouse, appear to be the most important source of social support and account for most of the association between social support and health. There is evidence that support from sources outside the family cannot compensate for what is missing from within the family[5]. The crucial role of the family is exemplified by the dominant place given to family related items in most instruments measuring social supports and networks.

In addition, the family is the major and most influential source of stress for most individuals. Ten of the top fifteen life events on the Holmes and Rahe Social Readjustment Scale occur within the family[6]. A large body of research has demonstrated the adverse effects of the death of a spouse and divorce, the top two stressful life events, on overall mortality and immune functioning[7,8].

Mechanisms: How Families Influence Health

These examples illustrate the two major mechanisms or pathways by which the family or family relationships can influence health, a psychophysiologic and behavioral pathway. In the psychophysiologic pathway, family factors such as stress or life events affect the emotional state of an individual family member resulting in direct physiologic changes that predispose the individual to becoming ill. There is growing research in this area, particularly in the field of psychoimmunology. Studies in animals and humans reveal that stress can lead to immunosuppression and an increase in illness[9]. Several well controlled studies demonstrated a decrease in cellular immunity during bereavement[10]. Divorced or separated individuals have significantly poorer immune function than matched married controls, and among married individuals, poor marital quality correlates with both depression and decreased immunity[11,12]. Immune function is also impaired in major depression, and researchers have suggested that changes occurring in the central nervous system during depression may be final common pathway between distressed or dysfuntional social relationships and decreased immunity leading to poor health[10].

There has been some recent interest in the physiology of family relationships. This interest began with the work of Salvador Minuchin and his colleagues at the Philadelphia Child Guidance Center, who studied a group of families who had children with poorly controlled or brittle diabetes[13,14]. They found that when the diabetic child became involved in family conflict, there was a rise in the child's free fatty acids, leading to diabetic ketoacidosis. More recently, Gottman and Levenson have been able to demonstrate how marital conflict and dissatisfaction leads to increased autonomic arousal and poorer self reported health[15,16].

Family relationships have been shown to have a significant influence on overall mental health, as well as the development of specific mental disorders, including schizophrenia, depression and substance abuse[2]. Mental health is highly correlated with physical health, and many studies have shown the influence of depression and other psychiatric disorders on physiologic processes, including immune functioning[10].

With the behavioral pathway, the family influences the individual's health behaviors, such as diet, exercise, smoking, compliance with medical treatment or visits to the physician, and these health behaviors affect the individual's health. It is in this area that health promotion and disease prevention takes place, as reflected in the priorities areas for Healthy People 2000 (See Table 1).

Health Promotion, Disease Prevention and the Family

The family is the primary social context in which health promotion and disease prevention takes place. WHO characterizes the family as the "primary social agent in the promotion of health and well being"[17]. Research on families and health demonstrates that the family strongly influences most of the priority areas for Healthy People 2000 and that a family-oriented

approach is the most effective and efficient way to meet the health objectives for the year 2000[18].

A healthy lifestyle is usually developed, maintained or changed within the family setting. Behavioral health risk factors tend to cluster within families, as family members tend to share the similar diets, physical activities, and tobacco and alcohol use[19]. Parents' health related behaviors strongly influence whether a child or adolescent will adopt a healthy behavior, and family support is an important determinant of an individual's ability to change an unhealthy lifestyle. In a 1985 Gallup survey of health related behaviors, over one thousand adults reported that the spouse or significant other was more likely to influence a person's health habits than anyone else, including the family doctor[20].

TABLE 1: HEALTHY PEOPLE 2000: PRIORITY AREAS

Health Promotion
1. Physical Activity and Fitness
2. Nutrition
3. Tobacco
4. Alcohol and Other Drugs
5. Family Planning
6. Mental Health and Mental Disorders
7. Violent and Abusive Behavior
8. Educational and Community-Based Programs

Health Protection
9. Unintentional Injuries
10. Occupational Safety and Health
11. Environmental Health
12. Food and Drug Safety
13. Oral Health

Preventive Services
14. Maternal and Infant Health
15. Heart Disease and Stroke
16. Cancer
17. Diabetes and Chronic Disabling Conditions
18. HIV Infection
19. Sexually Transmitted Diseases
20. Immunization and Infectious Diseases
21. Clinical Preventive Services

Almost every priority area from Healthy People 2000 is a family activity or is strongly influenced by the family. A few of these priorities deserve special attention. An emphasis on physical activity and fitness is usually a shared family value. Parent's exercise habits and attitudes have a strong influence on their children's level of physical activity[21]. Men at high risk for cardiac disease are more likely to participate in an exercise program if their spouses are supportive[22].

Nutrition is an obvious family activity. Despite changes in traditional family roles, women still do most of the meal planning and preparation for the entire family. To counsel men with elevated cholesterol about nutrition without involving their wives is unlikely to be successful. It is well documented that family members have similar diets and ingest similar amounts of salt, calories, cholesterol and saturated fats[23]. Studies have shown how eating behaviors and obesity can play important homeostatic functions within families[24]. 25% of mothers report that they use food as a reward for their children, and 10% use it as punishment[25]. Parents' encouragement of children to eat has been shown to correlate with childhood obesity[26]. It is no surprise that the family plays an important role in the development and treatment of the major eating disorders, anorexia nervosa and bulimia. In terms of the treatment of obesity, several randomized controlled trials have shown how the involvement of the spouse in weight reduction programs significantly improves long term results[24].

The important role of the family in alcoholism and substance abuse is well recognized, and there are few treatment programs that do not involve the family. Contraception and family planning should be a family, or at least couple, decision. There is enormous research on the family and mental disorders, particularly depression and schizophrenia[27]. Most violent or abusive behavior takes place within the home and between family members, and there is an increasing research on the violent family.

With regard to chronic disease, especially heart disease, cancer and diabetes, the family is an important source of support for complying with medical regimens. Based upon research on the influence of social and family support on compliance, the National Heart, Lung, and Blood Institute has recommended that all physicians use the following as one of three basic strategies for increasing compliance with antihypertensive regimens:

> Enhance support from family members-identifying and involving one influential person, preferably someone living with the patients, who can provide encouragement, help support the behavior change and, if necessary, remind the patient about the specifics of the regimen[28].

Family members are the primary caregivers for people with chronic disabling health problems[29]. Most elderly people with Alzheimer's Disease or other incapacitating illnesses are cared for at home by adult children and are never institutionalized. However, the physical and emotional burden of this caregiving is enormous and can have serious adverse effects on the physical and mental health of the caregiver. Institutionalization of the elderly and chronically ill results more from caregiver "burnout" and poor health, than from deterioration of the patient's condition. How well the family copes with the illness and supports the primary caregiver affects both the caregiver's and patient's well being.

Influence of the Family on Smoking

Because of its importance, it is worth focusing on the role of the family in tobacco use. Smoking is the number one health problem in the US today. 350,000 deaths per year are directly attributed to smoking, and it contributes to just about every serious chronic illness or cancer. It has been estimated that approximately 5 minutes of life is lost for every cigarette smoked - about half the time is takes to smoke one[30].

Like other health behaviors, the initiation, maintainance and cessation of smoking is strongly influenced by the family. Adolescents are much more likely to smoke if either parent or a sibling smokes. A teenage who has a parent and older sibling who smokes is five times more likely to smoke than a teenage from a nonsmoking family[31].

There is a very high concordance in smoking behavior within married smokers. Smokers are much more likely to marry other smokers, to smoke the same number of cigarettes as their spouse and to quit at the same time[32]. While some of this is explained by assortative mating (smokers marry smokers), studies also show smoking behaviors of spouses become more similar with longer marriages suggesting that spouses have a strong influence on each other's smoking behavior.

The spouse also plays an important role in smoking cessation. Smokers who are married to non-smokers or ex-smokers are more likely to quit and to remain abstinant, than smokers who are married to smokers[33,34]. Support from the spouse is associated with successful smoking cessation. In particular, supportive behaviors involving cooperative participation, such as talking the smoker out of smoking a cigarette, and reinforcement, such as expressing pleasure at the smoker's efforts to quit, predict successful quitting. Negative behaviors, such as nagging the smoker and complaining about the smoking, predict relapse[35,36].

Conclusion

The evidence that families have an impact on health is powerful and consistent[2,19]. This research demonstrates that families influence healthy behaviors including smoking, the number one health problem in the US, and that quality and quantity of social relationships, particularly within the family has as strong an influence on health as smoking. Based upon this research, it is time to stop thinking only about Healthy People for the year 2000, but starting thinking and gathering data about Healthy Families.

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FAMILY HEALTH: FAMILY HEALTH STATISTICS FOR TRACKING PROGRESS TOWARD THE YEAR 2000 OBJECTIVES

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Purpose and focus of this speech

This speech on family health statistics for tracking progress of the Healthy People 2000 national health objectives is less a presentation about what we know, and more a clarification about the existing data gaps and issues that must be addressed if we are to effectively monitor the health of families. I am a program planner from a medium size county in California facing the challenge of achieving the Year 2000 National Health Objectives for the Nation, through a family centered, community based approach. In this county, the public sector has begun the paradigm shift from an "individual oriented and categorical/problem specific delivery system" to a "family centered, community based perspective". It is a challenge for which we are not prepared.

Local governments do not have the data and information they need to serve families efficiently and effectively. Communities need the assistance of the National Center for Health Statistics and State and National experts to help redesign the nation's information gathering system from a national level, individual oriented data system to a family and community level information system. We need a more coherent system of data that can both satisfy the needs of national policy makers and also provide the information needed by local government to be more effective in serving "their" families in "their" communities.

"Families are the bedrock of our society"

There are many significant reasons for shifting our paradigm to a family centered approach. The family's influence on health is considerable. Experts suggest as much as one third of our risk for chronic disease is due to genetic predisposition. Another significant percentage of our health risk--30 to 40%--may be due to our behavior. Many of our unhealthy habits are learned from our families--tobacco use, alcohol abuse, family violence, diet, low self esteem, and lack of exercise are among the most obvious. In our society, parents provide their children key health information and make decisions regarding when and from whom medical care is consumed.

The family is the primary social unit in our society. It is through families that children develop, values are taught, acceptable behavior learned, and the foundation for a democratic society established. Society expects the family to be responsible for its members.

While our society has depended upon the family and given families great latitude and jurisdiction over the content and quality of family life, it has very little information about the family and how well it performs this assignment. The Federal government has been less willing to promote social policy that supports the family unit's ability to serve its members. Any deviation from this norm has met with strong opposition. Witness the debates and battles in communities across the nation about how to educate our youth about AIDS, sex, and family life.

What families receive from society is solely depended upon the community in which they reside, their friends, the neighborhood in which they live, the school in which their children are enrolled, and the church in which they worship.

Far too many families are not doing well in these turbulent times

While our expectations of the family have not changed, there have been dramatic changes over the last 20 years in the nature and functioning of the family. National statistics and trend data about the health status of individuals imply something about the possible effects these major disruptions are having on families in our society. Throughout Healthy People 2000, there is troubling information about the health and well being of individual family members.

We live in a world in which there is high mobility, in many cases families do not live in the same community as grandparents, or extended family. Today, nearly 70% of mothers of school age children work. A 1991 Office of Technology Assessment (OTA) report about adolescent health shows that 2/3 of the adolescents living with both parents are likely to have both parents working full time. Most mothers must work to provide sufficient economic support for the family. Women in a recent Yankelovich Clancy Shullman poll stated that if they didn't need the money they would consider not working, this percentage was up from 38% in 1989.

There have been dramatic increases in poverty levels, that effect disproportionate numbers of single parent families, African Americans, Hispanics, Native Americans, new immigrants, and children under six years of age. One in four children lives below poverty. In 1991, welfare consists of 12.5 million Americans, mostly children and their mothers, surpassing the previous peak of welfare enrollment of 1981, and the numbers have been increasing for 20 consecutive months.

While teenage pregnancy rates have decreased, the number of births to adolescents under 15 years of age have increased. Nearly one million teenagers become pregnant each year, 1/2 of these adolescents terminated their pregnancies through abortions, the other 1/2 give birth. Many of these teenage mothers are unmarried and will drop out of school, becoming dependent upon welfare, and thereby contributing to the increased number of children living in poverty.

While infant mortality has decreased somewhat, the number of low birth weight babies has not declined and there have been increases in the number of babies born addicted to substances and infected with AIDS.

Far too many of these families living in poverty are isolated in inner cities, exposed to high levels of drug abuse, violence, and provided too few constructive options for improving their family's educational, economic, social or health status.

There have been dramatic increases in the number of reported child abuse and neglect, a disproportionate number of which are from poor families. Women are more likely to be abused by their spouse than by a stranger. Nearly 1/2 of the homicide victims are related or acquainted with their killer.

There has been dramatic changes in the diversity and culture of the American family due to the changing ethnic composition of our society. Much of the U.S. population increase observed in the last ten years is due to the six million new immigrants entering our county.

Divorce has become a way of life. Over 20% of all children under 18 years of age, live within a single parent family. The 1991 report by the Office of Technology Assessment on the health status of adolescents shows that 6% of adolescents live in households without either parent; 30% live in households headed by a single parent, usually the mother. While the rate of divorce has remained stable at just under 1.2 million since 1979, the National Center for Health Statistics (NCHS) reports that the marriage rate dipped for the fourth consecutive year in 1988 to just under 2.4 million marriages. More people are not remarrying and the number of single parent households are increasing.

Studies show that parents spend 40% less time with their children than did parents in 1965. Men are increasingly isolated from their children due to longer work weeks, divorce, and work pressures that reduce the amount of time they spend with their families. A soon to be released market research study with high risk youth, conducted by Office of Disease Prevention and Health Promotion and 20 other Federal agencies, to determine appropriate communication strategies in reaching adolescents at high risk for health problems, found that most of the youth in the study had a tremendous among of unstructured, unsupervised time each day. These youth report spending most of their time alone or with friends on the street.

<u>But, despite these societal changes effecting families, most people report that "their family is the most important influence in their life"</u>

Even though these statistics suggest that the family is not performing according to our expectations, there is no one seriously recommending that the family be disregarded as our primary social institution. Rather most people feel even more strongly that the family needs to be the center of their life. In a recent poll of baby boomers in April, 1991, 91% of the men and 84% of the women said that they "expect family to play a more important part in their lives during the next 5 years".

Children and youth believe their family is the most important influence in their life. In the recently completed ODPHP market research study with youth at high risk, researchers learned that even adolescents from disruptive, dysfunctional families, in trouble with the court, living much of the time on the street, or found within treatment centers, believe emphatically that their family is the most important and constructive influence in their life. While some of us would not consider these parents constructive influences, adolescents in this study placed their families above all others in importance to them, and it is this family which must be strengthened if we are to help the adolescent succeed.

Most of the significant national reports released in the last five years have called for a national commitment to strengthening the family. Among these, <u>Code Blue: Uniting for Healthier Youth, Office of Technology Assessment's Report on Adolescent Health, Carnegie Foundation's Report on Middle Schools: Turning Points, National Commission on the Children: Beyond Rhetoric,</u> all say the family must be strengthened if our children and youth are to be prepared for the next century.

Each report challenges the nation to make its policies more supportive of families and recommends model programs that can address the family's changing needs and conditions. Each views the family as the center for health promotion and disease prevention for its members.

At the same time, the Federal government has been decentralizing their responsibilities for health and human services to states and local governments. The decentralization of federal programs to the local community is accompanied by the Federal expectation and mandate that local communities will develop comprehensive, family centered, community based service programs. These initiatives are expecting communities and local governments to figure out how to serve families in a new and different way, with far less funding.

Illustrative of these federal initiatives is the recommendation from the Bureau of Maternal and Child Health to states to build comprehensive, coordinated community based, family centered care as the method for improving the health of infants and children. The Office of Substance Abuse Prevention has encouraged each of its funded communities to shift their program paradigm into more community based models that strengthen families, neighborhoods and communities as the most effective approach to lead to "a drug free America".

If we are to succeed in improving the well being of families in the midst of ever changing social conditions and high turbulence, communities and local governments must learn much more about the status of their own particular communities and the families who reside in their local jurisdictions. They must learn "how" they can be supportive and helpful in strengthening the abilities of "their" families to meet the needs of their members? This requires a shift in emphasis from national based data collection efforts into a complementary system of national, state and local data gathering and information systems. We must shift our attention from expensive, isolated national data collection to building the capacity at state and local levels of government to monitor the health status of the families in their geographical area.

<u>At this time we are not prepared for this challenge</u>

Health planners and program developers in state and local governments know very little about the health of families in their communities. They know even less about what kind of programs are effective in strengthening families' capacities to fulfill these broad social mandates.

Why is it that in a country where families are the number one social institution there is so little information about families-- their needs, wants, practices, and how best to serve and strengthen them?

The first reason is that national policy does not address families as a unit, but rather has initiated programs that focus on the individual and is usually directed at a single issue and/or a specific problem. As a result, we have a myriad of fragmented, categorical programs/policies, that address single issues. Some focus on:

various body parts...heart, lung, and blood;

while others address specific chronic diseases... cancer, strokes, cardiovascular, diabetes, etc; and,

still others serve types of individuals... maternal and infant, elderly, pre-school, and adolescents; and,

finally there are programs that are centered around major problems... violence/abuse, drugs and alcohol, and injuries, etc.

In each of these individual program areas, the data/statistics collected monitors and counts the

incidence and prevalence of that issue, monitors the characteristics of the individuals at risk, may count the types and kinds of services provided; and perhaps, evaluate the performance of that service in reducing the particular problem under study. Program data collected by treatment organizations, do not monitor the effect of the treatment on that individual's family. If the family is dealt with at all, it is more likely in relationship to the individual being served, not in a family centered approach. Even child abuse programs retain information on the individual child under supervision, rather than on the whole family. Each child who has been abused has his/her own record and case plan. When more than one child is removed from the same family, each child may be placed with a different foster parent and be assigned a different worker.

The Federal government also collects individual data from national representative population samples, measuring how well these individual high priority problem issues are being addressed.

Most national data banks are aggregates of individual level data--key demographic characteristics (income, age, ethnic, sex), risk factors (exercise, weight, blood pressure, smoking rates, even stress), medical care use (number of visits, types and kinds of visits, cost of visits, etc), and specific mortality and morbidity rates.

We have trend data about individual risk factors, medical care use, and types and kinds of people more likely to be affected.

The National Health Interview Survey collects information about the individual members in a household, but is not analyzed by family or household. The questions are not designed to assess how the relationships among members of the household affects the behavior under study.

Some of our national and state policies and practices meant to insure fiscal integrity and efficiency actually disrupt the family. A classic example exists in the child abuse and neglect arena.

Grandparents who assume responsibility for their grandchildren, because of court intervention and removal of children from their daughters/sons custody do not receive any foster payments. They are not eligible for the same financial support, respite care and social/health care given to foster parents. They receive minimal encouragement in their heroic efforts to keep their families intact. It is not uncommon that the court eventually must remove the grandchildren from their grandmother's home due to the grandparent's physical exhaustion and financial limitations and place these same children in a foster home to whom they will now pay for these very same services.

Another example of our public programs failure to support the family is our society's unwillingness to address the long term care needs of our elder citizens. We provide no financial or social/health support to the growing numbers of adult children who are providing direct care and supervision of their fragile parents. Many of whom place their own employment in jeopardy to fulfill their obligations to their family.

In each of these cases we know little about the number, impact and cost of these national and state policies regarding families.

A second reason that the family is not monitored in our national information systems is that the "family" does not lend itself to measurement. We can't measure something that can not be defined. The traditional definition of what a family is, no longer fits very many families. But, there is great disagreement among us regarding a suitable definition for the family. Not all of us will agree that a white lesbian couple, with two adopted African American children is a family. Or, that a household of three generations of women and children are a family.

Most of the really interesting things about families do not lend themselves to measurement by traditional methods. Most of what we know about families has been learned through research efforts confined to a single discipline and addressing a particular dimension of the family.

Sociology examines the roles and functions of a family while Psychology studies the emotional influences of the family. Demographers trace the changing characteristics of individuals and groups. Social work may focus on studying families in which there has been abuse or neglect.

Consequently, we know an assortment of interesting fragments about family life in America. We know with some certainty that parents who abuse alcohol and drugs increase the chances that their children will become abusive of substances. We know that parents who are overweight and don't exercise, tend to have children that will also be overweight and not exercise. We know that a parent involved in their child's education increases the likelihood that the child will succeed and perform well in school. But, we don't have good information about how the family as a whole unit behaves, nor a real understanding of the family in all of its complexity.

<u>What local program planners need is different from this available data</u>

If local governments are to fulfill the challenges foisted upon them by popular opinion as well as by the Federal Government, program planners need a completely different information system from that which exists today.

Before building community based, family centered approaches that actually strengthen families and achieve the vision laid out in the <u>Healthy People 2000, National Health Objectives for the Nation</u>, program designers need specific information about their communities and the families that live in these communities .

Until local governments know the health status of families in their communities, know what specific unmet needs must be addressed in their geographical area and what program models are effective with the kind of families found in their communities, they can only "guess" about how to direct their resources and time into a service delivery system.

And, that is what local governments and program people do. They must speculate about what is needed by amalgamating the national level information on individuals by specific category with the disparate sources of data collected by the state and local departments of social, health, and justice. As you can imagine, this process of speculation has many difficulties.

One county in California undertook this challenge. It took two years of interagency planning to surmount the unbelievable obstacles to gathering and analyzing data about the same families collected from social services, justice, mental health, welfare, and the school. In the process, they began to design a program that was comprehensive and family centered in its approach, but the time and effort required will not be repeated by other less motivated counties in which there is no leadership driving the process. Most

counties are overwhelmed with maintaining the status quo.

There are several California counties who are in fact pursuing similar efforts, among them is Contra Costa County (CCC). The Board of Supervisors has made the commitment that the county will be supportive of families. They are building upon an existing track record for innovation in working with families in trouble. The county's Youth Services Board, consisted of each of the departments sponsored and interagency, Family Preservation Project funded by Edna McConnell, and supported by the Social Policy Center. Through this project, county officials learned how to prevent out of home placement of children in crisis, save county money and work constructively across agency boundaries.

Now, each department has pooled monies to hire a coordinator who will assist the county in adopting a comprehensive family focus in all county activity. The task is to help county agencies change the way they deliver services to families by being more pro active, comprehensive, community based, and family centered.

The program envisioned will work with all families, but focus on three specific goals:

> provide low income families with information, assistance, and support to improve their families' health;
>
> reduce the number of families who are risk for major health and social problems by placing inter-department programs in the schools, housing projects, within reach of welfare families;
>
> reduce the number of families in trouble, by preventing out of home placement of children through an intensive interagency family preservation program and return children home from placement by intensive family reunification efforts.

Everyone is committed, but where to start? The very first step is to acquire an informed understanding of the needs of these various groups of families and where they are geographically located in the county. A common data base must be built relying upon the existing data collected by each of the major departments of social services, health, mental health, substance abuse, justice, housing authority, welfare and community services administration. This data must be integrated with other diverse sources of information, eg:census data. New data must be collected about the families and their expressed needs. A survey of innovative models must be conducted to help us design programs that work and also to avoid the pitfalls others have already experienced and overcome.

The task is daunting for the most energetic, optimistic people. Local governments undertake such tasks by redirecting money from existing programs, shifting staff from existing responsibilities. Giving up vital services to pursue innovation is not a desirable tradeoff. At the local level, there are fewer people available who can assemble information, create new data collection efforts and guide communities translating abstract research findings into concrete program models.

To increase our chances of succeeding, Contra Costa County would like a closer partnership with the experts in the Federal government and research centers across the country. We would like to benefit from the wealth of knowledge already accumulated, and to use existing data collection instruments rather than create our own. We don't want to re-invent the wheel, we would prefer to imitate the successes and accomplishments of others.

Recommendations

If local governments are to fulfill the challenges presented by a changing world, they must be a part of a partnership with Federal and National level experts and local governments. Through this partnership, national experts would be available to assist with constructing a relevant information system that provides data about where we are, what must be done, and what programs are effective with whom. This data system would be complimentary with national level surveys and data bases.

Local communities must be provided tools to do its job, if it is to effectively change community services to support and strengthen the family. This suggests that training and technical assistance should be provided to state and local programs to improve their ability to monitor and support the family.

We need more comprehensive inter-disciplinary research on the family. We need to examine how the family can be a positive, health promoting resource for its members. This research should address the questions local program planners have generated and not be designed solely by academics, isolated from the real world in which public agencies work.

One of the journalist who had been held captive by Iraq during the Persian Gulf War was asked upon his release to make a few comments about his experience. He said that throughout his captivity, he gained strength by thinking of his family and remembering their times together. This particular journalist had traveled the world, had seen and reported on many historic events, but, during his imprisonment, he thought about his family. He said that spending time with his family was more important than anything else he had done.

Regardless of social, economic, or ethnic background, the family is the most fundamental influence in our lives. It is a worth and important goal for all of us to pursue ways in which we can strengthen the families ability to care for its own. Thereby, the nation will achieve the Year 2000 National Health Objectives.

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FAMILY DRINKING PATTERNS AND CHILDREN'S BEHAVIOR PROBLEMS

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Introduction

Adverse child health consequences of parental alcohol dependence are well documented. These negative consequences include impaired cognitive, affective and psychophysiological function (West and Prinz (1987), Johnson and Rolf (in Press), Russell, Henderson, and Blume (1984), Hughes (1977), Knop et al., (1985), Schuckit and Childes (1978), Marcus (1986)); higher rates of injuries and emotional problems (Putnam, 1985); higher likelihood of certain conditions, such as migraine, asthma, allergies, anemia, frequent respiratory ailments and weight problems (Schneiderman (1975), Moos and Billings (1982), Rolf and Johnson (1987)); and higher levels of use of medical services (Woodside, 1988). Most studies conducted to date have used relatively small, often clinical, samples since large samples of clinically-verified data have not been available. As a result, it is difficult to generalize their results to a more general population. Moreover, relatively little is known about the effects, if any, of non-problem parental drinking on children's health.

The link between parents' drinking and children's behavior problems can be conceptualized in two ways. The first is the effect that drinking may have on time spent in parenting. To the extent that significant amounts of time available for parenting are spent in drinking or recovering from drinking, less time can be spent in fulfilling parental obligations and in performing supervisory activities. Secondly, parental alcohol use may affect the quality of time parents spend with their children or the effectiveness of their parenting skills. An inebriated parent may experience impaired decision making or judgement or exhibit less effective or appropriate supervisory skills which, in turn, could lead to inconsistent parenting. At the most extreme, parental behavior may become abusive, violent, and conflictive. Thus, even if the total amount of time available to the child is not altered by the parent's drinking, the benefit to the child of that time may be reduced.

The 1988 National Health Interview Survey (NHIS) Alcohol Supplement and the Child Health Supplement conducted in the same year provide the opportunity to study the effects of parental alcohol use on child behavior among a national sample of non-institutionalized children. In particular, the Alcohol Supplement data are a rich source of information on both non-problem and problem drinking among parents in a non-clinical sample. The results presented represent initial efforts to examine the effects of parental alcohol use on children's behavior using the 1988 NHIS. This work is part of a larger study funded by NIAAA that will examine the relationship between parental alcohol use and several dimensions of children's health while controlling for variables that may confound the relationship.

Methods

The study sample was selected from the 1988 NHIS Child Health Supplement sample. Sample selection was guided by several considerations. First, analysis was restricted to single family households in order to avoid potential confounding effects that might arise from the presence of more than one family in the household. The sample was also limited to families in which all children were under 18 years of age and in which no related or unrelated adults over age 17, other than parents, resided. This restriction was adopted because of concerns that the effect of parental drinking might be diminished if other adult household members assumed parental role obligations. Thirdly, the sample was further restricted to families in which both parents were present since the effects of parental alcohol use on children's health may be quite different in single parent families.

The 1988 NHIS Alcohol Supplement was administered to only one randomly selected adult 18 years or older in each household. Alcohol respondents are included only if they were identified as either the household reference person or the reference person's spouse and if there was a matching Child Health Supplement record meeting the above criteria. Records from the Alcohol Supplement that identified the respondent as the spouse of an individual who was in the armed forces and living at home were excluded since no data are available on the family member who is serving in the armed forces.

Classification of Parent's Drinking

The drinking behavior of the parent responding to the Alcohol Supplement questionnaire was classified into seven groups, as shown in Table 1. Generally, the NHIS classification of lifetime abstainer, lifetime infrequent, former, and current drinker was maintained. Former drinkers who did not drink in the child's lifetime, that is, whose last drink was a year or more before the child was born, were distinguished from former drinkers who drank during the child's lifetime. The child behavior scores for children of former drinkers who did not drink during the child's lifetime were very similar to the lifetime infrequent drinker group, so the two categories were combined.

Former drinkers who drank during the child's lifetime, including during pregnancy, were classified into two groups: light/moderate and heavy/problem. The second category was combined because there were very few individuals that fell into the former heavy drinker category. Alcohol questionnaire respondents were classified as former drinkers who drank during the child's lifetime if they reported drinking twelve or more drinks in any one year but not in the twelve months prior to the interview and if the date of their last drink was within the child's lifetime plus one year. Respondents were classified as current drinkers if they reported consuming twelve or more drinks in the twelve months prior to the interview.

Child Behavior Measures

Two approaches were pursued in the study to measure child behavior. Both approaches used the 28 items on child behavior in the NHIS that are a subset of the parent report of the Child Behavior Checklist (CBCL) (Achenbach (1978); Achenbach and Edelbrock, (1979)) along with 2 additional items from the child questionnaire. In the first approach, preestablished scales of child behavior from the CBCL were modified using the NHIS items (These scales include more items than are contained in the NHIS). The second approach was based on the behavior subscales developed by Zill (1985, 1990) from the 28 CBCL items in the NHIS. The measures derived from each approach are the sum of the scores for each item in the measure; the CBCL items were scored as 0 (never true), 1 (sometimes true), and 2 (often true).

Achenbach (1978) and Achenbach and Edelbrock (1979) reported broad internalizing and externalizing factors, as well as subscales by sex from the parent report CBCL for children aged 6-11 and 12-16 years. Only the broad factors were used in our analysis for 6-11 year olds because there

Table 1
Categories of Drinking Behavior Developed from the 1988 NHIS Alcohol Survey Supplement

GROUP 1. Lifetime Abstainer
- < 12 drinks in lifetime

GROUP 2. Lifetime Infrequent Drinker or Former Drinker, but Abstainer in Child's lifetime
- < 12 drinks in any one year

OR
- 12+ drinks in 1 year but not in last year **AND** last drink is at least one year prior to child's birth

GROUP 3. Former Light/Moderate Drinker

GROUP 4. Former Heavy or Problem Drinker
- 5+ drinks on 52+ days/year when drank most

OR
- 9+ drinks on 12 days/year when drank most

OR
- problem drinker based on responses to 41 drinking behavior questions

OR
- positive response to question re: alcoholism.

GROUP 5. Current Light/moderate drinker
- calculated average daily ethanol intake <= .99 ounces

GROUP 6. Current Heavy drinker
- calculated average daily ethanol intake = 1+ ounces

OR
- 5+ drinks on 52+ days

OR
- 9+ drinks on 12+ days of past year.

GROUP 7. Current Problem Drinker
- based on responses to 41 drinking behavior questions

OR
- positive response to question re: alcoholism

were too few items in the NHIS for any given subscale. The behavior measures used for both age groups were not sex-specific, but rather included the items in a given factor for either sex (the union of the sex-specific items). There were too few items to derive the sex-specific factors. Moreover, the measures that combined items for either sex had the highest Cronbach alpha values. Table 2 shows the two CBCL measures and their items for 6-11 year olds and the four CBCL measures for 12-17 year olds.

Table 2
CBCL Behavior Measures and Items

Children aged 6-11 years

Internalizing Behavior (0.65)*	Externalizing Behavior (0.85)
Feels worthless	Cruel to Others
Unhappy, sad, depressed	Breaks things
Complains about love	Disobedient at school
Fearful, anxious	Argues too much
Cries too much	Very strong temper
Clings to adults	Stubborn, sullen, irritable
Withdrawn	Bullies, cruel, mean
Easily confused	Trouble getting along with children
Stubborn, sullen, irritable	Changes in mood
	Demands attention
	Not liked by others
	Complains about love
	Acts without thinking

Children aged 12-17 years

Uncommunicative Behavior (0.78)	Hyperactive Behavior (0.78)
Withdrawn	Can't concentrate
Secretive	Somewhat clumsy
Unhappy, sad, depressed	Can't sit still
Stubborn, sullen Irritable	Poor student
Changes in mood	Disobedient at school
Worries too much	Acts without thinking
Easily confused	Trouble getting along with children
	Easily confused
	Not liked by others

Aggressive Behavior (0.81)	Delinquent Behavior (0.85)
Very strong temper	Hangs with trouble makers
Bullies, cruel, mean	Cheats, tells lies
Argues too much	Disobedient at school
Disobedient at home	Acts without thinking
Changes in mood	Can't concentrate
Others out to get him	Disobedient at home
Can't sit still	Secretive
Acts without thinking	
Complains about love	

*Cronbach Alpha

Table 3
NHIS Behavior Measures and Items

Antisocial (0.68; 0.78)*	Anxious/Depressed (0.65;0.77)
Cheats, tells lies	Sudden changes in mood
Bullies, cruel, mean	Complains about love
Disobedient at school	Fearful, anxious
Not sorry after misbehavior	Feels worthless
Trouble getting along with teachers	Unhappy, sad, depressed
Breaks things (6-11)	Worries too much (12-16)
Hangs with troublemakers (12-16)	
Head Strong (0.75; 0.80)	**Hyperactive (0.72; 0.76)**
High Strung	Can't concentrate
Argues too much	Easily confused
Disobedient at home	Acts without thinking
Stubborn, sullen, irritable	One track mind
Very strong temper	Can't sit still

*Cronbach alphas for 6-11 and 12-17 years olds, respectively

Cronbach alpha, a measure of the internal consistency of a scale, was computed for each behavior measure. The alpha values were 0.65 and 0.85 for the internalizing and externalizing factors, respectively, for 6-11 year olds. The values for the scales for 12-17 year olds ranged from 0.78 to 0.85, with two of the four above 0.80. A Cronbach alpha of 0.8 is considered good, while 0.7 is acceptable.

The behavior measures developed by Zill (1985, 1990), and referred to here as NHIS measures, were derived from the literature on child behavior and were validated using confirmatory principle component analysis of the 28 CBCL items in the NHIS. Although there are 6 subscales for 6-11 year olds and 5 for 12-17 year olds, only four were used in the analysis presented here (see Table 3). The alpha values for the scales for 6-11 year olds ranged from 0.65 to 0.75, with only two of the scales above 0.7. The alpha values were higher for the 12-17 year olds, all were greater than 0.75.

Data Analysis

The sample was divided into two groups for analysis. The groups were based on whether the child's mother or father was the respondent to the Alcohol Supplement survey. Mean behavior scores by parent's drinking behavior were computed using

a calculated sampling weight that corrected the Child Health Supplement weight for parent non-response to the Alcohol Supplement questionnaire. This corrected sampling weight takes account of three factors: inflation for the probability of sample selection; first-stage ratio-adjustment; and poststratification by age, sex and race (Massey et al., 1989). The poststrata are those used in the full NHIS, but restricted to the portion of the sample that is under 18 years. These weights were further adjusted using a method developed for use with stratified cluster samples that effectively reduces the actual sample size to that of a simple random sample, leading to larger estimated standard errors (Leaf et al., 1991, page 28). Table 4 shows the actual and adjusted cell sizes for each level of drinking status by responding parents for children 6-11 and 12-17 years old.

Table 4

Actual and Adjusted Cell Sizes by Children's Age and Parent's Drinking Status
Source: 1988 National Health Interview Survey

Drinking Status	6-11 Years				12-17 Years			
	Father		Mother		Father		Mother	
	Adjusted	Actual	Adjusted	Actual	Adjusted	Actual	Adjusted	Actual
Group 1	77	82	308	330	81	103	226	279
Group 2	124	141	241	275	83	113	198	254
Group 3	46	54	163	191	60	71	112	146
Group 4	120	142	78	92	119	152	62	81
Group 5	480	588	445	552	358	485	328	431
Group 6	106	119	20	26	71	99	29	36
Group 7	184	222	57	70	113	149	47	68
TOTAL	1136	1348	1312	1536	886	1172	1000	1295

Hypothesis testing is based on conservative p-values (.01 or less) to further ensure that the null-hypothesis is not erroneously rejected because of misestimates of the standard errors on which the tests are based (these errors could arise as a result of the NHIS sampling procedures). The actual sample sizes for these analyses were 2,884 for the 6-11 year age group and 2,467 for the 12-17 year old group, although they varied somewhat depending on the behavior measure because of missing data. Adjusted sample sizes were 2,448 for the younger age group and 1,886 for the older one. Missing data did not exceed seven percent for any given behavior measure.

Results

Mean behavior scores by mother's and father's drinking status are presented in Tables 5 through 8. The superscript letters in the tables indicate the groups for whom mean behavior problem scores are significantly different from

Table 5
Mean Scores on CBCL Child Behavior Measures
for Children 6-11 Years Old
by Mother's and Father's Drinking Status, 1988 NHIS

Drinking Status	Internalizing Behavior		Externalizing Behavior	
	Mother	Father	Mother	Father
Group 1	1.20 (1.56)*	1.07 (1.73)	3.05 (3.26)	2.32 (2.79)
Group 2	1.74[a] (2.14)	1.63 (2.07)	3.86 (3.82)	3.17 (3.44)
Group 3	1.91[c] (2.03)	1.16 (1.50)	4.34[c] (3.78)	3.95 (3.46)
Group 4	2.91[c] (2.67)	1.99[b] (2.04)	5.76[c] (3.76)	4.19[c] (3.68)
Group 5	1.76[c] (1.98)	1.78[a] (1.85)	4.02[c] (3.69)	3.98[c] (3.43)
Group 6	2.49[b] (2.67)	1.51 (1.79)	5.12 (3.97)	3.50 (3.32)
Group 7	2.31[c] (2.06)	1.79[a] (1.87)	5.68[c] (4.20)	4.11[c] (3.33)
TOTAL	1.75 (2.04)	1.69 (1.88)	4.00 (3.73)	3.79 (3.42)

* Standard Deviation
a = p<0.01; b = p<0.005; c = p<0.001

Table 6
Mean Scores on NHIS Child Behavior Measures
for Children 6-11 Year Old
by Mother's and Father's Drinking Status, 1988 NHIS

Drinking Status	Anti-Social		Anxiety		Headstrong		Hyperactive	
	Mother	Father	Mother	Father	Mother	Father	Mother	Father
Group 1	0.65 (1.21)*	0.51 (0.85)	0.92 (1.18)	0.89 (1.25)	1.61 (1.77)	1.18 (1.41)	1.02 (1.38)	0.91 (1.54)
Group 2	0.76 (1.20)	0.62 (1.06)	1.33[a] (1.50)	1.17 (1.43)	2.08[b] (2.13)	1.77 (1.86)	1.44[b] (1.77)	1.54[a] (1.84)
Group 3	0.89 (1.35)	0.77 (1.03)	1.42[a] (1.38)	1.02 (1.25)	2.19[b] (1.97)	2.02 (1.84)	1.58[a] (1.72)	1.28 (1.46)
Group 4	1.46[c] (1.67)	0.79 (1.15)	2.07[c] (1.61)	1.41 (1.52)	2.64[c] (1.89)	2.22[c] (2.03)	2.42[c] (2.08)	1.52 (1.74)
Group 5	0.82 (1.29)	0.78 (1.11)	1.40[c] (1.44)	1.40[b] (1.41)	2.03[b] (1.85)	2.02[c] (1.77)	1.36[c] (1.64)	1.41 (1.52)
Group 6	1.09 (1.38)	0.63 (0.99)	1.70 (1.47)	1.11 (1.31)	2.26 (1.51)	1.73 (1.91)	1.65 (1.75)	1.34 (1.49)
Group 7	1.28[b] (1.64)	0.80 (1.12)	1.71[c] (1.44)	1.32 (1.40)	2.79[c] (2.09)	2.07[c] (1.77)	2.14[c] (1.61)	1.57[b] (1.65)
TOTAL	0.84 (1.32)	0.73 (1.08)	1.34 (1.43)	1.29 (1.40)	2.03 (1.93)	1.94 (1.81)	1.43 (1.68)	1.42 (1.60)

* Standard Deviation
a = p<0.01; b = p<0.005; c = p<0.001

the mean for lifetime abstainers. Statistical significance is based on t-tests calculated from the results of a weighted regression of each behavior score on parent's drinking status, where the adjusted weights are used. The results in the tables indicate that children whose parent's are current problem drinkers have significantly higher mean behavior scores than children whose parents are lifetime abstainers regardless of the parent's gender. Moreover, mean behavior scores for children whose mother's are former problem drinkers generally differ significantly from the mean scores of children whose mothers are lifetime abstainers.

Mean behavior scores for all measures are consistently greater for 6-11 year old children of current and former problem drinkers than the scores of lifetime abstainer's children (Tables 5 and 6). However, the mean scores of children of other types of drinkers also differ significantly from the reference category. The two exceptions are former infrequent drinkers and current heavy drinkers; the number in the latter group is very small. Significant effects of father's drinking status on child behavior measures are generally limited to the two problem drinker categories. Mean behavior scores on internalizing and externalizing behavior and for NHIS headstrong behavior are significantly elevated for children of current or former problem drinkers. They are also elevated for children whose fathers are current light to moderate drinkers. Father's drinking status has no significant effect on anti-social behavior in this age group.

The effect of problem drinking on child behavior is more clear cut in the 12-17 age group (Tables 7 and 8). Among CBCL child behavior measures, significant differences in mean behavior scores are noted primarily between children of lifetime abstainer parents and those of current problem drinkers for both mother's and father's drinking status. Moreover, on two of the scales, uncommunicative and aggressive behavior, children of former problem drinking mothers also show mean scores that are significantly higher than those of the abstainer mothers' children. Only hyperactive behavior is significantly associated with father's former problem drinking.

These patterns are also evident for this age group when scores are based on the NHIS child behavior subscales (Table 8). Children aged 12-17 years whose fathers are current problem drinkers have consistently higher mean scores on all NHIS scales than children of lifetime abstainer fathers. Mean scores based on mother's drinking status are higher for current problem drinkers for the Antisocial, Headstrong, and Hyperactive scales. Children of former problem drinking mothers also have significantly elevated means scores on the Antisocial, Anxiety, and Headstrong scales. Only the Headstrong scale is

Table 7
Mean Scores on CBCL Child Behavior Measures
for Children 12-17 Years Old
by Mother's and Father's Drinking Status, 1988 NHIS

Drinking Status	Uncommunicative Behavior		Hyperactive Behavior		Delinquent Behavior		Aggressive Behavior	
	Mother	Father	Mother	Father	Mother	Father	Mother	Father
Group 1	1.88 (2.16)*	1.87 (1.95)	2.65 (2.16)	2.41 (1.98)	1.78 (2.30)	1.61 (2.28)	3.05 (3.52)	2.72 (2.39)
Group 2	2.25 (2.37)	1.68 (1.63)	2.73 (1.92)	2.38 (1.54)	2.09 (2.18)	1.71 (1.93)	3.40 (3.36)	2.63 (2.42)
Group 3	2.05 (2.04)	1.78 (1.69)	2.76 (2.02)	2.89 (2.04)	1.92 (2.08)	2.10 (2.18)	3.40 (3.12)	3.05 (2.83)
Group 4	2.74[b] (2.44)	2.50 (2.45)	3.38 (2.67)	3.23[b] (2.40)	2.59 (2.82)	2.43 (2.61)	4.55[b] (3.75)	3.83 (3.71)
Group 5	2.04 (1.89)	1.92 (1.88)	2.65 (1.95)	2.60 (2.01)	2.08 (2.14)	1.91 (2.22)	3.28 (2.89)	3.18 (3.03)
Group 6	1.66 (1.96)	2.06 (1.86)	2.82 (2.04)	3.10 (1.94)	2.10 (2.29)	2.23 (2.12)	2.60 (1.90)	3.31 (2.62)
Group 7	2.87[b] (2.31)	2.82[b] (2.38)	3.59[b] (2.45)	3.35[b] (2.40)	3.12[c] (2.64)	2.83[c] (2.60)	4.62[b] (3.14)	4.93[c] (3.52)
TOTAL	2.12 (2.14)	2.09 (2.02)	2.78 (2.09)	2.81 (2.09)	2.08 (2.27)	2.09 (2.31)	3.39 (3.22)	3.40 (3.10)

* Standard Deviation
a = p<0.01; b = p<0.005; c = p<0.001

significantly related to father's former drinking status. These findings suggest that for 12-17 year olds maternal problem drinking may increase the child's risk of certain types of behavior problems at some future time even after the drinking has stopped.

Discussion

These preliminary descriptive results are consistent with the findings of previous clinically based studies: parental drinking appears to have adverse consequences on children's behavior. Generally, children of lifetime alcohol abstainers have lower behavior problem scores regardless of the behavior scale, child's age and parent gender than children whose parents have ever drunk beverage alcohol. Except for 6-11 year olds whose mothers responded to the alcohol questionnaire, these differences are statistically significant for only the problem drinker categories. Significant differences are generally noted for children of current problem drinkers, and in some instances, for children of former problem drinkers, especially former drinking mothers. Mother's drinking status, other than problem drinkers, appears to be more closely related to behavior problems for 6-11 year olds than for children 12-17 years. While drinking may impede parenting roles for both mothers and fathers, the maternal role is likely to be more critical for the younger children.

The study used two approaches to measure child behavior, the CBCL and the NHIS scales. Although some measures of child behavior have been developed from the 28 CBCL items in the NHIS, they differ from the measures developed from the larger CBCL. Thus, it seemed appropriate to use both approaches. Generally, the CBCL measures had slightly better internal consistency as measured by Cronbach alpha. The CBCL measures also showed somewhat stronger relationships with parent's drinking status than the NHIS measures, especially for mothers, among 6-11 year olds. This finding was not noted for 12-17 year olds. It is quite clear, however, that both approaches show the strong link of mother's and father's problem drinking to child behavior problems.

Table 8
Mean Scores on NHIS Child Behavior Measures
for Children 12-17 Years Old
by Mother's and Father's Drinking Status, 1988 NHIS

Drinking Status	Antisocial Behavior		Anxious Behavior		Headstrong		Hyperactive Behavior	
	Mother	Father	Mother	Father	Mother	Father	Mother	Father
Group 1	0.68 (1.27)*	0.71 (1.55)	1.67 (1.94)	1.53 (1.58)	1.72 (2.01)	1.42 (1.54)	1.29 (1.87)	1.08 (1.43)
Group 2	0.89 (1.32)	0.78 (1.17)	1.92 (2.00)	1.41 (1.57)	2.00 (1.94)	1.50 (1.66)	1.46 (1.79)	1.09 (1.30)
Group 3	0.95 (1.46)	0.99 (1.65)	1.84 (1.78)	1.56 (1.73)	1.90 (1.88)	1.95 (2.13)	1.37 (1.66)	1.43 (1.60)
Group 4	1.44[c] (1.94)	0.97 (1.55)	2.44[b] (1.98)	2.19 (2.31)	2.86[c] (2.16)	2.18[b] (2.15)	1.70 (2.00)	1.70 (1.98)
Group 5	0.87 (1.35)	0.95 (1.55)	1.81 (1.79)	1.69 (1.73)	1.98 (1.89)	1.92 (1.91)	1.29 (1.46)	1.23 (1.55)
Group 6	0.93 (1.35)	0.86 (1.38)	1.56 (1.28)	1.87 (1.81)	1.35 (1.41)	2.19 (1.79)	1.19 (1.57)	1.58 (1.57)
Group 7	1.30[b] (1.57)	1.51[c] (1.90)	2.23 (2.02)	2.50[c] (2.20)	2.93[c] (2.13)	2.92[c] (2.23)	2.02[b] (1.89)	1.88[b] (1.97)
TOTAL	0.90 (1.41)	0.98 (1.57)	1.85 (1.88)	1.83 (1.88)	2.00 (1.96)	2.02 (1.97)	1.39 (1.71)	1.39 (1.66)

* Standard Deviation
a = p<0.01; b = p<0.005; c = p<0.001

There are a number of other determinants of child behavior problems that may be correlated with parental drinking status that were not included in the analysis presented here. Without more complex analyses which include these other determinants, the results remain merely suggestive, not conclusive. Nevertheless, the findings suggest that the adverse effects of problem drinking are not limited to the problem drinker. Moreover, the adverse effects of maternal problem drinking on some child behavior problems may not be limited to the period of active drinking, but may persist even after drinking has ceased. This pattern is noted for father's as well, but to a lesser extent.

If these results are confirmed when more complex models are analyzed, parental drinking behavior may prove to be an important factor in identifying children at increased risk for behavior problems. Further research to explain this link between parents' problem drinking and child behavior problems may provide information that is important in formulating and implementing effective prevention and intervention strategies for this vulnerable population. Moreover, parental drinking behavior itself may provide an important target for prevention and intervention when children's behavior becomes problematical.

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PATERNITY AFFIDAVITS AND THE CHANGING FAMILY STRUCTURE: SOCIOECONOMIC CHARACTERISTICS AND HEALTH STATUS

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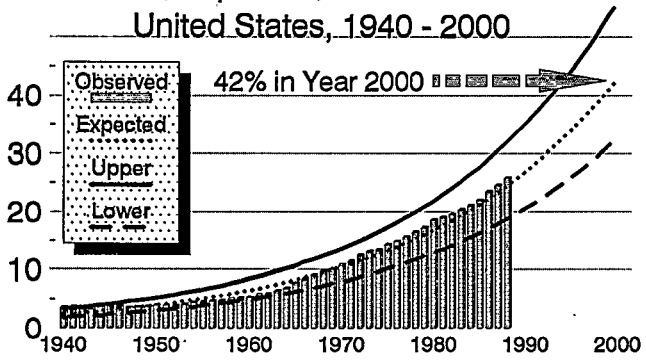
More than one out of every four live births in this country is to an unmarried woman. Nationally, the percent of unmarried births has been increasing steadily for at least half a century (Grove & Hetzel 1968). A logit transformation of the data (Figure 1) illustrates this trend. The expected values are a close fit to the observed values resulting in a coefficient of determination for the equation of greater than .96. If this trend continues as it has for the last half century, by the year 2000 more than 42 percent of all births will be to unmarried women.

Figure 1
Percent Unmarried Births
Observed, Expected, & Confidence Limits
United States, 1940 - 2000



This and other trends are contributing to profound changes in the structure of the American family (Santi 1988; Bumpass & McLanahan 1989; Wojtkiewicz, McLanahan & Garfinkel 1990; Santi 1990). Along with nonmarital fertility, a number of other social forces are also affecting marriage patterns and family structure. These include, but are not limited to, marital disruption - divorce, separation, or widowhood - (Cherlin 1981; Preston & McDonald 1979; Castro Martin & Bumpass 1989), the decline in remarriage, cohabitation as normative behavior (Bachrach 1987; Thornton 1988; London 1988 Bumpass & Sweet 1989a, 1989b), older age at marriage (NCHS 1990a), low overall fertility (NCHS 1990b), increased participation of women in the labor force (Goode 1963; Hannan, Tuma & Grenveld 1978), and the continuing individualization and secularization of society (Lesthaeghe & Surkyn 1988).

The literature is replete with studies of the effects of family structure on children. Economic factors such as poverty among women and children (Bumpass 1984; Hofferth 1985; Garfinkel & McLanahan 1986; Garfinkel & Oellerich 1989) with their concomitant issues of access to health care (Hein, Burmeister & Papke 1990) have a very direct impact on the children. Factors such involving parent-child relationships such as bonding and "quality time" (Heatherington et al. 1983) are more difficult to measure as they depend on the presence of an adult male figure in the household. A number of investigators have studied the variable patterns of adult male residence in households with children (Hardy, Duggan, Masnyk & Pearson 1989; Eggebeen, Crockett & Hawkins (1990); Mott (1990). Others have focused on psychological difficulties of the children (Wallerstein & Kelly 1980; Heatherington, Camara & Featherman 1983; Wallerstein & Blakeslee 1989), and their intellectual development and academic attainment (McLanahan 1985; Brooks-Gunn & Furstenberg 1986; McLanahan & Bumpass 1988).

While these socio-demographic changes and their sequelae are widely recognized and perhaps even accepted, it must not be forgotten that marriage and family are the institutions charged with the responsibility for procreation and the raising of children. As such, the purpose of this presentation is to assess the impact of these changes on the children themselves.

Even with the great increase in data and research in family demography that has occurred in recent years (Bumpass 1990), there is a need for much more work, especially relating to the health of children who are not born into the traditional two parent family. Birth certificate data systems have been the basis of much of the public health and demographic research regarding fertility and reproductive outcomes. Even though these databases are widely available and have been extensively analyzed, they still have much to contribute.

In the analysis of data from birth certificates, demographers and health statisticians have relied upon the traditional marital status dichotomy of "married" or "unmarried." However, in recent years, cohabitation has become a common alternative and/or antecedent to marriage. As Bumpass notes, "(M)ore than half of all persons in their 30s have lived in a cohabitating relationship and more than half of recent marriages were preceded by cohabitation (Bumpass 1989)."

In light of this, it may be more appropriate to think of marital status as a continuously distributed variable rather than as a dichotomous variable. When seen from such a perspective, a more complete understanding of the relationship between marital status, household composition, family structure, and birth outcomes is possible.

To this end, the research community is encouraged to make use of a previously untapped source of information regarding marital status: the paternity affidavit. Available in most states, a paternity affidavit is a simple one-page legal document in which the man voluntarily acknowledges that he is the natural father of the child. In so doing, he recognizes that he may incur "possible financial and legal responsibilities to the child." In Arkansas, the paternity affidavit is filed along with the birth certificate; the birth certificate is not later amended, even if the man were to subsequently acknowledge his role as father.

While an important indicator of the nature of the relationship between father, mother, and child, the paternity affidavit says nothing about actual household living arrangements. Rather, its value lies in improving our understanding of the changes that have come about in the interpersonal relationships that we know as marriage, family, and household composition, and, most importantly, their impact on public health.

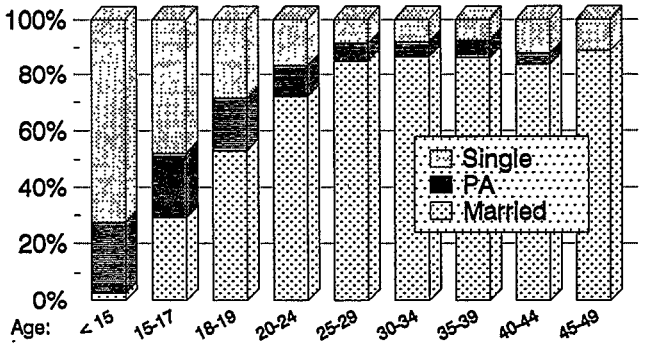
The 1989 Arkansas birth certificate files are the basis for this analysis. Along with all the information from the birth certificate, the database also indicates whether or not a paternity affidavit was filed. For the sake of convenience, married women are hereafter referred to as "Marrieds," those who had paternity affidavits filed are "PAs," and unmarried women without paternity affidavits are "Singles."

In Arkansas, about 27.1 percent of all births are to unmarried women; this is less than one percent above the national average. In 40 percent of these unmarried births, a paternity affidavit is also filed. Therefore, the paternity affidavits represent at least 10.9 percent of all births in the state. In the other 60 percent of nonmarital births, there is no paternity affidavit and information concerning the father is not available.

The primary focus of this analysis is on the percent nonmarital births, referring to the marital status at the time of birth. No information is available from the birth certificates regarding whether the marriage occurred before or after conception, much less about changes in marital status subsequent to the birth. As Smith & Cutright (1988) have made clear, this statistic is not an illegitimacy ratio or rate. Those particular measures are based on the population at risk, that is, the number of unmarried women in the population ages 15 through 44, while the denominator for the percent unmarried is, of course, the total number of live births.

Figure 2 illustrates a very strong relationship between marital status and the age of the mother at the time of birth.

Figure 2
Marital Status by Mother's Age
Arkansas, 1989

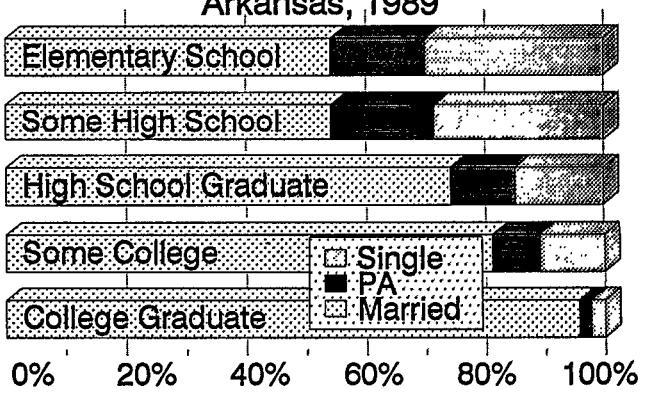


For the very young women under 15 years of age, only about 2.5 percent are married. In another 25 percent of the cases, a paternity affidavit is filed. But for 73 percent of the births, no father listed on the birth certificate. In Arkansas in 1989, there were only 167 of these very young mothers, less than one-half of one percent of the total.

The percentages increase steadily until the women are in their late 20s. At that age a plateau is reached whereby about 85 percent of the births are to married women, five percent are to PAs, and the remaining ten percent are to Singles.

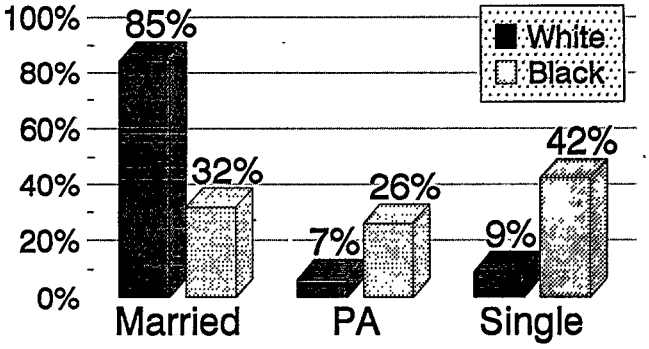
Figure 3 shows a very similar pattern with respect to the mother's education, which of course, is highly correlated with age. Only about 54 percent of the women with less than a high school education (the top two bars) are married as compared with 96 percent of the college graduates. Alternatively, about 16 percent of the lesser educated women are PAs and another 30 percent are Singles.

Figure 3
Marital Status by Mother's Education
Arkansas, 1989



In any discussion of marital status and birth outcomes, race is an important factor, reflecting, as it does, both socio-economic and cultural differences. As indicated in Figure 4, 85 percent of white mothers are married as compared with 32 percent of the black mothers. Another seven percent of the white women are PAs and nine percent are Singles. Among the black women, 26 percent are PAs and 42 percent are Singles.

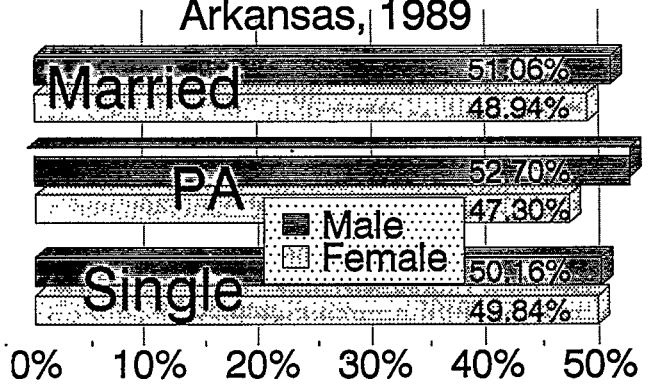
Figure 4
Marital Status by Mother's Race
Arkansas, 1989



When the parents are not married, the father has a choice: he can acknowledge the infant, in which case the parents file a paternity affidavit. Alternatively, he may choose to not acknowledge his paternity. As is evident from Figure 5, a paternity affidavit is slightly

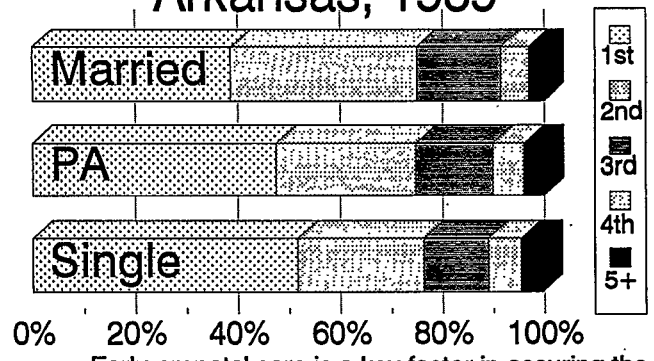
more likely to be filed if the child is male. Comparing PAs to the Singles, the difference is significant at .017. While statistically significant, the difference is very small in "real-world" terms. 52.70 percent of the paternity affidavit infants are male as compared with 50.16 percent of the Singles.

Figure 5
Marital Status by Sex of Infant
Arkansas, 1989



As previously noted, the age of the mother is closely related to her marital status. Single women tend to be younger, married women older, and the PAs in the middle. A similar relationship exists with regards to parity.. From Figure 6, it can be seen that among the married women, this birth was their first in 39 percent of the cases. Among the PAs, this was the case 47 percent of the time, and more than half (52 percent) of the Singles were primiparas. Singles were 25 percent more likely to be having their fourth or greater birth than were Marrieds while PAs were about 17 percent more likely to be having a high order birth.

Figure 6
Marital Status by Parity
Arkansas, 1989



Early prenatal care is a key factor in assuring the health of the infant. Of those who received prenatal care in the first trimester of their pregnancy (Figure 7), 81 percent were Marrieds, eight percent were PAs, and ten percent were Singles. Among women who received no prenatal care, only 38 percent were married, 19 percent were PAs, and 43 percent were single.

The optimal number of prenatal care visits (Figure 8) is about 13 to 15. Of the women in this category, 83 percent were married, eight percent were PAs and nine percent were Singles. At the left side of the figure are those who had none, the same group as in Figure 7. Women who have more than the optimal number of visits are high risk mothers with diagnosed conditions requiring close monitoring. Singles and PAs represent a large proportion of this group.

Figure 7
Marital Status by Trimester
Arkansas, 1989

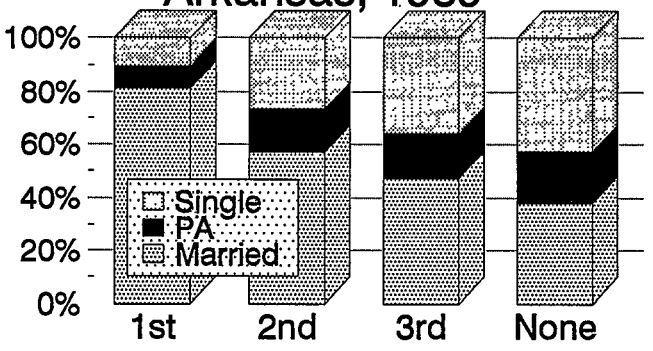
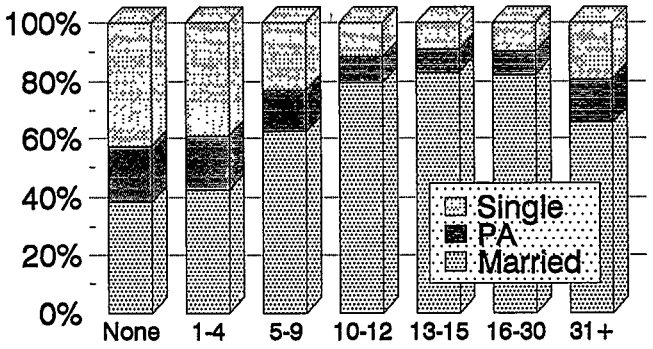


Figure 8
Marital Status by Prenatal Care Visits
Arkansas, 1989



Concerns about the effects of tobacco and alcohol consumption lead to several new questions on the most recent revision of the birth certificate.

Figure 9
Tobacco and Alcohol Consumption
During Pregnancy
Arkansas, 1989

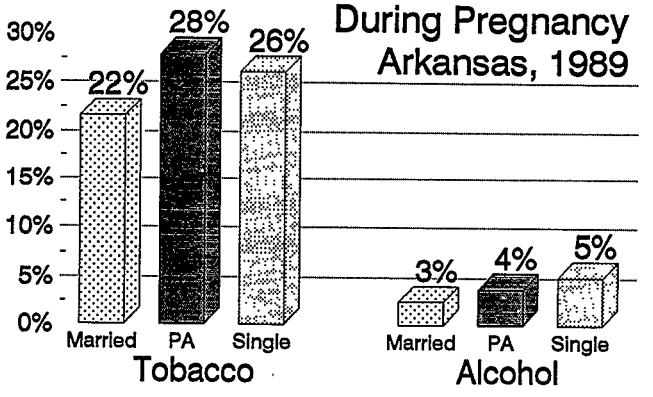
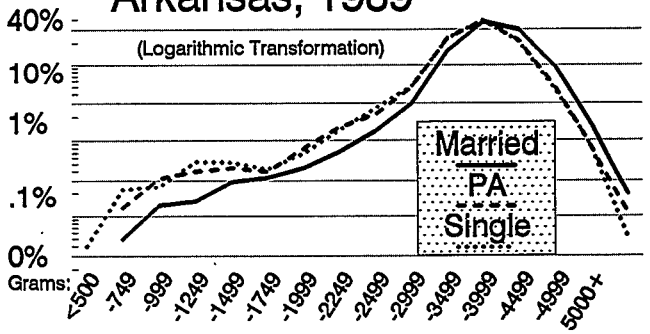


Figure 9 indicates that tobacco use was reported among 22 percent of married women, 28 percent of the PAs, and 26 percent of Singles. Alcohol consumption was found among three percent of Marrieds, four percent of PAs and five percent of Singles.

Birth weight is one of the most widely used outcome measures. Figure 10 shows that very low birth weight is two to three times as common among Singles as among Marrieds, with the PAs falling in between. At the other end of the birth weight distribution, birth weights in excess of 4,000 grams are found twice as frequently among Marrieds as among Singles and PAs.

Figure 10
Marital Status by Birth Weight
Arkansas, 1989



Clinical estimates of gestational age (Figure 11) follow a similar pattern. Singles are three times as likely to have infants with gestational ages of 30 weeks or less than are Marrieds. The PAs, once again, fall in between. Among the more mature infants, there is little difference between the Singles and PAs.

Figure 11
Marital Status by Clinical Gestational Age
Arkansas, 1989

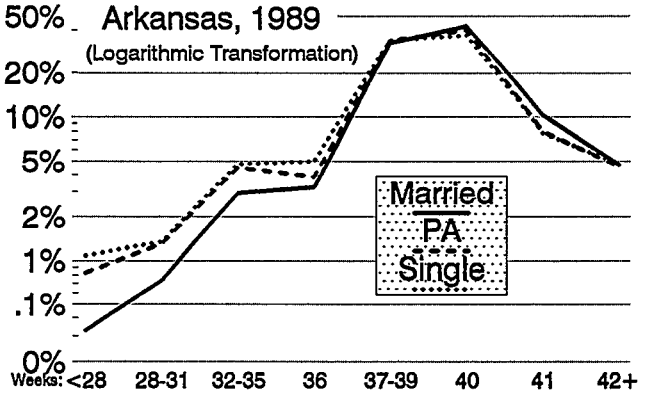
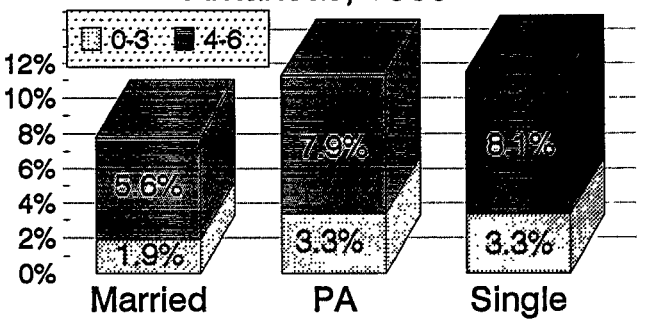


Figure 12 illustrates a third outcome indicator, the one minute Apgar score. The Apgar score is considered to be a reliable indicator of an infant's physical condition at the time of birth. PAs and Singles are about half again more likely to have Apgar scores of six or less than are the Marrieds. The differences between PAs/Singles and Marrieds are even more pronounced when the focus is narrowed to the very low Apgar scores. The infants of PAs and Singles are almost 75 percent more likely to have scores of 0 to 3.

Figure 12
Marital Status by Apgar Score
At One Minute: 0-3 and 4-6
Arkansas, 1989



As is evident from the foregoing, marital status, as defined by the "trichotomy" of Marrieds, PAs, and Singles is highly correlated with both the socio-demographic characteristics of the mother. Likewise marital status is an accurate and consistent predictor of a wide range of birth outcomes. As previously hypothesized, marital status may be conceived of as existing on a continuum. While marriage, per se, is important, many marriages are not very stable. If Castro Martin and Bumpass (1989) are correct, almost two-thirds of all recent marriages are likely to end in divorce. The degree of involvement of a man and woman in one another's lives may be a better indicator of "marriage" and family than mere possession of a marriage license.

Given the consistency of the patterns that emerge from these data, the couples (and their child) represented by the paternity affidavits fall between the Marrieds and Singles. One approach might be to suggest a scale of one to five where one is the Marrieds and five is the Singles. Since the sociodemographic characteristics of the mother and the birth outcome indicators of the infant appear to be closer to the Singles, the PAs would probably rate a four.

This does not indicate a very strong family unit, regardless of marital status. With the decline of the traditional two-parent family, increasingly larger numbers of children live in poverty. According to the Current Population Survey (1988), one in every five children lives in poverty; that is 15 percent of the white children and 45 percent of the black. Forty percent of the Nation's poor in 1987 were children under the age of 18.

The financial burdens associated with the raising of these children have been transferred to other sectors of society. Government, and hence the taxpayers, support a variety of social welfare programs aimed at providing services to children. On a national basis, the budgets of Medicaid, WIC, AFDC, Social Security, and other related programs cost tens, if not hundreds, of billions of dollars per year.

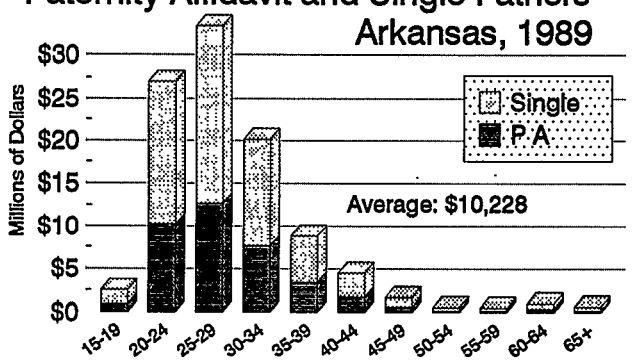
Given this rapid social change and the accompanying economic impact, it is not surprising that countermovements have emerged. Increasingly, one hears about "male responsibility," a phrase that has

legal as well as moral connotations. In addition, legislation has been passed by Congress and many state legislatures aimed at requiring noncustodial fathers to make a larger financial contribution to the support of their children. The new law requiring that the Social Security numbers of the parents be obtained when the birth certificates are filed is an example of such legislation that has had an immediate impact on those who work with Vital Records.

Garfinkel and Oellerich (1989) estimate that "(O)nly 60 percent of noncustodial fathers have a legal obligation to pay child support; of those with a legal obligation, only half pay the full amount and 24 percent pay nothing; and more than half of the mothers with children potentially eligible for support receive nothing." This excellent study assessed the financial impact of laws from three states on child support payments.

On a more modest scale, a simple model was developed to estimate the aggregate earnings of the unmarried fathers. The purpose was to determine what kind of a financial base was available to provide child support. Using data from the 1987 Current Population Survey, and standardizing for age, race, and region, estimates of aggregate income were developed. The average income of these men was estimated to be about $10,228 per year in 1987; nationally, the median income for all men 15 years and older was $17,752. These data are illustrated graphically in Figure 13.

Figure 13
Estimated Total First Year Male Earnings
Paternity Affidavit and Single Fathers
Arkansas, 1989



The reasons for this difference are easily understood. The unmarried fathers are, as has become apparent, quite likely to be young, black, and of lower education. Moreover, the $10,220 figure is the father's annual income *at the time of the child's birth.* The father continues to be obligated to provide financial support until the child reaches adulthood. Meanwhile, the income of the father will (presumably) be increasing.

With the rapid changes occurring in marriage and family, and sexual behavior and fertility, public health and other researchers must endeavor to more fully understand the social dynamics involved. To that end, every effort must be made to utilize all available data resources. Paternity affidavits are a valuable source of information that may further our understanding of these most profound of social changes.

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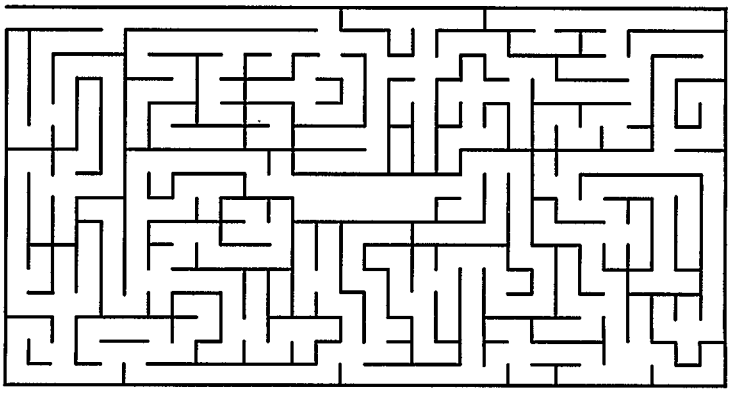
Third Plenary Session

New Concepts for the Decade of the 1990's



THE HUMAN GENOME PROJECT AND RELATED GENETIC RESEARCH: IMPLICATIONS FOR FUTURE PUBLIC HEALTH DIRECTIONS

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Genetics is a very personal science, dealing with individual variation, yet it has important policy implications. Let me begin by presenting two case histories that indicate both the stage the science has reached and the policy implications. I set these in the year 1995 in realistic anticipation of standards of care in just a few years and to emphasize that these are not real families but composites of what has happened and what can be expected.

Case 1: Genetic predispositions to common diseases. Peter and his wife Elizabeth are self-employed. They have just moved to Washington and chosen a doctor who is affiliated with one of the city's medical schools. She takes an extensive family history, revealing that Peter's father and grandfather died of heart attacks in their early fifties. In view of this history, she suggests tests to see if Peter has inherited one of the mutations that increase his risk of coronary artery disease. He would then be a candidate for drug treatment, although its efficacy in the genetic forms has not been established. The doctor determines that Elizabeth's sister has breast cancer and that her mother died from it. There is a test to tell whether she has inherited a genetic predisposition. If she has, then yearly mammography and breast self-exam could detect cancerous changes early. For both Peter and Elizabeth, if the tests come back negative their risks of disease are much lower than would be predicted by the family history.

Case 2: Carriers for serious single-gene disorders. Sally and John are a young couple who have just joined a Health Maintenance Organization (HMO). They are screened by the HMO to see if they carry mutations that cause cystic fibrosis (CF). Among whites, 1 in 25 are carriers. The results indicate that they are both carriers and have a 1 in 4 chance of having a child with CF each time Sally is pregnant. When Sally becomes pregnant, she can have prenatal diagnosis to determine whether the fetus has CF. If it does, Sally can choose to terminate the pregnancy.

Scientific underpinnings

These cases reflect advances made possible by recombinant DNA technology. It has already led to the discovery of genes which, when altered by specific mutations, increase the risk of coronary artery disease, and of other genes which increase the risk of cancer. The technology has, for instance, resulted in the discovery of genes that suppress cancerous changes. If these genes are mutated, the chance of cancer is increased. Considerable work is in progress to translate these discoveries into tests to detect individual predispositions. Recombinant DNA technology has also led to the identification of the gene for cystic fibrosis and the discovery of over 80 mutations that can cause the disease. Tests have already been developed to detect individuals who will manifest CF; they have inherited mutations from both parents. The tests will also detect carriers who have inherited a CF mutation from only one parent. Carriers are healthy.

These are just a few examples. What makes the technology so powerful is its ability to localize the gene responsible for a genetic disorder to a specific region of a chromosome without the necessity of understanding the pathogenesis of the disease. In addition to DNA probes and other paraphernalia, which are readily accessible, all that is needed is the cooperation of families in which the disorder has occurred in several members, suggesting that genes play a role. After localization, it has usually been possible to identify the actual gene and the mutations within it that result in disease. For CF, the time between localization and identification was 4 years. It took only another year before tests to detect CF mutations were available. The tests for CF and for other disorders can be used to indicate the presence of disease-causing mutations in unfertilized ova (without harming the ovum), in the embryo at any stage after fertilization, and at any time after birth. They can be done on any tissue that contains DNA (cells from fetal membranes or amniotic fluid, skin, mucosa, or blood.) Tests will be possible that predict the risks of both "single-gene" disorders, which follow Mendel's laws of inheritance, and complex, common disorders, which do not.

Drawbacks

Despite the elegance of the technology several factors must be considered before undertaking to make genetic tests widely available. A basic consideration is the validity of the tests.

As I have already indicated, the studies linking specific mutations to specific disorders have been and will continue to be done in families in which there are multiple cases. This introduces a bias of ascertainment, as only a fraction of all families with affected individuals will be tested. Two factors make bias an important consideration. First, more than one mutation can result in the same disease. Moreover, a mutation that predominates in one ethnic/racial group may not predominate in other groups. Thus, if the studies are performed in a relatively small number of families of one ethnic/racial origin, mutations will be missed. Tests developed on the basis of such limited studies may only detect a fraction of disease-causing mutations. Geneticists are well aware of this problem. However, it may not be practical to test for all disease-causing mutations even when they are known. At the present time, only a handful of the 80-or-so CF mutations can be tested for routinely.

Second, the genetic background in which a mutation exists can influence the appearance of the disease. The backgrounds will vary enormously because of the genetic variation that occurs for many genes (genetic heterogeneity) and the large number of possible combinations of variants of different genes. In families chosen for studies

because multiple members have the disease, the genetic background is probably not interacting in a significant way. In other families, however, the genetic background may interfere with the expression of the mutation. On testing, the mutation will be found in individuals without disease and who will never manifest it (false positives). Alternatively, the disease-causing mutation found repeatedly within some families may be a rare cause of the disease. Testing for it in all people with the disease will result in a high proportion of false negatives. There is, for instance, a rare form of spina bifida due to a single gene. Most cases, however, are not. We know that alterations of genes on chromosome 21 play a role in Alzheimer's disease in families with multiple affected members whose disease appears at a relatively young age. As the mutations are identified, it will be important to determine how often they appear in all patients with Alzheimer's.

Policies for the introduction of new tests

Before tests become widespread they should be adequately validated. This requires testing a large proportion, or representative sample, of all of those affected with the disease in order to determine the sensitivity of the test, that is, how often those with the disease have positive test results. It will also be necessary to test unaffected individuals to determine how often mutations incriminated in the family studies are present in the general population in the absence of disease. Adequate validation studies should be required by the Food and Drug Administration in considering premarket approval of genetic test kits, which are medical devices. As tests of less than perfect sensitivity and specificity are to be expected, the data from such studies should be available to potential users.

There are several issues that public health agencies at both the federal and state levels will have to confront regarding genetic tests.

Laboratory regulation. Tests may be provided by commercial or university laboratories using methods and materials that are not subject to FDA approval. Even when FDA-approved kits are used, there is no assurance that individuals who come for testing are similar to those on whom the test was validated or that laboratories will use the test reliably. Licensing of laboratories to perform genetic tests is one way of assuring quality control.

Reimbursement. Decisions regarding reimbursement for performance of tests will have to be made by the relevant state and federal agencies. Their policies are often adopted by private third party payers. In making these decisions, the agencies will compare the cost of the test against the benefits. If a high proportion of people with positive test results never manifest the disease, the test may result in little savings, particularly when further evaluation of those with positive results is needed, or when people with false positive results become anxious or suffer harm as a result of misplaced interventions. If little or nothing can or will be done for people with true positive results then the savings will be small at best.

Screening. In some instances, testing will result in substantial savings that cannot be realized in other ways. For instance, if testing was limited to infants who had a family history of phenylketonuria (PKU), only a small proportion of affected infants would be started on the special diet in time to benefit; most infants with PKU will not have previously affected relatives. (This is true of single-gene disorders in which the disease appears only if disease-causing mutations are inherited from both parents. Siblings may have the disease, but seldom will it appear in previous generations.) In such cases, public health agencies may decide to make genetic testing available to all who could benefit. This can be accomplished by requiring that people be screened, as most states require newborns to be screened for PKU, or that health care providers offer screening, as California requires providers of prenatal care to offer maternal serum alpha-fetoprotein tests. Having health department laboratories provide the test at little or no charge also facilitates widespread testing.

Ethical issues

Policies for reducing the chance of harm should be considered before tests are made widely available. To appreciate some of the problems, let us return to the couples described at the outset.

Discrimination. Recall that, based on their family histories, Peter is at risk of coronary artery disease, and Elizabeth of breast cancer. They decide to have the tests recommended by their doctor. The results indicate they both are at increased risk. Consequently, they apply for private health insurance (they aren't eligible for any group policy) and try to purchase more life insurance. They sign standard forms consenting to the release of information by their doctor.

The insurance companies ask their doctor to provide information about family history and the results of genetic tests. They do this to protect against adverse selection. A company sells private insurance at the standard premium to people it presumes to each be at the same risk of disease. When people like Peter and Elizabeth learn they are at increased risk and buy extra insurance at the standard premium to compensate, the company's calculation is upset; ultimately it will have to pay out more than its actuarial calculations allow. To protect against this adverse selection, the company must learn whether applicants are at increased risk. If they are, the company can refuse to insure them, charge them higher premiums, or exclude from coverage the condition that led them to purchase insurance in the first place. We are rapidly approaching the stage when differences in risks between many people will be distinguishable. This throws into question the principle on which private insurance is based.

Unlike Peter and Elizabeth, most workers in the U.S. do not have to purchase private health insurance but obtain it as a job benefit. To keep costs down, however, employers could use genetic and other testing to screen out workers (and their dependents) who are likely to incur high health costs. Thus for both private insurance and employer-based insurance, advances in risk

prediction may result in having more people who find it difficult to obtain health care coverage and, to an even greater extent, private life insurance. It will be the people at increased risk who will, ironically, have the greatest difficulty.

Coercion and directiveness. Recall that Sally and John were screened by their HMO and found to be carriers of cystic fibrosis mutations. I did not say whether they had a choice about being screened. The HMO might require CF screening as a condition of enrollment and deny membership to couples when both partners were found to be carriers. Alternatively, the HMO could say it will only cover their children who don't have CF. This puts pressure on Sally to have prenatal diagnosis. For a chronic, severe disease like CF, which often requires multiple hospitalizations, prenatal diagnosis and abortion is probably the least expensive course of action. This will often be the case for a variable period after disease-causing genes are discovered; considerable time may elapse before definitive interventions, which prevent or reverse the manifestations, are developed. In the interim, expensive care will often be needed to keep affected individuals alive.

Because of the time lag between acquiring the ability to predict and the ability to prevent or treat effectively, we may be confronted with a new eugenics, one based on minimizing costs. Although I doubt that carrier screening will become mandatory, people may be impelled to choose the least expensive reproductive option, prenatal diagnosis and selective abortion of affected fetuses. Obstetricians confronted with a couple in whom both partners are carriers could recommend prenatal diagnosis without presenting arguments for and against it. Couples at risk may be further constrained to choose abortion if they cannot obtain health care coverage for their affected infant or if state and federal governments cut back on support for chronically ill children. Their willingness to continue a pregnancy in the hopes that a cure will be found will be diminished if research to find cures is not supported. If carrier screening, prenatal diagnosis, and abortion of affected fetuses becomes the norm, couples who don't follow that pathway may be stigmatized. In a few years, it may be possible to learn whether the fetus is affected by testing fetal cells in the mother's blood. Then the obstetrician could perform the test without telling the couple anything until the results are available. In short, while offering ways to reduce the burden of disease, application of the new technologies that make testing possible could infringe on values at the core of our society. One of these is individual autonomy.

Confidentiality. Peter refuses to tell his younger brother about the genetic risk factor that may also predispose him to coronary artery disease. Peter fears that his brother will blame him for the news and will probably ignore it anyway. Moreover, it is not clear that his brother would be better off with the information. Peter's doctor knows that Peter will not communicate the results and must decide, therefore, whether she should notify him. As yet there are no legal criteria defining when physicians have a duty to warn others, except if failure to warn endangers anothers' life. Duty to inform could saddle physicians with an enormous load as predictive tests became more widely available. It would also alter the patient-doctor relationship.

With the assurance of confidentiality, patients will convey information that they might otherwise withhold. This will permit their doctor to understand and manage their health problems better. Although it is unlikely that a patient will withhold information regarding heart disease for fear that his or her physician will communicate it to others, patients will have greater reticence with mental illness, which is more stigmatic in our society. This fear may be even greater for communication to unrelated third parties, such as insurance companies which, as we saw, could refuse to pay for care once they have the information. Peter's doctor did obtain Peter's consent before she released information to the insurance companies but neither Peter nor she thought much about it. Physicians should explain to patients the implications of releasing personal data. Unfortunately, in our current system, patients at risk of future disease may be in a bind whether they give information or withhold it.

Problems of confidentiality apply to hospital and other patient records as well. Information regarding risks may unwittingly be released, possibly stigmatizing the patient or jeopardizing his or her access to health care. We need to find ways of limiting access to sensitive elements in medical records.

Conclusions

The human genome project, which is specifically directed toward localizing and identifying human genes, will accelerate the development of new genetic tests for predicting an individual's risk of disease, or his or her children's risk. Individuals' interest in having these tests will depend on the accuracy of the prediction, the nature of the disease, the options available to people with positive test results, and the negative impact of the test. We must be careful not to let the elegance of this new technology blind us to the different needs and attitudes of individuals and to the dangers to which unregulated tests can lead.

THE PUBLIC FINANCING OF PRIVATE HOPE

Glenn Wilson, University of North Carolina at Chapel Hill
Kathleen Leutze

"The Public Financing of Private Hope," the title of our forthcoming book, is the faultline in paying for personal health care. This morning's time constraints have required us to distill and greatly condense the discussion of the inescapable questions which require careful scrutiny and will fuel the debate now facing the country.

No one should be denied health care. This covenant was made when it was morally and economically comfortable to pledge that we would provide all that is possible. It was and continues to be more rhetoric than reality for many Americans, but our economic productivity and moral understanding will no longer sustain even the pretense that we can or should do all that is possible. The nation's investment in research and health professional education has produced more than we can pay for or fit into our values. Circumstances will in time compel the country to come to a new understanding.

The emotional and economic burdens of illness fall unevenly, but the potential of medical miracles comforts us all. Thus illness provides a fundamental stress test for every society: its sense of community, its values, and its humanity are measured in the organization and payment for personal health care.

The test scores of the United States, by nearly all counts, are poor and getting worse. The nation has a complex, pluralistic payment and delivery system that is confusing, inequitable, and extremely costly. We have continually "reformed" it over the last half century, but we have failed to provide access to basic services or equitable use of public funds for the world's most sophisticated scientific and technological medical care.

There is a new urgency in these familiar but unresolved issues.

The atmosphere is charged with proposals for change. The debate is dominated by (1) the advocates of the existing pluralism; (2) the apostles of efficiency and savings; (3) and the crusaders for some version of universal national health coverage. There is overlap in these broad approaches, but all must face some harsh questions. Will business, labor, or the electorate campaign for equity and comprehensive care for everyone and pay the bill as cost approaches twenty percent of the GNP? Failing that, will the sixty-five percent of the population that has generous employer-based, tax-subsidized insurance reduce their expectations in order to insure adequate care for everyone?

The proposed changes are targeted to correct perceived flaws, to fill the gaps, to improve efficiency, to drastically cut administrative costs, or to restrain the total cost by controlling specific services. Everyone appears to rely on enough, or nearly enough, savings from the current cost to avoid limits, or major increases in taxes or premiums.

It is the combination of equity, comprehensiveness, and cost control that strains our capacity and is a contradiction beyond the capability of our loose confederation of existing approaches. Health financing finds its ultimate expression in that fraction of wealth -- public and private -- that is made available for services. The term comprehensive has little meaning abstracted from a nation's values and economic capacity. Comprehensive in the American translation is grounded in abundance, not limits.

At the same time, our health financing reflects a society that does not distinguish between rights, responsibilities, entitlements, and accountability. The result is evident in both private and public confusion.

In our PERSONAL expectations, we are rarely concerned about price unless we or someone close to us needs medical treatment. At that particular point, willingness to pay is usually boundless, while ability to pay is barely if at all considered. Most consumers are at considerable remove from the cost transaction: and health care can appear to be virtually a free good.

Opinion surveys show confusion and considerable ignorance on how to balance expectations and cost. Nine out of ten Americans believe everyone should have the care a millionaire can expect, but many are unwilling to pay more taxes or premiums for this prospect, and some would pay a totally inadequate amount. A majority support a universal, government program, but the strongest consensus is opposition to paying for it.

There is an ingrained American demand for the availability of the best possible science and technology. We are driven by our day to day uncertainty of our place on the scale of well-being in a culture that idolizes health at any cost and seeks to deny death. Thus we must reckon with our demand for a surplus of resources if we are to restrain spending. The healthy want the best at hand just in case; the sick want it ready for immediate need. It is a reassurance price that we have been paying over the decades -- achieved by the duplication of personnel, facilities, and technology, some of it strained, but operated in general at a fraction of capacity, stimulating unnecessary use. And this despite the fact that half the population uses only four percent of annual health spending, and more than a quarter have no reported expense in a year. A third of us use ninety percent of expenditures.

In a larger perspective, the PUBLIC purpose is trapped in cross purposes. The current debate is a struggle to reconcile our search for health with our aversion to central authority -- especially federal authority. Government in the isolated role of paymaster receives universal blessing: it should finance what the private sector cannot afford or will not pay -- -- services for the poor, the disabled, the elderly, and treatments such as renal dialysis and transplantation. The public treasury is also welcome to give the most affluent employers and employees a publicly financed economic advantage in tax-subsidized insurance. Hence, those in least need enjoy an aggregate sixty billion dollar annual tax refuge. Premiums are a

benefit -- until recently an invisible part of the cost of productivity. The economically vulnerable are closed out of private insurance. Socialism for the rich and free enterprise for the poor is an intriguing capitalist paradigm.

Government has succumbed to the role we have thrust on it -- a powerful spender reduced to impotent efforts to control public spending. There can be no other outcome when contradiction overwhelms coherence in public policy.

In THE SEARCH FOR SOLUTIONS, there is a different context for this debate in contrast to previous reform efforts. The true cost of health care for most of the population was concealed in consumer prices, corporate records, and the tax books from 1950 to 1973. Economic growth provided money for increased wages, increased profits, increased taxes, and health care. The illusion was continued in the 1980's with consumer, corporate, and government borrowing. But over the decade, real wages for the workforce declined by 8%. Total household debt as a percent of spendable income rose nearly twenty percent and was eighty-five percent of after-tax income in 1990. Twenty percent of corporate income and twenty-five percent of federal income were required to meet interest payments in 1990. In this setting, how long will we pay twice as much -- or more -- for health care as we do, for example, for education?

Spending in the pursuit of health is a charge against the nation's economic output each year, regardless of whether the individual pays at the time of service, private insurance pays through employment benefits, or government pays with tax revenue. This oppressive fact has failed to gain wide currency, but the nation is now engaged in a zero sum game:

Health care or take home pay?
Health care or corporate profits?
Health care and new taxes?

We have evaded these questions and preached reform with increasing elaborations of pluralism. We confuse our advanced science and technology with the primitive nature of our financing - and call them both advanced because they are both complex. We have failed to distinguish between what is necessarily complex and what is contrived complexity. We have stumbled into defending our confection of financing approaches in the name of pluralism.

Pluralism -- as an ideal -- supposes that the public purpose will be defined and carried out in the public interest by the clash and reconciliation of different views. Unequal political influence and strident self-interests seriously compromise this ideal. The essential features of pluralistic approaches encompass revered cornerstones of American culture: they support the co-existence of diverse philosophies and institutions; they reinforce our belief in individuality, self-reliance, and creativity. It is the distortion of the concept, not pluralism itself, which now bedevils the health care system.

We are the only nation on the globe that has assumed the luxury that it is necessary and feasible to apply every available science and technology intensively to every human ailment. Moreover, we assert we can control cost by working just as intensively at dozens of separate and uncoordinated efforts. More tests, more procedures may extend a life. One more attempt to manage care, to regulate or redefine a benefit will reduce total expenditures.

These observations neither deny the advances of biomedicine or the many efforts for cost containment, but they do beg the question of where and how, or IF, we can design a system we can live with and manage.

Pluralism is thought by many to be its own beneficent reward. If this is the case, a few facts illustrate the reward for health financing in our private and public sectors. Consider the following:

Central to pluralism is free choice of physician, an ideal devoutly defended by patients and doctors. Patients searching for cures from the family doctor to the subspecialist, stimulated by doctors, are a significant factor to unnecessary spending.

Private insurance is another product of pluralism which generates inflationary costs -- with a multitude of custom-designed benefit packages tied to tailored premiums, duplication, discounts, exclusions, deductibles, co-insurance, waiting periods, and waivers.

The financing system is tightly ensnared in a web of particularism -- pluralism at its worst. The ability of special interests to stymie change by courting congressional patrons is a familiar story. We have, in large measure, taken health policy decisions out of the politics of democracy. We have substituted the politics of professional experts for the representative responsibility of elected officials. But the professionals have defaulted on their right to the claim that they can organize and finance health care in the public interest. Meaningful change, if it is to occur, must find a path through or around the multiple ranks of skillfully protected scientific, professional, and political barricades, each erected in the name of quality, service, cost control, or the interest of the people. The pluralism we have deified threatens to smite us. Pluralism in health care cannot guarantee equitable access, or cost control. It can only provide comprehensive care, American style, if the payers have well paid regular employment and tax relief.

The pluralistic remedies that we have become dependent on require critical reexamination, particularly managed care, competition, and elaborate cost shifting mechanisms.

The efficient delivery of useful care must be developed and refined in any health care system. The application of managed care -- based on outcomes research -- is the latest fashion for cost control, but it functions in a best to worst range. Managed care as a euphemism for claims control saves only sporadic dollars in sporadic settings. At best, it is an adjunct to financing -- not a solution in itself, either for cost or for quality care. Its cost control features derive from the orthodoxy of casualty insurance. Insurance should be recognized for what it is: a mechanism for financial protection against large economic losses that can be clearly defined. The industry itself historically recognized that its requirements did not match the needs of health financing, but we have forced health care itself into the insurance framework. Underwriting, risk assessment, definitions of specificity, claims and claims control are not a health care system.

Outcomes researchers proceed on the belief that it is possible to control the emotional and scientific decisions for

The 193 million individuals seeking service each year for thousands of different diagnoses from more than half a million different physicians and for the twenty-three million people who have thirty million hospital admissions and receive about 220 million days of hospital care.

We would like to believe and some pretend we are receiving and paying for objective weights and measures all neatly catalogued in a scientific document.

Mathematical models as a measuring rod for human behavior are not a new inspiration. Formulas provide the basis for precision, speculation, and some insight into human affairs. Even so, a quantifiable mould into which we can confidently pour the billions of transactions between patients and doctors will be truly a marvel.

We will ignore at our peril the fact that a clinical judgement, the advice of "my doctor", is not the same as a review panel that denies payment of a bill. A patient will nearly always have a different judgement than a cost-benefit analysis.

"There is something fascinating about science," Mark Twain observed. "One gets such wholesome returns of conjecture out of such a trifling investment of fact."

It is extraordinary that the experience of the Kaiser Permanente program and other prepaid, direct service medical group practice plans have been the stimulus for so many cost-saving innovations.

But there has been and continues to be a tragic flaw of oversimplification. Health care demand can be predicted with acceptable certainty in a population of 60,000 or more persons of known age and sex. The facilities, personnel, equipment, and cost required to meet that demand can be projected with equal accuracy. But the differences beg to be recognized: an organized health care program is not casualty insurance, or contracts with multiple independent groups of providers.

There have been high hopes for cost restraint in the competitive mix of these differing arrangements, but health care delivery eludes market competition. Health service is one part hope and fear, and one part the application of science by one human being to another human being. It is further stimulated by research and an industry based on providing exotic services and products which compete over improvement and sophistication, not price. Nor is such an environment conducive to financial access to care.

"Your health or your money?", "Your life or your money?" do not contain the seeds of a market. Most of us will not ask, "How much?" We are more inclined to plead, "Is this enough?" This is especially true when the treasure we push onto the counter has no meaningful direct financial consequence and little personal accountability.

Cost shifting, outcomes research, managed care, competition, and public-private financing all have laudatory objectives. Cost efficiencies ought to be pursued, but they have no demonstrated capacity in their present forms to assure access or to decelerate total cost increases. Dollars saved by IBM or General Motors will not automatically be available for coverage for the uninsured. To reward companies that reduce costs by taxing away their savings to pay for another group in the population will scarcely appeal to business, labor, or stockholders. Medicare savings cannot be shifted to Medicaid beneficiaries. Legislatively mandated employer benefits will have to compete with wages for the marginally employed. A reduction in the rate of increase in hospital costs did not reduce total spending. It will be interesting to see if hospital costs decrease by at least a quarter when those who are not insured become insured, and it is no longer necessary to shift their cost to those who pay.

Shifting the burden to the user through deductibles and co-insurance may restrain a few abusers of care, but misses the mark and may deny some necessary care. Fewer than one in ten people use the hospital in a year; one in four use no care. Restraint on the wide availability of costly technology will not occur with a tax on use. A tax on availability appears more appropriate.

The largest identified savings are in hospital budgets and doctors' offices -- where the highest costs for personnel, equipment, technology, and administration are generated. Savings from these sources, however, will not automatically or easily be returned to the payers. They can only be consistently and dependably saved in a single-payer system that is responsible and accountable.

The cost of care in the United States is increasingly compared to the cost in Canada. It is a serious error to assume that this country can have health care spending like Canada UNLESS:

I. The widespread availability and duplication of science and technology are sharply curtailed, and people are prepared to wait sometimes and do without some of the possible.

II. The current ratio of family doctors to specialists and subspecialists can be radically altered (51% of all doctors in Canada, are family doctors compared to 13% in the U.S.)

III. An unchallenged role for government authority and accountability can be established within a unitary financing system.

IV. Annual global budgets can be negotiated with hospitals.

V. An acceptable physician payment system can be negotiated.

VI. Extra billing for covered public benefits and private insurance which duplicates public benefits are prohibited, as in Canada.

It must be observed that the Canadians have achieved equity, but the cost control lid is uneasy on the pot of comprehensiveness.

In contrast, U.S. government rules are centered around requirements imposed in exchange for public money in fragmented attempts to control public spending. There is a crucial principle to keep in mind: if you cede to government explicit authority,

you can debate that authority; but if you live in a time, as we do, in which government intervention is required but authority is undefined, you end up with a tyranny of rules and no discernable accountability.

Federal and state governments have nevertheless intruded and been invited into the delivery of care, paying most of the cost of biomedical research, professional education, and the cost of facilities. The public now pays nearly half of the direct cost of care and if the tax subsidy is included, the share is more than half. Government will by one device or another bail out the corporate liability for retirees and provide care for the uninsured and underinsured. This will put government directly and indirectly in the position of financing the overwhelming share of the cost.

A greater federal role is inevitable; it is only a matter of time and the nature of its authority. It can assume the obligation of financing in increments, or in one draconian movement.

There are those who advocate the expansion or some variation of Medicaid.

Fewer than half of the current population qualified for Medicaid actually achieve eligibility. Any public program that provides insurance for the people who fall out of and through the cracks of private insurance will have eligibility requirements, whether based on income or other factors. The requirements will expand and contract with the public purse. In the face of that fact, it is unclear what social goal will be accomplished by adding thirty to fifty million uninsured and underinsured to Medicaid -- or to any public program designed to fill the voids of private insurance.

In the end, as we shift more of our burden to government, in splintered pieces or through national health insurance, the limits of public funding will become painfully obvious. Over time a nation cannot spend more than it produces. Our grandchildren will learn that at their cost. Health care will inevitably be capped by government spending limits and if we are not diligent, they will be inadequate limits, eroded by inflation. Economic growth, if it occurs, will help -- but it is a fantasy to believe that any modern economy can grow at a pace that will sustain buying health care on an open-ended, cost-plus basis.

This country appears destined to declare itself. Basic health care will be provided for one third of the population directly from the public purse. The definition of basic will fluctuate with the rise and fall of government revenue, deficits, and the country's tax mood. Two thirds of the nation will enjoy comprehensive health insurance paid for by employers, the cost passed to the consumer, subsidized by federal tax relief. We will name it comprehensive and call it equitable.

Legislated equitable comprehensive care for all with no significant increase in taxes or premiums also requires critical examination. The nation made a similar pledge to the elderly and the poor in 1965.

Government can, indeed it would seem it has an obligation to establish the amount of money that it will commit to health care. Government also should be compelled to state in clear terms whether health care is a right and, if so, assure equitable access to public money.

The potential for national health insurance in terms of equity, efficiency, and cost constraint depends entirely on its form and scope.

There is danger of both rigidity and mediocrity in a monolithic national system, but diverse approaches without clear boundaries and accountability present an equal peril.

At a minimum, government must insure that the innovations of pluralism do not exceed the public interest and must understand the differences between proscriptive, detailed rules and setting limits.

A universal national health insurance plan must recognize certain basic principles:

I. The driving forces in the cost of personal health care are hope, expectation, and need -- expressed as demand within the scientific, technological, and economic capacity of a country. Doctors and hospitals are but handmaidens.

II. The cost to society of applying all the scientific and technological output of a country to the human search for health and fear of dying cannot be sustained. Financing the private hope for health with public funds and little or no clear individual economic consequence is a dubious proposition.

III. Health care providers and patients have an infinite capacity to splinter services into multiple bills that increase total costs -- and to define symptoms and diseases so that the bill will be paid.

IV. To select the individuals or diseases to receive care, or treatments to be provided on a case-by-case basis is not compatible with elected government.

V. A democratic society requires equity in the use of public funds.

VI. Pluralistic health care delivery and pluralistic financing perceived as a free good fed with direct and indirect public money is too diffuse to be reformed, or its cost contained.

Recognition of these principles suggests the following plan:

I. Congress would establish the percent of the GNP that will be spent from public funds, directly and indirectly on personal health care. It must be expressed as a percent to require health care to live within general inflation and insure a constant share of the national output. After-tax dollars would be spent on an individual basis, as they are for other goods and services.

II. All existing programs--Medicare, Medicaid, Champus, the Veterans Administration, before-tax employer/employee purchased

insurance and tax deductions for medical expense--would be abolished.

III. The federal role would be limited to (1) setting the limits of the percent of GNP to be spent from the public treasury, (2) establishing a uniform level of benefits for every citizen, (3) collecting the money, and (4) assuring portability of coverage across state lines.

IV. Each tax payer would be required to pay a percent of the annual per capita cost of personal health care through payroll deduction or a quarterly tax, in a range of twenty-five percent of annual per capita cost for those whose gross income exceeds $100,000, to zero for those whose income is at or below the poverty line. A family health care tax would be capped at 5% of gross income.

This is not a revenue proposal. It has two purposes: one, to require the politically articulate to pay enough to insure their support of the long term quality of the public service; two, to place a tax on the demand for availability, not on utilization.

The balance of funding would come from the general revenue. All funds would come from the federal government to assure national equity of benefits.

V. The plan would be administered on a state basis, through a state agency, or a state appointed not-for-profit organization. It would be the obligation of the state to arrange and pay for the federally mandated benefits within age and sex-adjusted capitation payments from the federal government, and to assure access and quality of care.

VI. Extra billing by all providers and private insurance for the covered public services would be prohibited.

Such an approach will not be a panacea for every financing problem (nor can any arrangement offer such perfection). What this approach does offer is an important range of potential:

I. spending limits determined by a percent of national productivity;

II. self-evident, universal, personal financial accountability through a progressive health care tax for
   a. the cost of having the latest biomedical resources available, and
   b. for the demand for service;

III. an equitable share of public spending for every citizen;

IV. a limited and defined role for the federal government;

V. the opportunity to consolidate the administrative maze of multiple payers, plans, benefits, rules, and costs;

VI. a return of the patient-doctor relationship and decision making to doctors and patients within socially determined limits;

VII. the encouragement for states to design the most efficient method of paying for care within spending limits;

VIII. and finally, the opportunity for both federal and state government to demonstrate credibility for responsible governance in the public interest.

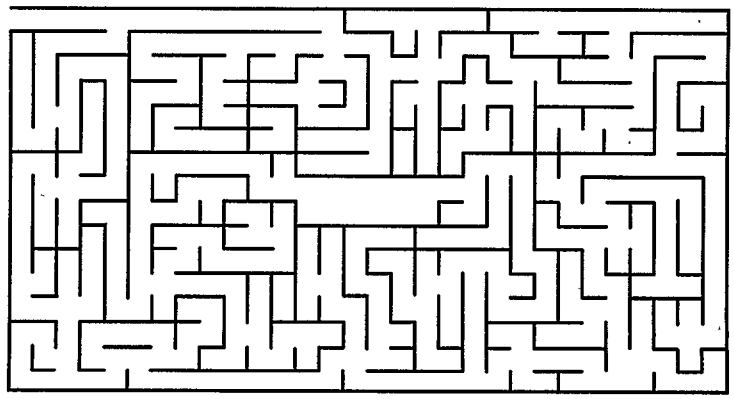
The nation's pragmatic concoction for financing health care is without a guidance system, to our current dismay. If it is to be any other way, there is a price to be paid for change. Who will pay it --- and how much --- are yet to be determined.

The nation ought to be in search of a system with the equity of national health insurance, the flexibility of pluralism, and with personal and social fiscal discipline.

The present debate is primarily a social issue that can only be solved politically --- it is only secondarily an economic puzzle -- and its resolution will reflect our ability to understand that balance.

Session U

Desktop Statistics CD-ROM



DEVELOPING THE USER INTERFACE FOR CD-ROM

Susan Feinberg, Ph.D., Illinois Institute of Technology

For the past two years, an NCHS development team from the Division of Data Services has been working to develop a program to release NCHS data on CD-ROMs. This project was the idea of Phillip R. Beattie, Director of the Division of Data Services. The project team was headed by Robert Sloss, who was responsible for software development. Members of the team included David Johnson from the Division of Vital Statistics, Marie Leahy and Kay Brown from Data Services, and myself as a consultant for technical documentation.

The survey is a principal source of information on the health of the population of the U.S. These data were made available on a CD-ROM because it is compact but has the luxury of space to store an enormous amount of data. The 1987 HIS CD-ROM contains nine data files with over 300,000 encoded records as well as documentation, help information, and search software called SETS. SETS stands for Statistical Export and Tabulation System. This CD-ROM is the first in a series of ROMs that NCHS will produce.

This CD-ROM is inexpensive to use because studies that once took almost $2,000 worth of computer tapes and a mainframe computer can now be performed with just one $13.00 CD-ROM, a ROM reader, and a PC. Because of its efficiency and cost-effectiveness, the CD-ROM will be used by people who have little experience with the HIS survey and search programs or with the mainframe computer. These users need a variety of interfaces to help them retrieve the data. An interface is an aid that helps people perform complex tasks.

The goal of the CD-ROM development team was to provide users with a tool to do research that was once done with the help of a mainframe computer and associated computer personnel. Before the final version of the 1987 HIS CD-ROM was distributed, an abbreviated CD-ROM was beta tested. This talk presents some of the information obtained from the beta test, findings that focus on developing the user interfaces. As our findings from the beta test indicate, users benefit from five different interfaces that can be used in any sequence and with any frequency.

What are these interfaces? They are paper documentation, on-line reference documents, help screens, dialogue boxes and pop-up boxes, and simultaneous translation of values and codes. The following figures illustrate these five different interfaces on the 1987 NHIS CD-ROM and on the 1987 Underlying and Multiple Cause of Death One in One Thousand record sample, a release that is presently being demonstrated at this conference and will be released as a CD-ROM later this year.

The interfaces and the program will be the standard for the family of CD-ROMs that NCHS will produce over the years. When users are familiar with the program and interfaces on one NCHS CD-ROM, they will be familiar with all the NCHS CD-ROMs.

Paper documentation. The paper documentation distributed with the CD-ROM consisted of approximately 700 words and two graphics. The advantage of paper documentation is that it can provide the user with the large picture.

It tells the user how to load the CD into the reader, install the program on the hard drive, and create a table. We had great success with this user interface because the paper documentation used cookbook instructions to help users complete the task and provided a graphic so that users could verify their procedure.

Figure 1 illustrates the paper documentation distributed in the jewel box with the CD-ROM.

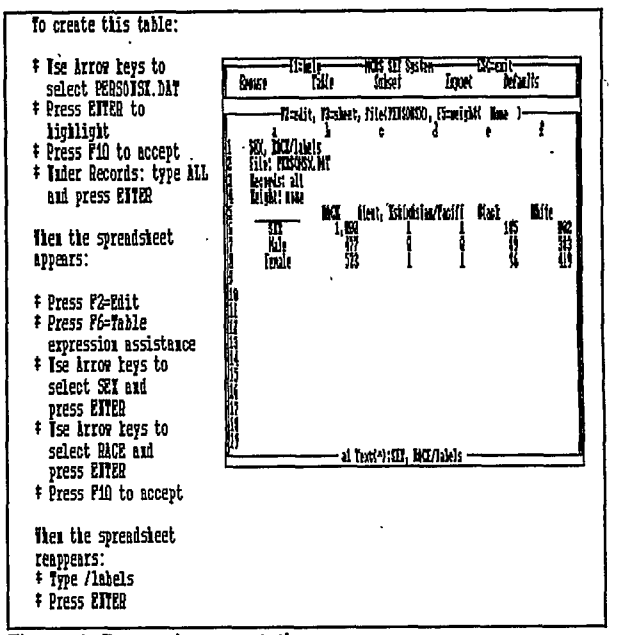


Figure 1. Paper documentation.

Users could also see that the table would appear in a spreadsheet format, a format familiar to many users. So paper documentation is still an important part of the user interface.

Paper documentation can display the large picture on pages that do not scroll and disappear with important information. But, the documentation and reference material for the survey and the search program would consist of over nine inches of paper. Nine inches of paper documentation overwhelms even the persistent user. So, the nine inches of reference material was stored on-line on the CD-ROM.

On-line reference documents. The documentation stored on the CD-ROM includes the record layout for the original data tape, the reference manual, source information, and reports. So that the user can access the 9 inches of information quickly, the program software provided a text search capability. Figure 2 illustrates the text search capability.

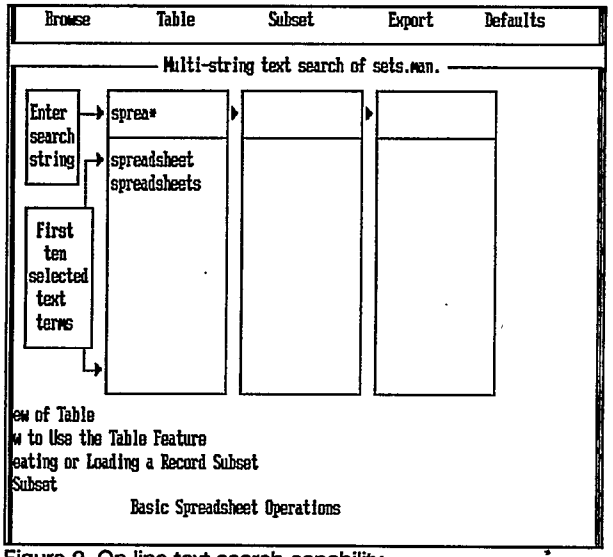


Figure 2. On-line text-search capability

The user can type a search string to locate information quickly. As the user types the word or words, the SETS software simultaneously searches for all occurrences of the word and allows the user to browse the documentation at each occurrence of the word. The user can also print the information.

On-line documentation has no disadvantages on a CD-ROM because of the enormous storage capacity and because the user can print out any inch or all nine inches of documentation. But most users browse very little of the on-line documentation at any one time. They want to begin using the CD-ROM for the retrieval of data.

Help screens. F1=help is available for every software screen, offering instructions, tips, and warnings to infrequent or novice users as well as tips for expert users to save them time. Figure 3 illustrates a context-sensitive help screen.

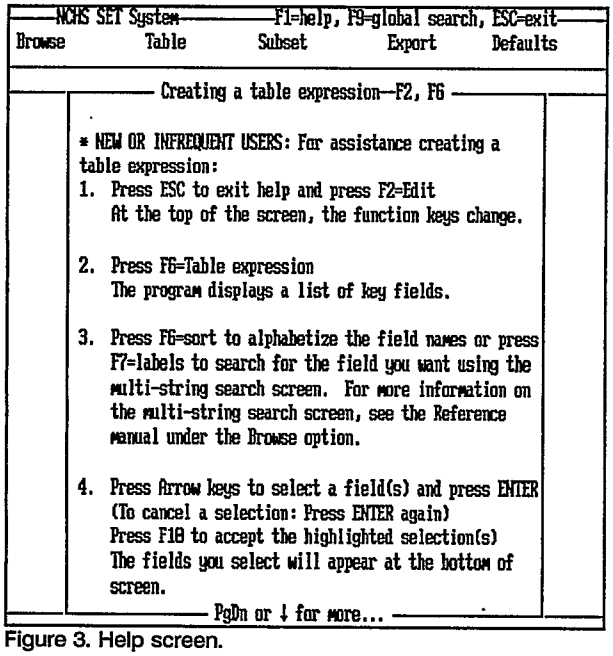


Figure 3. Help screen.

Context-sensitive means that behind every program screen is a help screen with pertinent information and instructions for that program screen. The help screens are an interface that help the user, especially new users, successfully complete tasks by providing timely information.

Dialogue boxes and pop-up boxes. The dialogue boxes and pop-up boxes ask users questions and allow users to specify a response. They are very valuable user interfaces for the broad spectrum of users who are learning how to use their PC for research. These users need to know how to select data from a large file and narrow the selection by generating a boolean expression. Users with spreadsheet or mainframe experience have little difficulty retrieving the data on their PC using the CD-ROM and do not need to use these pop-up boxes as aids.

Figure 4 illustrates a pop-up screen that helps the user write a boolean expression. For example, when the user wants to know: How many men between the ages of 25-34 died in New York in 1987? (this example uses the 1987 Underlying and Multiple Cause of Death One in One Thousand record sample), the user has to type a boolean expression or use the dialogue boxes to create a boolean expression.

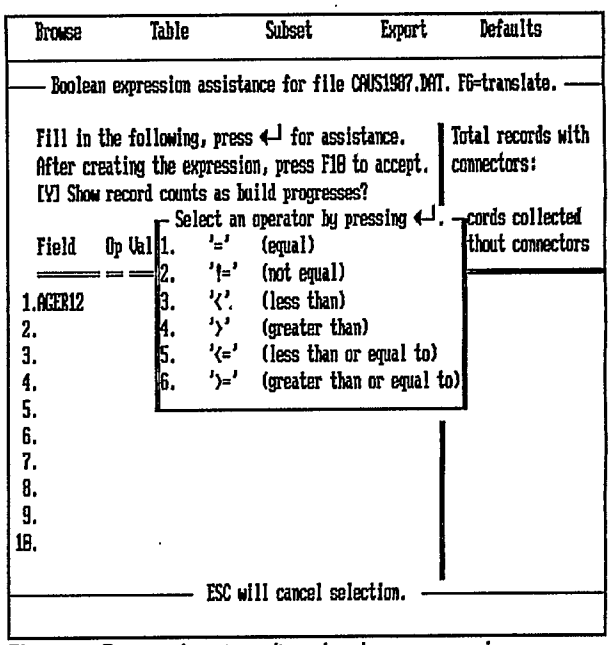


Figure 4. Pop-up box to write a boolean expression.

Other dialogue boxes offer the user such useful features as 10 options for displaying a table, including outputing the table display to a Lotus file. When the user becomes more experienced, the user doesn't have to use the pop-up boxes but can type the query immediately.

Simultaneous translation of codes and values. Within a complex data retrieval program, simultaneous translation of codes and values provides users with information users can't be expected to remember. For example, what are the options for ager12? Thus, simultaneous translation is an extremely

important interface. As the user places the cursor on the value, the software program simultaneously translates the value at the bottom of the screen.

Figure 5 illustrates the entire boolean expression that the pop-up box helps the user create. The software program simultaneously displays the number of records collected as the program retrieves the data.

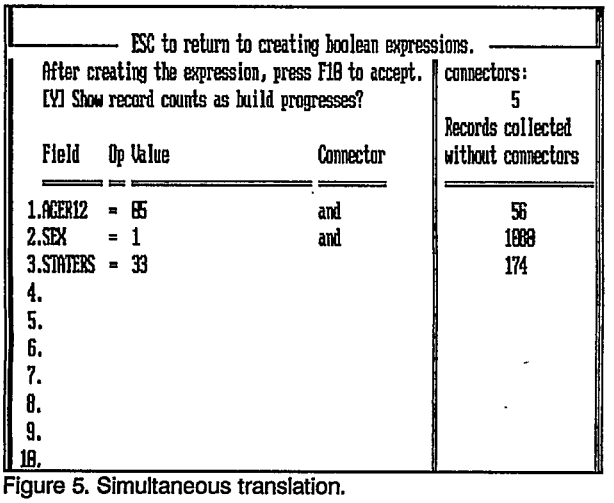


Figure 5. Simultaneous translation.

Remember that this example is only a sample of one in one thousand records; thus, only 5 records meet the criteria of the boolean expression.

The user can also use the function key, F6=translate, to decode the boolean expression, a useful translation if the user saves this record subset for later examination but cannot remember what the codes such as STATERS=33 meant.

Simultaneous translation also helps the user examine a single record. The record is encoded with data tape position and values. The software program automatically and simultaneously decodes (translates) the codes and values at the top of the screen and repeats the query expression at the bottom of the screen. Translation boxes at the top and bottom of the screen are an interface standard. Finally, the program also provides a gauge to tell users how far along the program is in completing a task. The user can decide if the search will take too long or if the search should be narrowed.

Help screens, dialogue boxes and pop-up boxes, and simultaneous translation of information on the display screen are interfaces limited to providing information on the currently displayed screens. These interfaces provide a tunnel vision rather than explaining the place of the displayed screen in the large picture of program manipulation. The paper documentation and on-line reference material is helpful when the user needs to see the whole picture, such as 1) what a table of data looks like and how to create it and 2) where the data came from, for example, the national health survey that was encoded for statistical purposes. To access the on-line reference material, the user selects the global search capability.

In conclusion, as a result of our beta testing, we discovered that users needed a variety of interfaces. So we developed five user interfaces that are the standard for the family of NCHS CD-ROMs. Furthermore, we discovered that improving and increasing the number of user interfaces is a continual process, improvements we have implemented in the soon-to-be-released 1987 Underlying and Multiple Cause of Death CD-ROM. Because the technology for future CD-ROMs offers graphical interfaces, multi-tasking in a windows environment, and smarter software programs, we expect to continually improve the interfaces to help users use NCHS CD-ROMs for desk top statistics. Eventually, we hope to offer states a SETS builder kit so that states can build their own CD-ROMs or databases.

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ANALYSIS OF LOCAL DATA FROM THE NHIS USING THE PERSONAL COMPUTER

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INTRODUCTION

This report describes the experience of the Medical and Health Research Association and the United Hospital Fund in using a personal computer for the analysis of NHIS datasets. The two organizations, MHRA and UHF, had already made extensive use of these datasets in earlier research using SPSS software with an IBM mainframe and our current experience provides a contrast between the two methods.

The conceptual framework we operated within was simple. We wished to perform statistical analysis of local NHIS data on a PC. We also wished to utilize readily available, reliable, well known hardware and software.

In both the earlier and current research efforts the local datasets were obtained by sorting the national NHIS datasets to extract local datasets for New York City. NYC is a Primary Sampling Unit of the NHIS, one of 31 areas in which the sample is self representing, with an annual sample size of about 3,000 persons.

In 1990 the Robert Wood Johnson Foundation provided grant support for an analysis of trends in health and health care of all New Yorkers for the eleven years from 1979 through 1989. This new grant expanded the required size of the data base considerably beyond that of previous work, with a sample size for the eleven year dataset of about 35,000 records.

THE DECISION TO USE PERSONAL COMPUTERS

Soon after the grant was received it was recognized that advances in the speed, memory, and storage capacity of the PC made it competitive with the mainframe for this purpose. In spite of our earlier experience with the mainframe, a number of potential avantages to the use of the PC were seen.

1. Statistical analysis more readily controlled by the project staff through the more informal and interactive approach permissible through the PC. In addition, queuing was expected to be minimized.

2. The distribution on a test basis by NCHS of the 1987 NHIS data written to a CD-ROM, with the encouragement of researchers to use the PC for analysis of NHIS data.

3. The potential for standardization of analysis by the use of standard statistical packages (SPSS, SAS, etc.).

4. The ease of converting mainframe programs to PC programs for this software.

5. The ease of transfer and exchange among PC users of programs written with standard software for NHIS data.

At about the time we were making the decision to use a PC, advances in mainframe and network architecture design threatened to reduce the competitive advantage of the PC for small to midsized computational tasks. However, at about this time also, the development of true multitasking and pseudo multitasking operating systems tended to maintain the advantage of the PC for this sort of computational work. We kept to our initial decision to use a PC. Moreover, we wished to show feasibility with a standard operating system (DOS 4.0) at the current state of PC development (486/25).

METHODS

Hardware and Software used -- The project employed a Gateway 2000 with a 486/25 microprocessor, a hard disk capacity of 200 MB, and 8 MB of RAM. The machine was delivered in December, 1990 for the study, "Trends in health and health care in New York City". It was affordable within the available budget, and met most of the needs for storage and speed anticipated for the project. A HP LaserJet III printer was purchased at the same time. The total coast was about $6,000. Data analysis began within one month of delivery and was completed within six months.

We have run direct comparisons of the computational speed of the Gateway 486/25 only against a NEC 286/12. For simple SPSS V3.0 routines with standard system configurations, we found that overall speed was increased about tenfold. This is what might naively be expected from the relative speeds of the microprocessors, the caching, and the hard drive. More advanced SPSS applications, particularly with custom system configurations, achieve even greater speedups. These configurations are still under development and have not yet been operationalized.

SPSS was chosen as the statistical software for the project in part because it is widely available and widely used and in part because it had already been used for previous mainframe work and was

familiar to project staff. Moreover, the earlier use of SPSS on an IBM mainframe offered the potential for maintaining some SPSS variable transformations intact. To a large extent, SAS offered similar advantages and was also available on the IBM mainframe used previously, but we had no experience with it. SUDAAN 5.4 was purchased, in anticipation of dealing with statistical sampling issues, but has not yet been used.

Sorting data and converting data from tapes to diskettes -- As currently supplied by NCHS, the NHIS datasets are written to 10½ inch diameter, nine track reel tapes. The tape is ½ inch wide and a nine bit word is recorded lengthwise using the nine tracks, one bit per track, odd parity. The coding is EBCDIC and the format is IBM Standard Label (SL). This format utilizes an 80 byte field at the beginning of the tape for a volume label. Individual files are preceded by an 80 byte header label and tape mark and followed by a tape mark and an 80 byte trailer label. Information stored in the header and trailer labels includes file name, record length and blocksize.

To utilize these datasets on a PC, however, the coding must be converted to ASCII and the files written either to floppy diskettes or directly to a PC hard drive. All header and trailer labels are lost.

A variety of hardware and software exists which will exchange data between these two environments and virtually all mainframe operations can perform this task easily at low cost. Commercial vendors can also perform the task. Charges vary considerably, but are typically somewhere in the range of $10 - $30 per MB. We utilized the Data Processing Facility at NY Medical College.

Sorting the datasets to obtain a defined sample can be done either prior to or following the data conversion process. We sorted first, using the following procedure. The New York data were first sorted on the CUNY/UCC IBM mainframe using the standard utility, SYNCSORT. The sorted files were written to new Standard Labelled tapes in EBCDIC. For reasons of data integrity, the original NCHS/NHIS tapes were used entirely in a read only mode. The tapes containing sorted datasets were also standard labelled, but further labelled 'read only' to maintain data integrity. Only the local datasets were converted to ASCII and written to diskettes. This was done simply by creating a DOS BACKUP file. The usual DOS RESTORE command was used to write the datasets to the hard drive. No additional software was used. The DOS VERIFY toggle was switched ON throughout and the accuracy of the file being transfered was automatically checked during transfer. Again, no additional software was used. Subsequent file comparisons indicated no errors in writing ASCII files to the hard drive.

The procedure of sorting first on the mainframe was adopted primarily because of the large size of the full (national) NCHS/NHIS datasets. The NHIS PERSON file, for instance, for a typical year, contains on the order of 125,000 records of about 335 bytes each, or, about 42 MB of data. Thus 11 years of the national PERSON file alone contains about 460 MB of data. Performing the New York City sort reduces this to about 3% of the original, i.e., about 14 MB of data for the 11 years. This is well within the capacity of most hard drives, whereas the national datasets would probably exceed the capacity of most hard drives for the datasets alone, prior to writing any other statistical files. The NHIS PERSON file is the largest of the NHIS datasets. The remaining datasets, the HOUSEHOLD, CONDITION, HOSPITAL, and DOCTOR VISIT files are considerably smaller. Nevertheless, typically, the total size of all the NHIS datasets is about 2½ times that of the PERSON file, i.e., about 35 MB for the 11 years of data for NYC.

If we define a standard urban population unit of one million, we obtain some useful estimates of dataset sizes (Table 1.).

Table 1. Sorted dataset sizes for a standardized urban unit of one million population for one year of data and eleven years of data.

File Type	1 Year	11 Years
Person	163KB	1.80MB
Dr. Visit	33KB	3680KB
Hospital	19KB	206KB
Household	67KB	737KB
Condition	118KB	1.30MB
Total	400KB	4.41MB

ANALYSIS OF NHIS DATA

To date, all data analysis has been performed using SPSS/PC+ in V3.0 or V3.1 depending upon the application. This choice was made in part because it was available and in part because some previous work had been performed using this version of the software.

For the statistical application procedures used in this stage of the project, several approaches to the

question of overall program architecture were considered, largely empirically, with attention to the following.

1. Defining the dataset Processing Quarter and Processing Year as true statistical variables.

2. Ease of working with datasets for single Processing Years.

3. Ease of working with lumped datasets in which several Processing Years were combined.

4. Ease of introducing new variables (transformations on existing variables) and of adding subsequent new variable transformations to existing SPSS system files.

5. Speed of executing application procedure.

In general, we found that the commonly used SPSS approach of creating large system files which included several processing years and most variable transformations proved most efficient. Specific application procedures were then run from the system files thereby created.

The programs which write the system files ('system' programs) typically involve a time scale on the order of hours to execute depending upon the size of the dataset and the number of variable transformations involved. A sample 'system' program for one processing year is shown in Figure 1. However, once the system files are written, 'procedure' programs, which employ SPSS statistical procedure commands are used to generate statistical output. These programs are typically short, easy to write, and run in time scales on the order of minutes. These programs typically write output to an SPSS listing file which can then be examined or printed at any time. Because of the ease of writing and executing such SPSS 'procedure' programs we tended to keep them short and limited in scope. A sample is shown in Figure 2.

As a consequence of this programming style, we were able to work in a highly interactive mode relative to the output. The output for each run was typically fairly small and could be easily examined and new or modified procedures identified and then run, often in a matter of minutes. This interactive mode of working with data and output would be still be quite difficult to achieve on most mainframe operations today since some queuing still tends to be present.

In the early stages of this work, largely because of previous approaches to these datasets, we typically combined datasets into two and three year groups and wrote system files for these combined year groups. However, in later stages, we created several large system files for the entire 11 years of data containing large subsets of the processing variables. For these system files Processing Year and Processing Quarter were true statistical variables. 'Procedure' programs could then be written and executed in which statistics (means, etc.) could easily be computed as a function of Processing Year or Processing Quarter.

CONCLUSIONS

There is little doubt that the substitution of the personal computer for the mainframe for the analysis of NHIS datasets resulted in more rapid and more thoroughly considered data analysis of the NHIS data for New York City. The increased speed of newer machines removes most of the advantages offered heretofor by mainframes, while at the same time permitting increased interaction between staff at all levels. In particular, the ability to rapidly review preliminary output and define new runs, markedly decreased the time required in selecting and evaluating statistical methods of analysis and obtaining final statistical output.

Of particular importance, is the availability of standardized statistical packages, SPSS, SAS, STATSOFT, SUDAAN, etc. Because of the clear NHIS documentation provided by NCHS manuals, and data conversion readily available, such statistical software can easily and effectively analyze NHIS data, even as supplied in its present form on tape. The advent of this data on CD-ROM will enhance the process still further.

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early stage of the work. M. Krasner for critical comments and for reading the manuscript. S. Ritzel for performing many of the runs.

Figure 1. Sample SPSS 'System' Program.

```
set /listing='tr1wX89s.lis'.
dos del tr1wX89s.lis.
set /listing='tr1wX89s.lis' /screen=off
/printer=off /length=59 /width=narrow
/eject=on /include=on /echo=on /more=off
/viewlength=maximum /blanks=-1.
title 'program name: tr1wX89s.com'.
subtitle 'trends #1 weighted 1989'.

data list file '2089.dat' fixed /
                p003    003-004
                p025    025-025
                p027    027-028
                p043    043-043
                p046    046-047
                p058    058-059
                p064    064-064
                p065    065-066
                p070    070-070
                p098    098-099
                p100    100-101
                p108    108-110
                p111    111-111
                p112    112-114
                p115    115-115
                p120    120-121
                p122    122-123
                p124    124-126
                p127    127-128
                p129    129-131
                p219    219-227
                p291    291-299.

var labs        p003    'processing year'
                p025    'sex'
                p027    'age of respondent'
                p043    'race recode'
                p046    'hispanic origin'
                p058    'family income'
                p064    'family relationship recode'
                p065    'size of family'
                p070    'health status'
                p098    'restricted activity days 2 weeks'
                p100    'bed days 2 weeks'
                p108    'bed days 12 months'
                p111    'bed days 12 months recode'
                p112    'doctor visits in past 12 months'
                p115    'interval since last doctor visit'
                p120    'number two-week doctor visits'
                p122    'number short stay hospital episodes 12 mos'
                p124    'short stay hospital episode days 12 mos'
                p127    'number short stay hosp eps 12 mos ex del'
                p129    'number short stay hosp eps days 12 mos ex
                        del'
                p219    'final basic weight annual'
                p291    'estimated doctor visits 12 months'.

compute         p219r=p219/(1000).
formats         p219r (f8.3).
var labs        p219r 'weight recode'.

weight by p219r.

subtitle 'processing year'.
frequencies /variables p003 /histogram /barchart.

compute         age1=p027.
Formats         age1 (f1.0).
var labs        age1 'age mhra recode #1'.

if (p027<=4) age1=1.
if (p027>4 and p027<=17) age1=2.
if (p027>17 and p027<=29) age1=3.
if (p027>29 and p027<=44) age1=4.
if (p027>44 and p027<=64) age1=5.
if (p027>64 and p027<=74) age1=6.
if (p027>74 and p027<=99) age1=7.
val labs        age1    1 'less than 5 years'
                        2 '5 - 17 years'
                        3 '18 - 29 years'
                        4 '30 - 44 years'
                        5 '45 - 64 years'
                        6 '65 - 74 years'
                        7 '75 years and above'.

subtitle 'age1 distribution'.
frequencies /variables age1 /histogram /barchart.

compute         p058r=p058.
formats         p058r (f2.0).
var labs        p058r 'family income recode'.
recode          p058r (27 thru 99=sysmiss).

compute         piX89=99.
formats         piX89 (f2.0).
var labs        piX89 'poverty index'.
if (p058r<=5) piX89=1.
if (p065=01 and p058r<=5) piX89=1.
if (p065=02 and p058r<=7) piX89=1.
if (p065=03 and p058r<=9) piX89=1.
if (p065=04 and p058r<=12) piX89=1.
if (p065=05 and p058r<=14) piX89=1.
if (p065=06 and p058r<=16) piX89=1.
if (p065=07 and p058r<=18) piX89=1.
if (p065=08 and p058r<=19) piX89=1.
if (p065>=09 and p058r<=20) piX89=1.
if (p058r>5 and p058r<=12) piX89=2.
if (p065=01 and p058r>5 and p058r<=12) piX89=2.
if (p065=02 and p058r>7 and p058r<=15) piX89=2.
if (p065=03 and p058r>9 and p058r<=19) piX89=2.
if (p065=04 and p058r>12 and p058r<=20) piX89=2.
if (p065=05 and p058r>14 and p058r<=21) piX89=2.
if (p065=06 and p058r>16 and p058r<=22) piX89=2.
if (p065=07 and p058r>18 and p058r<=23) piX89=2.
if (p065=08 and p058r>19 and p058r<=24) piX89=2.
if (p065>=09 and p058r>20 and p058r<=25) piX89=2.
if (p065>=09 and p058r=26) piX89=5.
if (p058r>12 and p058r<=18) piX89=3.
if (p065=01 and p058r>12 and p058r<=18) piX89=3.
if (p065=02 and p058r>15 and p058r<=20) piX89=3.
if (p065=03 and p058r>19 and p058r<=21) piX89=3.
if (p065=04 and p058r>20 and p058r<=23) piX89=3.
if (p065=05 and p058r>21 and p058r<=24) piX89=3.
if (p065=06 and p058r>22 and p058r<=25) piX89=3.
if (p065=07 and p058r>23 and p058r<=25) piX89=3.
if (p065=08 and p058r>24 and p058r<=25) piX89=3.
if (p065>=06 and p065<=08 and p058r=26) piX89=6.
if (p058r>18) piX89=4.
if (p065=01 and p058r>18) piX89=4.
if (p065=02 and p058r>20) piX89=4.
if (p065=03 and p058r>21) piX89=4.
if (p065=04 and p058r>23) piX89=4.
if (p065=05 and p058r>24) piX89=4.
val labs        piX89   1 'poverty'
                        2 'near poverty'
                        3 'middle'
                        4 'upper'
                        5 'above 100% poverty'
                        6 'above 200% poverty'.
subtitle 'family income recode entire population 1989'.
frequencies /variables p058r /histogram /barchart.
subtitle 'poverty index entire population 1989'.
frequencies /variables piX89 /histogram /barchart.
compute         povin=piX89.
formats         povin (f1.0).
var labs        povin 'poverty index'.
```

```
recode          povin (1=1) (2=2) (3=3) (4=4) (5=5) (6=6)
                (else=sysmis).
val labs        povin   1 'poverty'
                        2 'near poverty'
                        3 'middle'
                        4 'upper'
                        5 'above 100% poverty'
                        6 'above 200% poverty'.
val labs        p070    1 'excellent'
                        2 'very good'
                        3 'good'
                        4 'fair'
                        5 'poor'
                        6 'unknown'.
compute         hs1=p070.
formats         hs1 (f1.0).
var labs        hs1 'health status recode #1'.
recode          hs1 (1=1) (2=2) (3=3) (4=4) (5=4) (else=sysmis).
val labs        hs1     1 'excellent'
                        2 'very good'
                        3 'good'
                        4 'fair/poor'.
var labs        p046 'hispanic origin'.
val labs        p046    00 'multiple hispanic'
                        01 'puerto rican'
                        02 'cuban'
                        03 'mexican-mexicano'
                        04 'mexican-american'
                        05 'chicano'
                        06 'other latin american'
                        07 'other spanish'
                        08 'spanish, dk type'
                        09 'unknown if spanish origin'
                        10 'not spanish origin'.
compute         p046r   =p046.
formats         p046r   (f2.0).
var labs        p046r   'hispanic origin recode'.
recode          p046r   (00=00)  (01=01)  (02=02)  (03=03)
                (04=04)  (05=05)  (06=06)  (07=07)
                (08=08) (09=09) (10=10) (else=sysmis).
value labels    p046r   00 'multiple hispanic'
                        01 'puerto rican'
                        02 'cuban'
                        03 'mexican-mexicano'
                        04 'mexican-american'
                        05 'chicano'
                        06 'other latin american'
                        07 'other spanish'
                        08 'spanish, dk type'
                        09 'unknown if spanish origin'
                        10 'not spanish origin'.
compute         eth1=1.
Formats         eth1 (f1.0).
var labs        eth1 'ethnic origin mhra recode #1'.
if (p043=1 and (p046r=9 or p046r=10)) eth1=1.
if (p043=2 and (p046r=9 or p046r=10)) eth1=2.
if (p043=3 and (p046r=9 or p046r=10)) eth1=1.
if (p046r=0 or p046r=1 or p046r=2 or p046r=3
or p046r=4 or p046r=5 or p046r=6
or p046r=7 or p046r=8) eth1=3.
val labs        eth1    1 'white'
                        2 'black'
                        3 'hispanic'.
compute         eth2=1.
Formats         eth2 (f1.0).
var labs        eth2 'ethnic origin mhra recode #2'.
if (p043=1 and (p046r=10)) eth2=1.
if (p043=1 and (p046r=09)) eth2=5.
if (p043=2 and (p046r=10)) eth2=2.
if (p043=2 and (p046r=09)) eth2=5.
if (p043=3 and (p046r=10)) eth2=4.
if (p043=3 and (p046r=09)) eth2=5.
if (p046r=0 or p046r=1 or p046r=2 or p046r=3
or p046r=4 or p046r=5 or p046r=6
or p046r=7 or p046r=8) eth2=3.
val labs        eth2    1 'white'
                        2 'black'
                        3 'hispanic'
                        4 'other'
                        5 'unknown'.
compute         rad2w   =p098.
formats         rad2w   (f2.0).
var labs        rad2w   '2 wk rest act. days recode'.
recode          rad2w   (15 thru 99=sysmis).
compute         rad2wt  =rad2w.
formats         rad2wt  (f1.0).
var labels      rad2wt  'rest. act. days in past 2 weeks truncated'.
recode          rad2wt  (00=0) (01=1) (02=2) (03 thru 14=3)
                (else=sysmis).
val labs        rad2wt  0 'none'
                        1 'one'
                        2 'two'
                        3 'three or more'.
compute         bed2w   =p100.
formats         bed2w   (f2.0).
var labs        bed2w   '2 wk bed days recode'.
recode          bed2w   (15 thru 99=sysmis).
compute         bed2wt  =bed2w.
formats         bed2wt  (f1.0).
var labs        bed2wt  'bed days in past 2 weeks truncated'.
recode          bed2wt  (00=0) (01=1) (02=2) (03 thru 14=3)
                (else=sysmis).
val labs        bed2wt  0 'none'
                        1 'one'
                        2 'two'
                        3 'three or more'.
compute         bed12   =p108.
formats         bed12   (f3.0).
var labs        bed12   'bed days in past 12 months'.
recode          bed12   (366 thru 999=sysmis).
compute         bed12t  =bed12.
formats         bed12t  (f1.0).
var labs        bed12t  'bed days in past 12 months truncated'.
recode          bed12t  (000=0)  (001=1)  (002=2)  (003  thru
                365=3) (else=sysmis).
val labs        bed12t  0 'none'
                        1 'one'
                        2 'two'
                        3 'three or more'.
compute         bed12r  =p111.
formats         bed12r  (f1.0).
var labs        bed12r  'bed days in past 12 months recode'.
recode          bed12r  (0=0)  (1=1)  (2=2)  (3=3)  (4=4)
                (else=sysmis).
val labs        bed12r  0 'none'
                        1 '1 - 7 days'
                        2 '8 - 30 days'
                        3 '31 - 180 days'
                        4 '181 - 365 days'.
compute         md12    =p112.
formats         md12    (f3.0).
var labs        md12    'dr visits in past 12 month recode'.
recode          md12    (998 thru 999=sysmis).
compute         md12t   =md12.
formats         md12t   (f1.0).
var labs        md12t   'dr visits in past 12 months truncated'.
recode          md12t   (000=0)  (001=1)  (002=2)  (003  thru
                365=3) (else=sysmis).
val labs        md12t   0 'none'
                        1 'one'
                        2 'two'
                        3 'three or more'.
val labs        p115    0 'never'
                        1 'less than one year'
                        2 '1 to less than two years'
                        3 '2 to less than five years'
                        4 '5 years or more'
                        5 'unknown'.
compute         ilv1    =p115.
formats         ilv1    (f1.0).
var labs        ilv1    'interval last dr visit recode'.
recode          ilv1    (1=1) (2=2) (3=3) (4=4) (else=sysmis).
```

```
val labs      ilv1    1 'less than one year'
                      2 '1 to less than 2 years'
                      3 '2 to less than 5 years'
                      4 '5 years or more'.
compute       md2w    =p120.
formats       md2w    (f2.0).
var labs      md2w    '2 wk dr visits recode'.
recode        md2w    (15 thru 99=sysmis).
compute       md2wt   =md2w.
formats       md2wt   (f1.0).
var labs      md2wt   'dr visits in past 2 weeks truncated'.
recode        md2wt   (00=0) (01=1) (02=2) (03 thru 14=3)
                      (else=sysmis).
val labs      md2wt   0 'none'
                      1 'one'
                      2 'two'
                      3 'three or more'.
compute       sshe    =p122.
formats       sshe    (f2.0).
var labs      sshe    'short stay hosp eps 12 mos recode'.
recode        sshe    (98 thru 99=sysmis).
compute       sshet   =sshe.
formats       sshet   (f1.0).
var labs      sshet   'short stay hosp eps 12 mos truncated'.
recode        sshet   (00=0) (01=1) (02 thru 97=2)
                      (else=sysmis).
val labs      sshet   0 'none'
                      1 'one'
                      2 'two or more'.
compute       sshex   =p127.
formats       sshex   (f2.0).
var labs      sshex   'short stay hosp eps 12 mos ex del recode'.
recode        sshex   (98 thru 99=sysmis).
compute       sshext  =sshex.
formats       sshext  (f1.0).
var labs      sshext  'short stay hosp eps 12 mos ex del
                      truncated'.
recode        sshext  (00=0) (01=1) (02 thru 97=2)
                      (else=sysmis).
val labs      sshext  0 'none'
                      1 'one'
                      2 'two or more'.
compute       sshd    =p124.
formats       sshd    (f3.0).
var labs      sshd    'short stay hosp eps days 12 mos recode'.
recode        sshd    (366 thru 999=sysmis).
compute       sshdt   =sshd.
formats       sshdt   (f1.0).
var labs      sshdt   'short stay hosp eps days 12 mos truncated'.
recode        sshdt   (000=0) (001=1) (002=2) (003 thru
                      365=3) (else=sysmis).
val labs      sshdt   0 'none'
                      1 'one'
                      2 'two'
                      3 'three or more'.
compute       sshdx   =p129.
formats       sshdx   (f3.0).
var labs      sshdx   'short stay hosp eps days ex del 12 mos
                      recode'.
recode        sshdx   (366 thru 999=sysmis).
compute       sshdxt  =sshdx.
formats       sshdxt  (f1.0).
var labs      sshdxt  'short stay hosp eps days ex del 12 mos
                      truncated'.
recode        sshdxt  (000=0) (001=1) (002=2) (003 thru
                      365=3)                  (else=sysmis).
val labs      sshdxt  0 'none'
                      1 'one'
                      2 'two'
                      3 'three or more'.
compute       sshdxt2 =sshdx.
formats       sshdxt2 (f1.0).
var labs      sshdxt2 'short stay hosp eps days ex del 12 mos
                      truncated #2'.
recode        sshdxt2 (000=0) (001=1) (002=2) (003=3) (004
                      =4) (005=5) (006=6) (007 thru 365=7)
                      (else=sysmis).
val labs      sshdxt2 0 'none'
                      1 'one'
                      2 'two'
                      3 'three'
                      4 'four'
                      5 'five'
                      6 'six'
                      7 'seven or more'.
save /outfile 'tr1wX89s.sys'.
display.
sysfile info 'tr1wX89s.sys'.
```

Figure 2. Sample SPSS 'Procedure' Program.

```
set listing='tr022wp.lis'.
dos del tr022wp.lis.
set listing='tr022wp.lis'.
title 'program name: tr022wp.com'.
subtitle 'ilv1 by {povin, eth2} by age1 weighted 89'.
set /screen=off /printer=off
/length=59 /width=narrow
/eject=on /include=on
/echo=on /log=off /more=off
/viewlength=maximum /blanks=-1.

get file 'tr1wX89s.sys'.

subtitle 'crosstabs povin by ilv1 89'.
crosstabs /tables povin by ilv /options 3 4.
subtitle 'crosstabs eth2 by ilv1 89'.
crosstabs /tables eth2 by ilv1 /options 3 4.
subtitle 'crosstabs povin by ilv1 by age1 89'.
crosstabs /tables povin by ilv1 by age1 /options 3 4.
subtitle 'crosstabs eth2 by ilv1 by age1 89'.
crosstabs /tables eth2 by ilv1 by age1 /options 3 4.
```

USING RTECS(R) TOXICOLOGY DATA ON CD-ROM TO SELECT CHEMICALS FOR EPIDEMIOLOGIC AND INDUSTRIAL HYGIENE STUDIES

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Introduction

The invention of movable type by Johannes Gutenberg made books widely available and launched the first great information revolution. Five hundred years later, the establishment of on-line databases began a second information revolution and made a phenomenal amount of material available to the individual; the equivalent of a Library of Congress or National Library of Medicine. The third great information revolution followed the second by fewer than twenty years. CD-ROMs fuse the accessibility of a personal library--an enormous personal library!--with the search and retrieval functions of on-line databases.

Many databases are now available both on-line and on CD-ROM. Each system has its advantages. On-line databases are more up-to-date and may have searching features not found in the CD-ROM equivalents. CD-ROM disks may have a high one-time price, but there are no connection charges to use them. Another advantage of CD-ROM disks is that the user is not dependent upon a host computer for data retrieval. There is no need to worry about transmission blips or loss of connection, important considerations when downloading a large file, or about the database being inaccessible because the host computer is not functioning.

Because CD-ROMs, and even on-line databases, are such recent inventions, their main use has been for background bibliography and information. For example, a researcher might consult these databases because she needs data on a chemical she is investigating, or statistics, for geographic areas comparable to hers, on the incidence of a particular disease.

This paper focuses on a new way to use the information in CD-ROM databases, active rather than reactive.

The National Institute for Occupational Safety and Health, is the arm of the Centers for Disease Control mandated to investigate workplace safety and health hazards and to recommend standards to the regulatory agencies. The goal of NIOSH is a safe workplace for every American worker.

> The Occupational Safety and Health Act of 1970 (Public Law 91-596) declared that exposure standards should be set so that "to the extent feasible . . no employee will suffer material impairment of health or functional capacity even if such employee has regular exposure to the hazard . . . for . . . his working life."

In the twenty years since the passage of the Occupational Safety and Health Act, NIOSH has conducted hundreds of workplace-based industrial hygiene and epidemiological studies. The purpose of these studies is to determine the level of workplace exposures and to determine if those exposures are associated with increased risk of disease.

On the basis of its epidemiological and industrial hygiene studies, NIOSH makes specific recommendations to the Occupational Safety and Health Administration as part of proposed health standards, to other regulatory agencies, to workers, and to employers. These recommendations include criteria for suggested exposure limits for specific hazards.

Some of NIOSH's research investigations arise from Health Hazard Evaluations in which NIOSH is asked, by a company, its workers, or their union to determine if working conditions are hazardous. Other studies arise in response to new toxicology findings or to confirm the results of previous epidemiologic studies. Recently some of the researchers in our Branch, Industry Wide Studies, have begun trying a new method to predict whether potential hazards exist. Because the number of potential chemical and physical hazards in the workplace is so large, and because new chemicals, and novel physical conditions, are added each year, it would take thousands of working lifetimes to investigate them all. Clearly, systems of ranking potential hazards are needed, so that the greatest hazard--either because of the number of potentially exposed workers, or because of the severity of the consequences of exposure, or both--is investigated first.

Several models of occupational risk and prioritizing algorithms have been developed by NIOSH [1,2,3] and other researchers[4,5], to identify high-risk jobs with intensive and/or multiple exposures or highly toxic chemicals to which large numbers of workers are exposed.

We have been using the quarterly updates of a NIOSH database, the Registry of Toxic Effects of Chemical Substances (RTECS(R)), as a predicting tool of substances currently being discussed in the literature which may have adverse health effects and to which significant numbers of workers may be potentially exposed.

RTECS(R), mandated by the Occupational Safety and Health Act of 1970 (it was then called the Toxic Substances List), is a compilation of published chemical toxicological and related data, updated quarterly.[1,6,7] RTECS(R) is available on-line in TOXNET, one of the National Library of Medicine specialized MEDLARS (Medical Literature Analysis and Retrieval System) services, and through other on-line services. RTECS on a CD-ROM disk can be purchased from SilverPlatter Information Services[8], from Micromedex[9], and in the CCINFO series from the Canadian Centre for Occupational Health & Safety[10]. We have been working with RTECS(R) on the CCINFO CD-ROM

disk but the same searches could be run on-line or on the SilverPlatter disk.

Another NIOSH database, the National Occupational Exposure Survey (NOES)[2], has data on estimated numbers of workers potentially exposed to particular substances or physical hazards. NOES is not yet available either on-line or in CD-ROM, but some summary NOES data have been added to RTECS®. The NOES summary in an RTECS® record includes the observed (during the survey) numbers of different industries and occupations that used the substance, and the estimated total numbers of all potentially exposed workers and of potentially exposed female workers. These summaries are updated periodically. And as the RTECS® inventory grows, NOES data are added for new records.

Methods for Toxicology Updates

We have developed search strategies for determining substances with potential adverse health effects in a number of areas of interest to NIOSH, such as carcinogenicity, liver, kidney, or neurobehavioral toxicity, or affecting reproduction. We are refining and standardizing these procedures so they can be run, almost automatically, as RTECS® is updated quarterly.

The process includes:

1. Applying dynamic search strategies, continuously reviewed and refined, to the latest CD-ROM update of RTECS®,
2. editing the output files into tables for clear presentation,
3. reviewing the tables for substances of interest,
4. retrieving more information on substances of interest.

(1) Search Strategies

Two basic criteria are included in every search strategy.

First, the substance record must have been recently updated (that is, since the last time the procedure was performed). The "recent update" term is included to limit the lists to substances for which new information has appeared in the literature fairly recently.

Second, the substance record must include National Occupational Exposure Survey summary data, so that some estimate can be made of the possible public health impact of a particular substance.

These two criteria do not reduce the number of substances to be reviewed to a reasonable number. The latest CCINFO CD-ROM version of RTECS® includes over 17,500 substances whose records were updated in the winter of 1990-91. Among those, over 4,200 have NOES data. The RTECS® database also includes over 3,700 substances with human toxicity data, and almost 1,500 with both human toxicity references and estimates of numbers of potentially exposed workers. Obviously, additional limiting factors are needed.

A third criterion focuses on the health effect of interest: carcinogenicity or toxicity to a particular organ or system. Each search strategy retrieves a unique set of substance records. Developing the search strategy involves reviewing, for a particular organ or system, the RTECS® Toxic Effects Codes and Health Effects, and deciding which to include. This is not a trivial process. For example, some of the liver health effects in the RTECS® index are associated with acute toxicity; others, with carcinogenicity. Depending on the search strategy, these substances are potential carcinogens, liver toxicants, kidney toxicants, reproductive effectors, neurobehavioral toxicants (Table 1), or are associated with another adverse health effect of interest to a particular researcher.

Table 1 Search Strategies* for Health Effects of Interest to NIOSH Researchers

Possible Effect	Search Terms
potential carcinogen	(ORGANISM OBSERVED: Human and Carcinogen) or (INVESTIGATED EFFECT: tumorigenicity)
kidney toxicant	(Kidney, ureter, bladder–changes in tubules) or (Kidney, ureter, bladder–decreased urine volume or anuria), or (Kidney, ureter, bladder–depressed renal function tests), or (Kidney, ureter, bladder–interstitial nephritis), or (Kidney, ureter, bladder–proteinuria)
liver toxicant	(Changes in gall bladder structure or function) or (Cholestatic jaundice) or (Fatty degeneration) or (Fibrous hepatitis) or (Hepatitis) or (Jaundice or hyperbilirubinemia) or (Jaundice, other or unclassified) or (Impaired liver function tests) or (Other liver changes)
reproductive effector	(INVESTIGATED EFFECT–reproductive)
neurobehavioral toxicant	(Behavioral-agression) or (Behavioral-alteration of classical conditioning, or (Behavioral-alteration of operant conditioning), or (Behavioral–altered sleep time (including change in righting reflex)), or (Behavioral-analgesia), or (Behavioral-anorexia (human)), or (Behavioral-ataxia), or (Behavioral-change in motor activity (specific assay)), or (Behavioral-change in psychophysiological tests), or (Behavioral-coma), or (Behavioral-convulsions or effect on seizure threshold), or (Behavioral-excitement), (Behavioral-general anesthetic), or (Behavioral-hallucinations, distorted perceptions), or (Behavioral-headache), or (Behavioral-irritability), or (Behavioral-muscle contraction or spasticity), or (Behavioral-muscle weakness), or (Behavioral-rem sleep changes), or (Behavioral-rigidity (includes catalepsy)), or (Behavioral-sleep), or (Behavioral-somnolence (general depressed activity)), or (Behavioral-stiffness), or (Behavioral-tetany), or (Behavioral-toxic psychosis), or (Behavioral-tremors), or (Behavioral-wakefulness), or (Depressed), or (Depression), or (Neurotoxin)

* All search strategies include a term for recent updates (e.g., DATE OF LAST UPDATE: 9012 OR 9101)and a term to select records with NOES data (i.e., ALL INDEXES: NOES)

(2) Editing the Output

The output file is formatted to retrieve from each record only the name of the substance, the Chemical Abstract Society (CAS) registry number, the NOES estimate, and as little other information as possible (since it will be deleted in order to make the table easy to read). The file is still sizable and a number of word-processing editing manipulations is required (in WordPerfect) to condense it to a compact, readable table. We have written WordPerfect macros to automate many of these manipulations.

An output table includes substance names and CAS registry numbers and numbers of potentially exposed total and female workers.

(3) Reviewing the Tables

Researchers in our Branch review the output tables in their areas of special interest, using number of workers potentially exposed to a substance as a rough ranking index. Some efforts have been made to develop additional ranking factors.

(4) Retrieving Additional Information

If a researcher becomes interested in investigating one of the substances in a list of potential toxicants, additional information is needed to assess feasibility. More detailed information for each substance, including bibliographic references, can be retrieved from RTECS®. A researcher could consult with the Surveillance Branch of NIOSH to define a detailed NOES search to determine the distribution of potentially exposed workers by industry and occupation or by occupation within industry, duration of potential exposure, and controls (or lack thereof) of exposure, among other parameters. A search of NIOSHTIC, our database of literature in the field of occupational safety and health (also available on CD-ROM), might produce additional references. Other on-line and CD-ROM toxicological databases such as TOXLINE, MEDLINE, and HSDB (Hazardous Substance Data Bank) can also be consulted for pertinent information.

A number of other database search procedures have been developed in our Branch to further rank chemicals selected based on linkage of RTECS® and NOES.

One scheme, which has been applied to the entire RTECS® database rather than the records updated in the last quarter, uses the approximately 85 codes in RTECS® for different reproductive effects, including paternal effects, maternal effects, and embryonic, fetal, or newborn abnormalities to generate a list of possible reproductive effectors. The complete NOES database (rather than the summary NOES data in some RTECS® records) is then searched for potential toxicants with a specified minimum number of workplace-exposed men or women. Linkage of these databases provides lists of sex-specific potential occupational reproductive toxicants. Additional weighing factors can then be applied to the toxicants in each list to create a flexible database of reproductive toxicants. Although this procedure has not yet been implemented on the RTECS® CD-ROM and applied to the recently updated records, it could be modified to do so.

Results

The most recent RTECS® CD-ROM includes nearly 107,000 records. Limiting the retrieval to records updated in December 1990 and January 1991 reduces the number to 17,483. Additional search parameters include **human** as the organism of interest {3124 records} and **NOES** to select records with data on occupational exposure {4262 records}. The term(s) for the health effect of interest further limit the output. For example, the search term "INVESTIGATED EFFECT: Reproductive" retrieves 5267 records. Linking this term with Boolean ANDs to the three general terms described above, the search retrieves 621 records. Table 2 gives the numbers retrieved during the first 1991 searches. Additional limiting criteria (such as "at least 10,000 workers estimated to be potentially exposed") can be used to reduce the number of substances included in a table.

Table 2 Results of 1991 Searches

Search Term(s)	Number of Records Retrieved	Number of Records with Est. >10,000 Workers
LAST UPDATE: 9012 or 9101	17483	
ALL INDEXES: NOES	4262*	
ORGANISM OBSERVED: human	3124	
INVESTIGATED EFFECT: toxic	94035	
INVESTIGATED EFFECT: tumorigenic	3398	
Kidney terms (Table 1)	229	
AND NOES	110	
AND HUMAN	81	40
Liver terms (Table 1)	592	
AND NOES	178	
AND HUMAN	128	60
Neurobehavioral terms (Table 1)	20148	
AND NOES	1328	
AND HUMAN	644	273
INVESTIGATED EFFECT: reproductive	5267	
AND NOES	1097	
AND HUMAN	621	268
Carcinog:	1595	
AND NOES	463	
AND HUMAN	265	118

* When (LAST UPDATE: 9012 or 9101) and (NOES) were linked with a Boolean "AND", the number of records retrieved was 4262. That is, every RTECS® records with NOES data had been updated, although these updates may changed some other information, rather than the NOES data in the record.

The first sets of tables of toxicants extracted from the quarterly RTECS® updates were circulated in our Branch this winter and spring. Table 3, an example of these tables, lists possible carcinogens with an estimate of at least 100,000 potentially exposed workers. One reason that critical judgement must be applied to the output tables is that many of the toxicants are pharmaceutical products (chiefly antibiotics and antitumor agents).

As this system is developed and refined, we hope it will have a number of useful applications.

Discussion

Predicting and investigating potential hazards has obvious public health benefits. Naturally it would be better to eliminate or reduce these hazards before, rather than after, workers become ill or are injured.

However, there are disadvantages in trying to forecast future problems. First of all, we often predict toxicity to humans on the basis of animal research. A number of studies have shown that some substances toxic to animals may be more, or less, toxic to humans,

Table 3 RTECS® Winter 1990-91 Updates of Possible Carcinogens* with NOES Data and at least 100,000 Potentially Exposed Workers

CHEMICAL NAME	CAS	NOES ESTIMATES All	Female
ACETALDEHYDE	75-07-0	216533	97770
ACETIC ACID, VINYL ESTER	108-05-4	129024	36642
ASBESTOS	1332-21-4	215265	9727
BENZENE	71-43-2	272275	143066
BENZIN	8030-30-6	471013	57366
1,2-BENZISOTHIAZOLIN-3-ONE,1,1-DIOXIDE	81-07-2	225094	97727
2-BIPHENYLOL	90-43-7	617394	379044
CARBON TETRACHLORIDE	56-23-5	104174	20699
p-CRESOL, 2,6-DI-tert-BUTYL-	128-37-0	591238	163774
DICHROMIC ACID, DISODIUM SALT	10588-01-9	136313	24542
DIETHYLENE GLYCOL	111-46-6	890145	261558
p-DIOXANE	123-91-1	429330	149697
ETHANE, 1,1,1-TRICHLORO-	71-55-6	2528300	762399
ETHANOL, 2,2',2"-NITRILOTRI-	102-71-6	1726272	573604
ETHYL ALCOHOL	64-17-5	2069125	1014002
ETHYLENE OXIDE	75-21-8	270683	120086
ETHYLENE, TETRACHLORO-	127-18-4	688110	177342
ETHYLENE, TRICHLORO-	79-01-6	401373	175316
FORMALDEHYDE	50-00-0	207013	104994
2-FURALDEHYDE	98-01-1	135914	6706
HYDROGEN PEROXIDE, 30%	7722-84-1	1006752	727702
HYDROQUINONE	123-31-9	442749	144063
LEAD	7439-92-1	767619	236378
METHANE, DICHLORO-	75-09-2	1438196	352536
MINERAL OIL	8012-95-1	1100229	433405
NITROGEN OXIDE	10024-97-2	112585	74465
NITROUS ACID, SODIUM SALT	7632-00-0	928532	274167
PHENOL	108-95-2	584372	120977
PHTHALIC ACID,BIS(2-ETHYLHEXYL) ESTER	117-81-7	340800	106918
PROPANE, 1,2-EPOXY-	75-56-9	421140	317309
PROPYL ALCOHOL	71-23-8	226129	84196
STYRENE	100-42-5	333212	86902
TITANIUM OXIDE	13463-67-7	2749569	540849

*265 RTECS® listings satisfied the following search strategy: (update 9012 or 9101) + (NOES) + (organism observed-human) + carcinog:. This table is limited to the 33 substances with at least 100,000 estimated workers potentially exposed.

or may affect different organ systems in humans. Conversely, there could exist substances toxic to humans for which no animal effects have been demonstrated. Second, if we are predicting possible future illness, we need some indication of "pre-illness." Data showing the existence of biomarkers of exposure, subtle changes in cell metabolism, or overt damage can provide an "Early Warning System" of toxicity. However, biomarkers may not be available for the suspected agent or affected systems.

Third, a cohort suitable for epidemiologic investigation--that is, a number of individuals in the same occupation and industry, ideally in just a few facilities, may not be found, even for a substance to which hundreds of thousands or even millions of workers are exposed.

Fourth, it may not be possible adequately to characterize past or even current occupational exposures, because technology to quantify exposure to a particular substance may not exist.

Despite these drawbacks, the public health benefit of a predictive system is great: preventing fires is always to be preferred to putting them out. And CD-ROM databases have provided us with a simple, efficient way to discover and rank substances that are potential hazards. As this technology develops and more and different kinds of information are linked together, we are sure to find novel and even more powerful methods of putting this information to use in the service of public health.

SUMMARY

Search strategies to select chemicals for possible epidemiologic and industrial hygiene studies have been developed by researchers at the National Institute for Occupational Safety and Health (NIOSH). The method employs periodic systematic review of NIOSH's Registry of Toxic Effects of Chemical Substances (RTECS®) on CD-ROM. Each search strategy links records updated in the last quarter, a keyword to include only records with data from the National Institute for Occupational Safety and Health's National Occupational Exposure Survey (NOES) data, and one or more statements to define the field of interest (bladder cancer, kidney toxicants, chemicals with deleterious reproductive effects, etc.).

Output records are retrieved in a stripped-down version, including only the chemical name and CAS number of the toxicant and summary NOES data: estimated total numbers of potentially exposed workers (all workers and female workers) and observed (during the survey) numbers of industries and occupations. The stripped-down version is imported into WordPerfect and converted into a table, which is distributed to interested researchers within the Industrywide Studies Branch of NIOSH.

Individual researchers who wish to assess the feasibility of studying the effects of a particular toxicant can then consult the complete RTECS® record and the cited references. A more detailed NOES search--available from the National Institute for Occupational Safety and Health's Surveillance Branch--often includes a tally of number of workers potentially exposed by occupation and by industry, and by occupation within industry. The NIOSHTIC bibliographic database of occupational safety and health, and such toxicology databases as TOXLINE, MEDLINE, and Hazardous Substances Data Bank, may also be consulted. These sources may help in evaluating the possible adverse outcomes associated with exposure to a substance and in determining if there are sufficient numbers of potentially exposed workers for an epidemiologic study, and the industries and occupations where they might be found.

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7. RTECS® Registry of Toxic Effects of Chemical Substances. Publications Office, NIOSH, 1991.

8. SilverPlatter Information, Inc. One Newton Executive Park, Newton Lower Falls, MA 02162-1449, (800) 343-0064.

9. Micromedex, Inc., 600 Grant Street, Denver, CO 80203-3527, (800) 525-9083.

10. Canadian Centre for Occupational Health & Safety, 250 Main St. E, Hamilton, ONT L8N 1H6, (800) 263-8276.

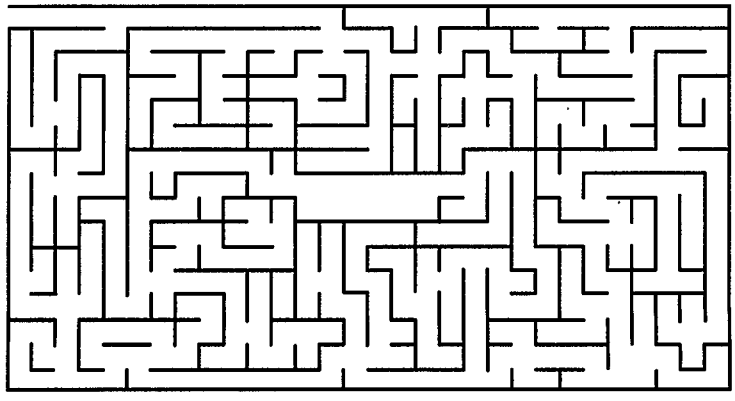
1990 CENSUS ON CD-ROM

James R. Clark
U.S. Bureau of the Census

(Not available for publication)

Session V

New Data from Vital Records



CESAREAN SECTION DELIVERIES: IMPROVED DATA FROM THE 1989 NATIONAL STANDARD CERTIFICATES OF LIVE BIRTH AND FETAL DEATH

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Before 1989, most national estimates of the incidence of Cesarean section (C-S) and vaginal birth after Cesarean delivery (VBAC) in the United States were based on hospital discharge survey data. The most prominent estimates are the series reported by Placek and Taffel, with data from the National Hospital Discharge Survey, a representative sample of some 300 hospitals throughout the country [Placek, Taffel 1980, 1988; Placek, Taffel, Moien 1983, 1985; Taffel, Placek, Moien 1985, Taffel, Placek, Liss, 1987; Taffel, Placek, Moien, Kosary 1991]. With the implementation of the new national standard certificates of live birth and fetal death, most states will now have routine access to reasonably current, statewide statistics on trends in Cesarean delivery [Freedman, Gay, Brockert, et al. 1988; Taffel, Ventura, Gay 1989]. The new certificates collect data not only on the incidence of C-S, but also differentiate between primary and repeat Cesareans, and report the incidence of successful VBAC. As the aforementioned reports describe the general contents of the new certificates, interested readers are referred there for additional information.

The purpose of this paper is to explore the descriptive epidemiology of C-S among 1989 occurrence deliveries in the state of Arkansas. The live birth and fetal death certificates used in Arkansas are identical in all but a few minor respects to the national standard forms, with all checkboxes on the bottom portion included, in the same order. Thus, the strengths and weaknesses of the new certificates for collecting and analyzing data on trends in Cesarean delivery and its correlates should mirror the experiences that can reasonably be anticipated elsewhere around the nation. The analysis was done with occurrence data not only because method of delivery is more highly associated with the characteristics of the facility at which the delivery occurred than with the maternal state or county of residence, but also because several states adjacent to Arkansas delayed implementation of the new certificates until after January 1, 1989. Unless otherwise stated, all analyses reported in this paper include all live births and fetal deaths of gestation 20 weeks or more occurring in the state of Arkansas during 1989.

General Characteristics of Cesarean Deliveries

The total C-S rate for Arkansas in 1989 was 26.9 per 100 deliveries. This rate continued a state trend of rising C-S rates that, prior to 1989, generally followed the national trend (Figure 1). However, the rate of increase in Arkansas in the years since 1986 has exceeded that in the national data, which in fact showed a decline in the C-S rate from 1988 to 1989 [unless otherwise noted, all subsequent references to national 1989 data are from Taffel, Placek, Moien, Kosary 1991]. Figure 1 also shows the overall C-S rates by hospital, classified into levels of obstetrical care. In 1989, the C-S rate for Level III hospitals in Arkansas was significantly lower than at either Level I or Level II facilities ($p<.001$). In the years prior to 1989, method of delivery was reported on Arkansas vital certificates through an open-ended question. Although the 1989 C-S rate is somewhat higher than that for 1988, the data from the new question format appear consistent both with the recent trend and across hospital level of obstetrical care.

Reports on national C-S trends often include data on primary and repeat Cesarean delivery rates. These rates use denominators which require more information than is provided on the new national standard certificates. Specifically lacking is an indication of the method of delivery in previous pregnancies. Although the new certificates differentiate by primary and repeat C-S, the number of women at risk is not known. Using all deliveries as the denominator, the primary C-S rate in Arkansas in 1989 was 17.2 per 100 deliveries (compared to 17.1 nationally). The proportion of all C-S that were repeat C-S in Arkansas in 1989 was 36.1% (compared to 35.6% nationally). It is possible to more closely identify the population at risk for repeat C-S, taking as the denominator all deliveries to women of gravidity two or more. This will include some women who have never had a Cesarean, but more closely approximates the true denominator. The distribution of C-S by age of mother is shown in Figure 2. When calculated using total deliveries within each age stratum, both primary and repeat C-S rates increase with age of mother. The VBAC rate for Arkansas in 1989 (number of VBACs divided by total repeat C-S plus VBACs) was 11.4%. Although this is somewhat lower than the national average (reported as 18.5% in 1989, up from 12.6% in 1988), VBAC programs have only recently been implemented in several hospitals in the state.

Patterns of C-S by race, educational attainment, live birth order and marital status of mother, gender, birth weight and five-minute Apgar score of infant are similar to those reported elsewhere [Zdeb 1980; Goldfarb 1984; Kirby 1987]. In Arkansas, women who initiate prenatal care in the first trimester have significantly higher rates of C-S (28.4 per 100 deliveries for first trimester care, compared to 23.6 for later or no prenatal care). The same is true for women with ten or more prenatal visits (28.8 per 100 deliveries, compared to 22.4 for women with fewer than ten or no prenatal visits).

New Information on Risk Factors

The new national standard certificates of live birth and fetal death contain essentially identical checklists of risk factors including maternal risk factors, obstetrical procedures, complications of labor and/or delivery, abnormal conditions of the newborn (not included on the fetal death certificate), and congenital anomalies. Most important ante- and

intrapartum risk factors are incorporated into these checklists. These data items vary in reported frequency by hospital and across states. These data also vary in relation to method of delivery. For example, among Arkansas women delivering by primary C-S, 15.0% had no reported complications of labor and/or delivery. Among repeat C-S, however, the comparable rate was 74.6%. This suggests that important complications are not always reported, that significant conditions or problems have been omitted from the checklist, or that the clinical obstetrics syndrome of 'once a Cesarean, always a Cesarean' remains an important contributor to the repeat C-S rate. Among women delivered by VBAC, 67.1% had no reported labor or delivery complications.

In an effort to explore the internal consistency of these data and to evaluate the additional contribution to our understanding of risk factors for Cesarean delivery, a series of logistic regression models was fitted. Two separate groups of analyses were conducted: 1) estimates of the risk of primary Cesarean delivery were computed among all deliveries not indicated as being by VBAC or repeat C-S, and 2) estimates of the risk of VBAC were computed for all deliveries reported as VBAC or repeat C-S. In each group of analyses, 'crude' odds ratios (adjusted for maternal age less than 20 or more than 35, and for maternal race) were computed; multivariate models were constructed including those variables with p-values less than 0.10.

Risk Factors for Primary Cesarean Delivery

The analysis of risk factors for primary Cesarean delivery was conducted on 31,060 deliveries, which included all non-repeat C-S and non-VBAC deliveries. After controlling for maternal age and race, a number of factors showed significant associations with primary Cesarean delivery. Those risk factors with odds ratios significant at $p < .05$ are shown in Table 1. Among the maternal reproductive and demographic characteristics which increase the odds of primary C-S were first live birth and first pregnancy, very low and moderately low birth weight, very preterm and moderately preterm delivery, multiple gestation, maternal age 35 or more, early initiation of prenatal care and five or more prenatal visits. Delivery at a Level II obstetrical hospital also increased the odds of primary C-S. Several obstetrical procedures increased these odds: amniocentesis, electronic fetal monitoring, induction of labor, tocolysis and ultrasound. Because the checklists lack specificity, it is not possible to determine the timing during the pregnancy of these procedures. The maternal risk factors associated with increased odds of primary C-S are all plausible [Danforth 1985]. Among the labor and delivery complications associated with primary C-S, all are commonly cited indications for Cesarean delivery with the exception of moderate/heavy meconium.

Several characteristics are associated with reduced odds of primary C-S. These include low educational attainment, mother unmarried, birth at a Level III obstetrical facility, stimulation (augmentation) of labor, and precipitous labor of less than three hours duration. Maternal risk factors which decreased the likelihood of primary C-S were maternal smoking during pregnancy, maternal weight gain of less than twenty pounds, previous deliveries of more than 4000 gram infants or preterm/small for gestational age infants, renal disease, and hemoglobinopathy.

Because of computer processing limitations, several iterations of the multivariate logistic regression model were run. Only those variables with p-values less than 0.10 were retained in each successive model, and all variables were treated as categorical data. The results of the final model are shown in Table 2. This model was computed for 26,284 cases, including 21,225 vaginal and 5,059 primary C-S deliveries. Four variables contributed most of the missing values which necessitated case-wise deletion (prenatal visits, maternal weight gain, maternal education, and live birth/pregnancy order). The full model correctly classified 91.3% of all deliveries, with sensitivity of 97.2% and specificity of 66.6%. Only four factors reduce the odds of primary Cesarean delivery: maternal education less than high school, birth at a Level III obstetrical facility, stimulation of labor, and precipitous labor. Among the risk factors with the strongest association with primary C-S were: cephalopelvic disproportion (OR=24.20), breech/other malpresentation (OR=9.59), placenta previa (OR=8.46), cord prolapse (OR=7.32), fetal distress (OR=4.11), dysfunctional labor (OR=4.08), genital herpes (OR=3.07), and abruptio placentae (OR=3.06). Although most of the other variables in the full model are statistically significant, the increased risks for primary C-S are small.

Risk Factors for Vaginal Birth after Cesarean Delivery

A similar series of analyses was performed to identify risk factors associated with successful VBAC. A total of 3,827 repeat C-S and VBAC deliveries constituted the cases for these analyses. Successful VBACs were coded to the value 1, and repeat Cesareans to 0 for these logistic regressions. Characteristics which increase or decrease the odds of VBAC, adjusted for maternal age and race, are shown in Table 3.

All variables with adjusted odds ratios significant at $p < .10$ in the multivariate logistic regression analysis are shown in Table 4. A total of 3,480 cases were analyzed, with prenatal visits and clinical gestational age accounting for most of the case-wise deletions. This model correctly classified 90.3% of all cases, with sensitivity of 98.3% and specificity of 27.1%. Several factors increase the likelihood of successful VBAC: precipitous labor (OR=8.05), stimulation of labor (OR=4.03), induction of labor (OR=3.12), and cardiac disease (OR=2.59). Women delivering at a Level III obstetrical facility are 1.69 times more likely to deliver by VBAC than are women delivering at other hospitals. Electronic fetal monitoring is associated with an increased odds of VBAC. Cephalopelvic disproportion, ultrasound, plural birth, and first trimester prenatal care are more likely to result in a repeat Cesarean delivery.

Discussion

The foregoing analysis demonstrates both the strengths and the weaknesses of the new standard certificates for the analysis of patterns of C-S delivery. A wealth of data on maternal risk factors, obstetrical procedures/interventions, and complications of labor and delivery are now available. Unfortunately, these indicators are not comprehensive, and the data have not been carefully validated through medical records review. Primary and repeat C-S clearly have different risk factors, and it is likely that previous C-S remains the most frequent indication for a repeat C-S. Although the results of these analyses are generally consistent with other reports, because these data are for a single year, in one state, the odds ratios may not be stable and may not be generalizable to other areas of the United States.

Several additional factors may influence C-S delivery. These include characteristics of physicians [Berkowitz, Fiarman, Mojica et al. 1989], availability of electronic fetal monitoring as opposed to its reported use [Leveno, Cunningham, Nelson et al. 1986], malpractice insurance premiums [Rock, 1988], and socioeconomic status [Gould 1989]. None of these factors are adequately measured through data collected on the new national standard certificates. Several items should be added to the checklists to provide data relevant to C-S and VBAC deliveries. Under complications of labor and/or delivery, specific mention of other than breech presentation, whether a version was performed, and whether the patient underwent trial of labor should be added. Under maternal risk factors, gestational diabetes should be reported separately from diabetes, and other STDs should be specified more precisely. Under obstetrical procedures, amniocentesis should be differentiated by early/late, chorionic villus sampling should be added, and an indication of whether the patient was screened for maternal serum alpha-fetoprotein should be included. It is imperative that the checklist data be validated through careful chart review by individuals knowledgeable of clinical obstetrics to verify the completeness and accuracy of the information reported on the new birth and fetal death certificates. The new certificates may go a long way toward fulfilling the promise suggested by Williams and Chen [1983], both by enabling the more precise specification of risk factors, and by providing more detailed data for monitoring trends in C-S rates on a regional, state and national basis. Although the current rates of C-S in the United States may not be an 'epidemic' [Tanio, Manley, Wolfe 1987], it is time to take a more careful look at the trends and risk factors for primary C-S, and the characteristics of those women most likely to have successful VBAC deliveries.

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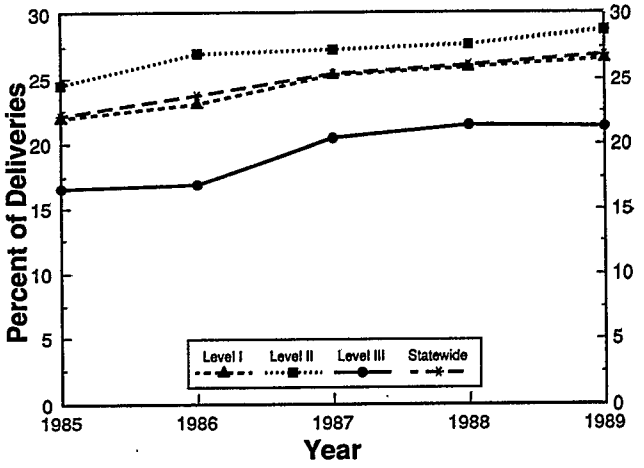
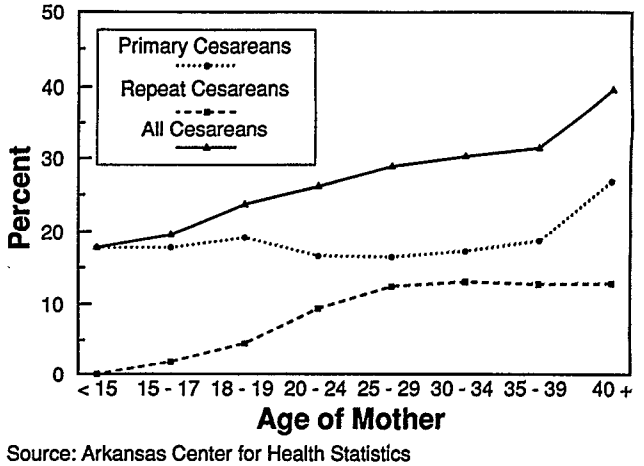
FIGURE 1
CESAREAN SECTION RATE PER 100 DELIVERIES
ARKANSAS OCCURRENCE DATA, 1985-1989



Source: Arkansas Center for Health Statistics

FIGURE 2
CESAREAN SECTION RATES BY AGE OF MOTHER
ARKANSAS OCCURRENCE DELIVERIES, 1989



Source: Arkansas Center for Health Statistics

TABLE 1

RISK FACTORS FOR PRIMARY CESAREAN DELIVERY ADJUSTED FOR MATERNAL AGE (LESS THAN 20, 35 OR OLDER) AND RACE (BLACK)

	General	Obstetrical Procedures	Maternal Risk Factors	Complications of Labor and/or Delivery
INCREASED ODDS	Birth at Level III Hospital Primigravida Primipara Maternal Age 35+ Initiate Prenatal Care Before 3rd Trimester More than Four Prenatal Visits Plural Birth Birth Weight < 1500g Birth Weight 1500-2499g Gestational Age < 32 Weeks Gestational Age 32-36 Weeks	Amniocentesis Electronic Fetal Monitoring Induction of Labor Tocolysis Ultrasound	Diabetes Genital Herpes Hydra/ Oligohydramnios Chronic Hypertension Pregnancy-Associated Hypertension Eclampsia Uterine Bleeding Maternal Weight Gain > 34 lbs.	Febrile (> 100° F) Meconium Abruptio Placentae Placenta Previa PROM 12+ Hours Seizures during Labor Prolonged Labor > 20 Hours Dysfunctional Labor Breech/Malpresentation Cephalopelvic Disproportion Cord Prolapse Fetal Distress
DECREASED ODDS	Birth at Level III Hospital Mother Unmarried Maternal Education < High School	Stimulation of Labor	Mother Smoked during Pregnancy Maternal Weight Gain < 20 lbs. Previous Birth > 4000g Previous Preterm/SGA Infant Renal Disease Hemoglobinopathy	Precipitous Labor < 3 Hours

Table 2

Multivariate Odds of Delivering by Primary Cesarean Section Arkansas Occurrence Non-Repeat and VBAC Deliveries, 1989

Risk Factor	Adjusted Odds	95% C.I.	P-value
Maternal Age 35+	1.35	(1.21,1.49)	<.001
Primipara	1.71	(1.60,1.89)	<.001
Weight Gain >34 Lbs.	1.11	(1.05,1.16)	<.001
Plural Birth	2.65	(2.34,3.01)	<.001
More than 4 Prenatal Visits	1.25	(1.12,1.40)	<.001
Mother less than H.S. Grad.	0.84	(0.80,0.89)	<.001
Birth Weight 1500-2499g	1.21	(1.11,1.32)	<.001
Birth at L-III Hospital	0.67	(0.58,0.78)	<.001
Diabetes	1.25	(1.06,1.49)	.001
Genital Herpes	3.07	(2.58,3.65)	<.001
Chronic Hypertension	1.27	(1.00,1.62)	.047
Preg. Assoc. Hypertension	1.63	(1.49,1.78)	<.001
Eclampsia	1.84	(1.50,2.24)	<.001
Stimulation of Labor	0.72	(0.67,0.77)	<.001
Ultrasound	1.10	(1.05,1.16)	<.001
PROM 12+ Hours	1.25	(1.11,1.41)	<.001
Mod./Heavy Meconium	1.10	(1.00,1.21)	.045
Abruptio Placentae	3.06	(2.54,3.69)	<.001
Placenta Previa	8.46	(6.31,11.35)	<.001
Seizures in Labor	2.59	(1.33,5.07)	.006
Prec. Lab. < 3 Hours	0.20	(0.12,0.33)	<.001
Prolonged Lab. 20+ Hours	1.96	(1.67,2.30)	<.001
Dysfunctional Labor	4.08	(3.64,4.56)	<.001
Breech/Other Malpres	9.59	(8.65,10.63)	<.001
Cephalopelvic Disp.	24.20	(20.21,28.97)	<.001
Cord Prolapse	7.32	(4.91,10.90)	<.001
Fetal Distress	4.11	(3.84,4.39)	<.001

One variable included in the model was not significant at p <.10: Primigravida.

TABLE 3

RISK FACTORS FOR VAGINAL BIRTH AFTER CESAREAN SECTION (VBAC) ADJUSTED FOR MATERNAL AGE (LESS THAN 20, 35 OR OLDER) AND RACE (BLACK)

	General	Obstetrical Procedures	Maternal Risk Factors	Complications of Labor and/or Delivery
INCREASED ODDS	Birth at Level III Hospital Primipara Birth Weight < 1500g Gestational Age < 32 Weeks Mother Education < High School	Electronic Fetal Monitoring Induction of Labor Stimulation of Labor	Cardiac Disease Previous Preterm/SGA Infant	Meconium Precipitous Labor < 3 Hours Fetal Distress
DECREASED ODDS	Plural Birth Mother Unmarried Initiate Prenatal Care in First Trimester More than Four Prenatal Visits Gender - Male	Ultrasound	None	Breech/Other Malpresentation Cephalopelvic Disproportion

Table 4

Multivariate Odds of Delivering by VBAC Arkansas Occurrence Repeat and VBAC Deliveries, 1989

Risk Factor	Adjusted Odds	95% C.I.	P-value
Birth at L-III Hospital	1.69	(1.33,2.16)	<.001
Plural Birth	0.47	(0.26,0.85)	.012
Prenatal Care in 1st Tri	0.87	(0.75,1.00)	.044
Mod/Hvy Meconium	1.59	(1.21,2.09)	<.001
Prec. Lab. < 3 Hrs	8.05	(3.53,18.39)	<.001
Breech/Other Malpres	0.64	(0.40,1.03)	.068
Cephalopelvic Disp.	0.11	(0.04,0.31)	<.001
Cardiac Disease	2.59	(1.19,5.64)	.017
Electr. Fetal Monitoring	1.53	(1.34,1.76)	<.001
Induction of Labor	3.12	(2.49,3.92)	<.001
Stimulation of Labor	4.03	(3.24,5.00)	<.001
Ultrasound	0.75	(0.67,0.85)	<.001

Variables included in the model which were not significant at p <.10 or better were: Previous preterm/SGA infant, more than four prenatal visits, birth weight < 1500g, and gestational age < 32 weeks.

QUALITY OF NEW MEDICAL DATA FROM THE REVISED TEXAS CERTIFICATE OF LIVE BIRTH

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Recent revisions to the Texas Certificate of Live Birth (rev. 4/89), patterned on the U.S. Standard Certificate of Live Birth (rev. 1/89), make available for analysis a wealth of information on conditions surrounding pregnancy and birth. The format of the birth certificate has changed considerably from previous years: many checkboxes rather than blanks were added to the certificate for new medical information. These checkboxes were intended to make easier the collection of new information by prompting those filling out the form for specific information.

We now have available about a year and eight months of these new data for evaluation and analysis (most certificates through December, 1990). Since Texas is moving quickly toward receiving certificates in computerized form directly from hospitals, evaluation of data quality at this point will be critical in reducing future errors at the hospital level and at other levels. Our most pressing concern is the accuracy of information from the medical portion of the certificate, since it contains most of the new information and since the format differs considerably from what hospitals were previously filling out. Critical areas to examine at this time are the characteristics of births with missing data, and how well the certificates are being filled out and entered.

Missing medical information

The medical portion of the Texas birth certificate differs slightly from the U.S. Standard Certificate of Live Birth. First, names of certain categories have been modified. "Medical Risk Factors for this Pregnancy" on the Standard Certificate was changed to "Medical Factors for this Pregnancy" on the Texas certificate. "Other Risk Factors for this Pregnancy" became "Other Factors for this Pregnancy", and "Complications of Labor and/or Delivery" was changed to "Events of Labor and/or Delivery". Additionally, Texas deleted genital herpes and uterine bleeding from the Medical Factors category, removed cephalopelvic disproportion, anesthetic complications, and fetal distress from the Events of Labor category, and added an unknown checkbox, premature rupture of membranes, and STD's to the Medical Factors category. Texas also collects pre-pregnancy weight while the U.S. Standard Certificate only collects weight gained during pregnancy. Texas does not collect Apgar scores or information about transfers of the mother and infant to other facilities.

Also in response to physicians' concerns about confidentiality of individual medical information, the new Texas certificate is perforated, the medical checkbox portion is filled out at the hospital, then detached and mailed separately from the legal portion. The two certificate parts are entered separately into the computer, and then the different codes on the top and bottom matched according to a computer algorithm. This process generates significant amounts of missing data because certificate bottoms are not sent in a timely fashion or at all, are left blank, or are altered so that codes used to match the two parts of the certificate are unreadable (the most obvious sign of resistance to collection of this information by the state). If the above mentioned changes in the wording, content, and physical format of the certificate had not been made, Texas could not have implemented the revised birth certificate because of objections by the medical community.

In 1990, 6.5 percent of all birth certificate bottoms were either not returned, unmatchable, or left blank, down from 7.8 percent in 1989 (see Table 1). This drop results from a smaller percentage of unreturned or unmatchable certificates, as Table 1 shows. Of the certificates on which at least one piece of information is noted, only a little more than three in five are completely filled in (Table 2). Overall, the Texas Department of Health (TDH) received complete medical information for 58 percent of certificates in 1989-1990.

Blank or missing certificate bottoms account for about half or more of missing data for most categories on the bottom of the certificate, excepting pre-pregnancy weight, weight gain during pregnancy, and congenital anomalies of the child (see Table 3). Most missing data for these three categories come from within the categories themselves. Pre-pregnancy weight (added by Texas to its own certificate) and weight gain during pregnancy were reported for only

Table 1. Missing information by type from the medical portion of the revised Texas birth certificate, April 1989 - December 1990.

Type of Data	April-December 1989		Provisional 1990	
	n	percent	n	percent
Information recorded for at least one category	216,527	92.2	274,371	93.5
Medical portion blank or all categories unknown	3,948	1.7	6,399	2.2
Medical portion not returned or unmatchable	14,289	6.1	12,669	4.3

Table 2. Missing information on the medical portion of the revised Texas birth certificate by selected characteristics of mother, attendant, and place of delivery, 1990 (provisional).

Characteristic		Number of non-blank or non-missing bottoms	Percent non-blank or non-missing bottoms of all certificates	Percent of non-blank or non-missing bottoms completed entirely	Average blank/ unknown categories on incomplete bottoms
TOTAL		274,371	93.5	61.8	2.8
Age					
	10 - 14 years	832	94.5	49.6	2.7
	15 - 19 years	39,521	93.8	57.1	2.7
	20 - 29 years	159,560	93.5	61.8	2.8
	30 - 39 years	71,430	93.3	64.5	3.0
	40 - 54 years	2,906	92.9	61.8	2.9
Ethnicity					
	Hispanic	100,477	94.5	57.5	2.7
	White	130,893	92.9	66.0	2.9
	Black	37,089	93.0	57.8	2.9
	Other	5,912	92.4	65.8	3.0
Marital Status					
	Married	226,784	93.4	64.1	2.8
	Unmarried	47,587	93.8	50.0	2.7
Educational Attainment					
	Less than 12 years	90,357	93.4	54.0	2.7
	Exactly 12 years	93,744	93.5	63.2	2.8
	More than 12 years	87,240	93.2	68.9	3.1
Birth Attendant					
	Medical Doctor	259,175	93.8	61.8	2.8
	Doctor of Osteopathy	6,614	91.3	57.2	2.6
	Certified Nurse-Midwife	3,924	98.1	64.5	2.4
	Lay Midwife	3,074	76.4	72.1	2.3
	Other	1,279	89.8	55.0	3.3
Place of Birth					
	Hospital	268,405	93.8	61.6	2.9
	Birthing Center	2,864	83.4	73.2	2.2
	Residence	2,288	75.4	67.4	2.8
	Clinic/Doctor's Office	24	85.7	50.0	3.4
	Other	753	89.4	59.9	2.6

about two thirds of all live births, and were by far the least reported item on the birth certificate. Following these two items were congenital anomalies of the child and questions involving alcohol use. The best-reported category, unsurprisingly, was method of delivery. Tobacco use during pregnancy was unexpectedly well-reported. Resistance to the alcohol and tobacco questions, however, may be hidden in missing certificates or in answers of "no use". This appears to be true for the alcohol use item, however, comparisons of the proportion of mothers using tobacco are surprisingly near tobacco use figures for women of childbearing age obtained through the 1988 Texas Behavioral Risk Factor Survey.[1]

Missing information for new medical data on birth certificates does exhibit unusual biases which suggest selective withholding of information. Generally, we expect more missing information for teenaged, minority, less educated, and unmarried mothers, who have less access to prenatal and other kinds of care. However, mothers for whom certificate bottoms were either missing or left blank exhibit exactly the opposite characteristics. As Table 2 shows, the mothers who were older, white, married, and better educated had a greater percentage of missing or blank certificate bottoms.

Examining bottoms which contain at least one piece of medical information, the expected trend for

missing data emerges. White mothers in their twenties and thirties who are married and better educated are more likely to have complete medical information on the bottom of the certificate than other mothers (see Table 2). Of certificates which have one or more categories on the bottom left blank, a similar pattern to the blank and missing bottoms arises: the average number of missing categories is slightly higher for better educated, older, and married women. Since the most important component of missing bottom information is blank or missing bottoms, the effect is either to skew the data in the opposite way we would expect it to be skewed or to balance the effect of missing data from mothers for whom information normally is missing.

These unusual biases probably result from resistance by some physicians to the collection of medical data on the birth certificate. The women for whom no bottoms or blank bottoms are returned are typically those women who deliver in private hospitals and are attended by a medical doctor. Examination of missing/blank bottoms by birth attendant and place of birth suggest that this hypothesis may be valid. For example, while Certified Nurse-Midwives returned at least one piece of medical information for 98.1 percent of births that they attended, only 93.8 percent of medical doctors did the same (see Table 2). Although hospitals had the best record for returning certificate bottoms compared to birthing centers, clinics or doctor's offices, residences, and other locales, only 93.8 percent of certificates returned by hospitals were not missing certificate bottoms. Query letters sent to hospitals regarding each certificate with a missing bottom resulted in the return of about one third of these certificates with some information recorded on them in 1990. As use of the revised certificate continues, more stringent measures should be taken to reduce missing data. This subject also requires more investigation to determine the characteristics of the facilities and individuals who register births but do not return bottoms or return blank ones.

Accuracy of Recording and Data Entry

While reducing missing data will be crucial to improving the quality of new medical data from the birth certificate, what hospitals are recording on those certificates and how information is keyed are more critical to data quality. Examination of certificate bottoms indicates that persons filling out the certificates need much more guidance about the specific kinds of information which belong in each category of the certificate, and that limiting the amount of information re-

Table 3. Missing information by category on the medical portion of the revised Texas birth certificate, 1990 (provisional).

Category	Number of unknowns	Percent unknowns from blank/ missing bottoms	Percent unknowns from within category
Medical factors for this pregnancy	28,267	67.5	32.5
Tobacco use during pregnancy	32,168	59.3	40.7
Average number of cigarettes per day	36,864	51.7	48.3
Alcohol use during pregnancy	37,156	51.3	48.7
Average number of drinks per week	39,580	48.2	51.8
Pre-pregnancy weight	89,829	21.2	78.8
Weight gained during pregnancy	94,949	20.1	79.9
Obstetric procedures	29,516	64.6	35.4
Events of labor and/or delivery	32,113	59.4	40.6
Method of delivery	26,972	70.7	29.3
Abnormal conditions of the newborn	35,454	53.8	46.2
Congenital anomalies of child	44,973	42.4	57.6

corded on the certificate should be considered as an option to improve the quality of information.

Evaluation of samples of information from four categories on the certificate bottom— Medical Factors for this Pregnancy, Events of Labor and/or Delivery, Abnormal Conditions of the Newborn, and Congenital Anomalies of the Child— show that incorrect recording of information by the person registering the birth was the largest source of error in these data (see Table 4). Because the percentage of births recording information in these categories is small, the samples were drawn only from certificates which recorded one or more pieces of information in the specific category in order to examine the accuracy of information about conditions themselves.

About two to eight percent of the conditions on the computer file were mis-keyed by data entry operators at TDH. Twenty to 46 percent of the information recorded by the person registering the birth was reported incorrectly on the certificate. Medical Risks and Events of Labor had smaller error rates in reporting (27 and 20 percent, respectively) than Abnormal Conditions and Congenital Anomalies (46 and 39 percent). Persons filling out the certificates seem to get tired, or exasperated, by the time they get to these two categories, which are the last on the certificate, and check marks on the paper get sloppy. Also, they have some difficulty in distinguishing between Congenital Anomalies and Abnormal Conditions, so that conditions get cross-recorded.

Other problems in reporting arise not from resistance to reporting but from a tendency to report any piece of information in which TDH possibly might be interested, especially in the space provided for recording information not specifically listed in the checkboxes— the "other" categories. The headings on the categories seem to cause the most confusion, prompting persons filling out these records to put anything which might seem to fit in these categories into the "other" blank, resulting in, for example, reporting of congenital anomalies as abnormal conditions and vice-versa. "Prematurity" seems to fit into every category of the certificate, as do "twins", "no prenatal care", "congenital anomalies", "infant of drug abuse/diabetic mother", "skin tags", and "previous c-section". The "other" blank in the Congenital Anomalies category, the last category on the certificate, seems to be considered by some as a kind of "comments" section for the whole certificate bottom, inflating the general number of anomalies reported. "Planned home birth", for example, was recorded in the "other" blank of the Congenital Anomalies category on several certificates. This is consistent with the puzzling rise in the proportion of "other" conditions found by at least one other state.[2] These kinds of entries were the largest source of errors in recording.

Although a hospital or midwife may mis-record an event on a certificate, some of these errors are corrected during data-entry. The overall error rate for each category, therefore, is smaller than the sum of the error rate for hospital misrecording and keying error. The total percentage of certificates classified within a category which should not be counted within that category runs from 6 percent for Events of Labor and Delivery to 40 percent for Abnormal Conditions of the Newborn (see Table 4). Many of these conditions were ambiguously marked by hospitals and data-entered within a category because the check marks were close to or touching an incorrect box, or were between boxes. The small size of the boxes presents problems to persons both trying to read the small print and mark the box correctly. Because some persons filling out the certificates either used typewriters or printers which were shifted a line or they could not seem to hit a box by hand, some conditions, especially congenital anomalies, were inflated.

As an example of how such misrecording can affect the reporting of a specific condition, we examined the accuracy of recording and keying of anencephaly. Since anencephaly is an immediately identifiable and fatal anomaly, it is ideal for checking the accuracy of reporting on the birth certificate. To examine quality of data for this checkbox, two procedures were followed. First, infant death certificates recording anencephaly as a cause of death were matched with birth certificates to ascertain whether anencephaly was reported and keyed correctly from the birth certificate. Second, birth certificate bottoms on which anencephaly was punched were located and evaluated for

Table 4. Correctness of reporting and keypunching for selected categories from the medical portion of the revised Texas birth certificate, 1990 (provisional). Samples exclude categories marked "None".

Category	Number of bottoms in sample	Percent correctly recorded and keypunched	Percent incorrectly keypunched by TDH	Percent incorrectly recorded by individuals	Percent which should not be in category
Medical factors for this pregnancy	55	71 %	2 %	27 %	25 %
Events of labor and/or delivery	65	78	2	20	6
Abnormal conditions of the newborn	48	48	6	46	40
Congenital anomalies of child	62	53	8	39	29
Anencephaly	167	75	17	8	23

recording and keying errors. We hope to query hospitals about these cases at a later date.

In 1990, 48 anencephalic infant deaths were reported in Texas. For the 30 of these infants for whom the medical portion of the birth certificate could be found, one was blank in the Congenital Anomaly category, seven were clearly marked "None", and two should have been keyed as anencephalic infants but were mis-keyed to "none noted". In all, 22 (73 percent) of these infant deaths were recorded on the birth certificate as having anencephaly. This result is unsurprising; other studies of congenital anomaly reporting on birth certificates have shown them to be a poor source for this kind of information.[3]

On the birth certificate in 1990, 187 cases of anencephaly were keyed into the computer. Of the 167 cases for which the medical portion of the birth certificate could be located, 75 percent were both correctly reported and keypunched. Seventeen percent were incorrectly keyed by TDH; some of these were incorrect entries from certificates which were ambiguously marked. Eight percent were incorrectly reported by hospitals. Almost one quarter of cases keyed on the birth computer file as anencephalic infants should not have been recorded as such. As mentioned earlier, some of these were from certificates which had ambiguous markings. These certificates should have been set aside for querying or the ambiguous markings should have been considered unkeyable.

One important reason to query these anencephalic births is to ascertain whether we are in fact getting increased reporting of this anomaly. In the past, the number of infant deaths due to anencephaly and the number of infants reported as having anencephaly on the birth certificate have followed one another quite closely, and were usually within ten cases of one another. In 1989 and 1990, however, the number of anencephaly cases reported on the birth certificate zoomed upward. Even using the information described previously on the accuracy of reporting and keying of this anomaly to lower our estimate of the number of anencephaly cases, the estimated number of anencephaly cases from the 1990 birth certificate was still 137, about three times the number of infant deaths reported with that condition. It is unlikely, however, that the anomaly is that much better reported on the birth certificate. The estimated rate of cases using the revised information from the birth certificate would be 5.6 per 10,000 *live births*. The Birth Defects Monitoring Program, however, reported a national rate of 3.14 per 10,000 *live births and fetal deaths.*[4] Possibly some of these "better reported" cases result from those individuals filling out the certificates simply missing the "None" box on the certificate. The anencephaly checkbox is placed directly below this box. Again, querying these certificates may help pinpoint this problem. From our experience with this category, one might also look at other conditions on the certificate which are next to "none" or other frequently checked parts to ascertain whether their incidence is inflated.

Some problems of ambiguous or mis-reporting can be corrected by alerting the hospital to these problems, and keying errors could be corrected by double-entry, which because of budget constraints cannot be done at this time. Many of these problems, however, seem to be inherent in the design of the certificate. Our experience indicates that removing the "other" categories so that persons filling out certificates do not have this option would be an improvement— a case of less is better. Checkboxes should be bigger. Perhaps brief instructions should be included on the back of the certificate.

We also may need to rethink whether the collection of much of this information should be a function of the birth certificate or whether it is better collected using other instruments such as surveys or birth defect registries. It is well known that congenital anomalies are underreported on birth records, and recent evidence suggests overreporting for some anomalies.[5] Since Texas is currently evaluating the viability of a birth defects registry with information from the birth certificate as its base, this might be the time to issue serious warnings on the reliability of the birth certificate for collecting this kind of information.

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Notes

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ETHNIC DIFFERENCES IN MATERNAL WEIGHT GAIN DURING PREGNANCY

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INTRODUCTION

Maternal weight gain (MWG) during pregnancy is an important predictor of birth outcomes. Laros and Abrams (1986) found a 20.1 gram increase in birth weight for each 1 kilogram increase in maternal weight gain. A comparable relationship was found in a meta-analysis by Kramer (1987). The Institute of Medicine has recently issued recommendations that the optimal weight gain for normal women should be between 25-35 lbs. Weight gain should be slightly higher for underweight women, while lower for overweight women (IOM, 1990). Furthermore, the Institute has also addressed possible ethnic differences in optimal weight gain during pregnancy. The Institute recommends that Black women "should strive to gain weight at the upper end of the target range" since "for a given weight gain, Black women had babies that were lighter than non-Black." These recommendations were based on the 1980 Natality survey (Taffel, 1986), which was limited in many key respects. Although Blacks and Whites were compared, other ethnicities were not included. Numerous sources were utilized in order to ascertain data on weight gain and other factors. Most importantly, the survey contained only limited information on confounding variables.

Information now being collected on the revised New York City birth certificate provides a new opportunity to investigate the relationship between maternal weight gain and birth weight by ethnicity while correcting for some of the methodological problems mentioned. The purpose of this paper is to conduct an analysis of ethnic differences in maternal weight gain, and in turn, to show how these differences may be associated with disparities in birth weight.

Since the investigation of maternal weight gain using a population-based registry is novel, the first aim of this study is to address the representativeness of the sample, i.e., how does the population with anthropometric data differ from that without? The second aim of the study is to describe the pattern of weight gain among different ethnic groups. Because of the large sample size, more specific ethnic groups can be identified. Therefore, it is possible to note the variability in a heterogeneous population located within a small geographic region. Thirdly, important covariates to both birth weight and maternal weight gain need to be identified. Ultimately, we aim to attain a clearer understanding of how ethnicity influences the relationship between maternal weight gain and birth weight.

METHODS

All singleton births occurring to New York City residents in 1988 were included in the analysis. In 1988 the New York City's Bureau of Vital Statistics added two anthropometric variables to the birth certificate: one concerning maternal pre-pregnancy weight and the other concerning maternal weight gain during pregnancy, each of which were coded to the nearest pound. Plural births were excluded because of different growth and development processes, and non-residents were excluded to reduce heterogeneity of the study population.

Birth certificates are compiled by medical staff shortly after delivery by using interview and medical record data, and these are then filed with the New York City Department of Health. The determination of ethnicity is based upon possible numerous permutations of self-reported maternal race and ancestry. For this study, the population was classified a priori into five groups: Puerto Rican, Other Hispanic, Asian, (Non-Hispanic) White and (Non-Hispanic) Black. These categories represent broad ethnic divisions in New York City, large enough for statistical analyses, but also represent cultural differences among the population. Of course, a great deal of heterogeneity may be found in each group: "Other Hispanics" constitutes Mexicans, Cubans, and all others from Spanish-speaking Central and South American countries; "Asians" includes people from Southeast Asia to the Middle East, etc. Statistical analyses were performed with SAS.

RESULTS

In 1988, a total of 132,226 births occurred in New York City (**Table I**). Of these, 12,199 (9.2%) of the births were excluded for being either plural or nonresident, leaving 120,027 live births available for analysis. The mean maternal age of the study population was 27.0 years, the mean pre-pregnancy weight was 138.7 lbs, the average gestational age was 274.8 days, while the mean birth weight was 3,245.5 gms. Of the women in the study 32.7% were Black, 26.4% were White, 15.1% were Puerto Rican, 16.1% were Other Hispanic, 8.6% were Asians, while 1.0% were of unknown ethnicity.

Of the study population suitable for the analysis 68,036 (56.7%) contained information concerning maternal weight gain. **Table II** demonstrates that the likelihood of having maternal weight gain coded on the birth certificate was associated with many factors. The cases containing maternal weight gain information were more likely to be Asian (66.4%) or White (61.1%), and less likely to be Black (54.0%), Puerto Rican (51.5%) or Other Hispanic (54.9%). Having maternal weight gain information was positively correlated with weeks of gestation, education, parity and an infant birth of over

2500 grams. Smokers (defined as more than 1/2 pack per day during pregnancy) and drinkers (defined as greater than 2 drinks per week during pregnancy) were more likely to have maternal weight gain information than nonsmokers and nondrinkers. However, illicit drug users (those who have ever used cocaine, marijuana or narcotics during pregnancy) were less likely than their abstaining counterparts to have weight gain information. All differences were statistically significant ($p<.001$).

TABLE I: Population Characteristics
NYC Birth Certificates, 1988

	N	Mean(sd)
Total Live Births	132,226	
– Nonres, plural	–12,199	
Study Population	120,027	
Maternal Age (yrs)	119,707	27.0 (5.9)
Prepreg. Wt.(lbs)	71,046	138.7 (28.5)
Gest. Age (day)	113,370	274.8 (20.2)
Birth weight (gms)	120,005	3245.5(608.4)
Ethnicity		Percent
Black	39,298	32.7
White	31,708	26.4
Puerto Rican	18,088	15.1
Other Hispanic	19,341	16.1
Asian	10,370	8.6
Unknown	1,222	1.0

TABLE II: MWG Information
by Selected Characteristics

		% Without MWG	% With
Total	(120027)	43.3%	56.7%
White	(31708)	38.9%	61.1%
Black	(39298)	46.0%	54.0%
Puer. Ric.	(18088)	48.5%	51.5%
Oth. Hisp.	(19341)	45.1%	54.9%
Asian	(10370)	33.6%	66.4%
34–35 gest wks	(4843)	46.2%	53.8%
36–37 gest wks	(13209)	43.5%	56.5%
38–40 gest wks	(40259)	40.7%	59.3%
40–41 gest wks	(37568)	40.0%	60.0%
41+ gest wks	(9784)	42.5%	57.5%
BW <2500gms	(10477)	57.5%	42.5%
<HS graduate	(31606)	49.4%	50.6%
HS graduate	(48705)	44.8%	55.2%
post HS	(35561)	33.2%	66.8%
Nulliparous	(61297)	46.9%	53.1%
Medical Risk	(19550)	38.8%	61.2%
Tobacco	(8618)	35.3%	64.7%
Alcohol	(1713)	39.2%	60.8%
Cocaine	(2637)	57.9%	42.1%
Marijuana	(1016)	54.1%	45.9%
Narcotics	(931)	58.4%	31.6%

The weight gain patterns were assessed for those women whose weight gain information was available (**Table III**). The mean for the sample was 28.3 lbs. Puerto Rican women showed the greatest maternal weight gain (28.8 lbs) followed by Other Hispanics (28.5 lbs). Blacks gained a mean weight of 28.3 lbs, and Whites gained 28.0 lbs. While these four groups varied by less than a pound in mean maternal weight gain, Asians gained, on the average, 1.5 pounds less than the next highest group (26.5 lbs). However, all groups were within the recommended range on a populational level.

TABLE III: Mean Maternal Weight Gain
by Ethnicity

Ethnicity	N	Mean MWG (sd)
Puerto Ricans	9,319	28.8 (12.2)
Other Hispanics	10,626	28.5 (11.3)
Blacks	21,209	28.3 (12.4)
Whites	19,384	28.0 (10.6)
Asians	6,880	26.5 (9.5)

However, when maternal weight gain was divided into categories, a more diverse pattern of weight gain emerges (**Figure I**). To make comparisons with the 1980 Natality Survey, weight gain categories were a priori chosen to be less than 16 lbs, 16-20 lbs, 21-25 lbs, 26-35 lbs and greater than 35 lbs. Of the women with weight gain information, 12% had inadequate weight gain (or less than 16 lbs), but 16.0% of the Blacks had inadequate weight gain. They were followed by Puerto Ricans (13.0%), Asians (11.6%), and Other Hispanics (11.2%). White women were least likely to have inadequate weight gain (9.2%). The percentage of women who gained the recommended weight (that is 26-35 lbs) was larger for White (37.8%) and Asian (37.0%) women than Black (29.8%) or Puerto Rican (30.2%) women. Other Hispanics (33.9%) were intermediate. However, the percentage of Asians women with maternal weight gain over 35 lbs dropped most sharply to 15.5%, while smaller differences existed between Whites (21.8%), Blacks (23.1%), Other Hispanics (24.0%) and Puerto Ricans (25.1%).

Maternal weight gain categories were then analyzed for associations with other known predictors of birth weight. **Figure II** illustrates the percentage of women in each maternal weight gain category at each gestational week. As expected, weight gain is positively correlated with gestational age. The two lightest weight gain categories comprised 35.4% of all births at 35 weeks gestation and only 24.3% of all births at 42 weeks. On the other hand, the two heaviest weight gain categories comprised 46.9% of all births at 35 weeks gestation and 59.6% at 42 weeks.

Maternal substance use during pregnancy is another important predictor of birth weight. **Figure III** shows the percentage of women in each weight gain

category that were positive for each specific substance (i.e., nicotine, alcohol, marijuana, cocaine and narcotics). Cigarette smoking was most strikingly related to weight gain. Overall, 8.2% of the population smoked cigarettes, but among women gaining less than 16 lbs, 13.1% were cigarette smokers while only 1.2% of women gaining over 35 lbs were smokers. Similar, although less striking, was the relationship between cocaine and weight gain. Of the population with maternal weight gain information cocaine was positive for 1.6%. However, 4.2% of women with inadequate weight gain were positive for cocaine.

In addition, a relationship between high risk pregnancy and maternal weight gain was also found. A high risk pregnancy was defined as any pregnancy positive for at least one medical risk factor as listed on the birth certificate, such as cardiac or renal disease, previous low weight or pre-term birth, eclampsia, STDs, etc. Women with a high risk pregnancy had an increased likelihood of inadequate weight gain at 14.2% compared to normal pregnancies at 11.5%

To control for the confounding effects of drug use, high risk pregnancy status and gestational age, the subsequent analyses exclude any birth positive for those risk factors and are presented by gestational week. **Figure IV** shows the mean birth weight for each increasing weight gain category by ethnicity among a sample of pre-term births (i.e., 35 weeks gestation). It should be noted that some of the data points represent few observations. For example, 14 observations are represented for Asians at less than 16 lbs, and only 7 at greater than 35 lbs. However, the data points can represent up to 144 observations.

An increase in maternal weight gain was not consistently related to an increase in mean birth weight, although the overall pattern is one of increase. For pre-term births with inadequate weight gain, Whites generally had the most depressed mean birth weight of all ethnic groups. However, the mean birth weight of White infants was most sensitive to increments in weight gain since the slope increased more steeply when compared to other ethnic groups. When the mother gained at least 36 lbs the mean birth weight was comparable to the other ethnic groups. In comparison, Other Hispanics consistently had the highest mean birth weight, especially when the mother had inadequate weight gain. Therefore, mean birth weight of Other Hispanics responded little to increasing maternal weight gain. For the most part, the birth weight of Puerto Rican, Asian and Black women were intermediate.

Quite a different picture emerges among full-term births. **Figure V** shows the relationship among live births at 39 weeks gestation. The data points represent from 150 to more than 1,000 observations. The relationship between maternal weight gain and birth weight is even clearer in this instance. Except for a slight depression in birth weight among Other Hispanics from less than 16 lbs to 16-20 lbs, mean birth weight increased steadily with increasing maternal weight gain for all ethnic groups.

White women had heavier babies than Black women in all weight gain categories, and, for the most part, had heavier babies than Asians and Puerto Ricans. Other Hispanics are quite comparable in mean birth weight to Whites in all weight gain categories.
Furthermore, mean birth weights among Puerto Ricans and Blacks were more sensitive to increments of maternal weight gain since their rates of increase were the steepest. However, the mean birth weights for all groups were most sensitive to a change in weight gain from 26-35 lbs to greater than 35 lbs., except Asians who had appreciably lower birth weights when gaining over 35 lbs when compared to the other four ethnic groups.

Figure VI shows the same interaction among post-term births, here confined to 42 weeks gestation. The sample size for each data point ranged from 50 to 400 observations. As with pre-term births, the variability in mean birth weight among the five ethnic groups increased and the relationship between birth weight and weight gain was more erratic. The greatest variability in mean birth weight was found among those mothers with inadequate weight gain. Puerto Ricans and Blacks had the lowest mean birth weights, but as with term births, those groups had the sharpest increase of birth weight in relation to weight gain. However, for post-term births Other Hispanics were no longer comparable in mean birth weight to whites at all weight gain categories. Also of note is the sharp increase for the mean Asian birth weight when maternal weight gain increases from 26-35 lbs to greater than 35 lbs. Until that increment, no relationship between maternal weight gain and birth weight had been noted, which is also in contrast to the pattern found among term and pre-term births for that group.

DISCUSSION

Overall, the relationship between mean birth weight and maternal weight gain differs by ethnicity in a complex manner. In concordance with previous research, a depression in mean birth weight among Blacks in comparison to Whites was found. However, this trend was reversed for pre-term births. Furthermore, among minority groups in New York City, a great deal of variability can be found. At term, Other Hispanics were comparable to Whites in weight gain, while Blacks and Puerto Ricans seemed most sensitive to increasing maternal weight. Asian birth weights, for the most part, were the most independent of an association with maternal weight gain.

Figure VII shows that the depression in birth weight of Blacks and Puerto Ricans was not due to either group gaining substantially less weight than the other ethnic groups within each weight category. The mean maternal weight gain was very similar within each weight gain category except when over 35 lbs. Here, Asians gained less weight on average, which may explain the depression in birth weight for that weight gain category found among term births in comparison with other ethnic

groups. However, Blacks and Puerto Ricans actually gained more than Other Hispanics and Whites in this weight gain category.

We also looked at pre-pregnancy weight for each ethnic group. Previous research has shown that the effect of maternal weight gain on mean birth weight is stronger for under- and normal-weight women than overweight women (Abrams & Laros, 1986). Therefore, it might be expected that Blacks and Puerto Ricans, who seemed most sensitive to weight gain, would be under- or normal-weight while Asians would be heavier. However, this relationship was not found (**Table IV**). Asians were substantially lighter and Blacks substantially heavier than the other ethnic groups. The drawback of looking at just pre-pregnancy weight is obvious in that it is not a perfect predictor of nutritional status, since the mean height of the different ethnicities could and probably does differ.

TABLE IV: Mean Prepregnancy Weight by Ethnicity

Ethnicity	N	Mean Prewt (sd)
Blacks	14,490	145.6 (30.2)
Whites	14,256	137.7 (25.0)
Puerto Ricans	6,346	136.5 (27.3)
Other Hispanics	8,411	133.2 (22.4)
Asians	5,806	125.6 (19.9)

excl. smokers, drinkers, illicit drug users and high risk pregnancies

In conclusion, we have found that maternal weight gain differs significantly by ethnicity and, secondly, that the effect of maternal weight gain on mean birth weight differs by ethnicity, even after controlling for the confounding effects of drug use, risk status and gestational age. However, many questions are raised in interpreting these results and in determining why these differences exist. There are many data considerations. We saw that Blacks, Puerto Ricans and Other Hispanics were less likely than Whites and Asians to have maternal weight gain information. Also, many important confounding variables are under-reported, particularly drug histories. However, it is difficult to gauge how increasing ascertainment may change the study results. Furthermore, the confounding effect of cultural, economic and medical variables such as education and prenatal care was not addressed.

These are preliminary results of research investigating the appropriateness of the weight gain recommendations of the IOM. For there are no data showing why Black women and White women with very similar biological, cultural and nutritional profiles should have infants varying in birth weight. Instead, there is a plethora of research showing that less educated, teenage, underweight, cigarette-smoking women with no prenatal care do have lower birth weight babies. However, it is incorrect to assume that a woman from a minority group falls into those categories and should therefore strive for greater weight gains during pregnancy, especially when preliminary findings are showing that a higher percentage of Black and Puerto Rican women in our study gain very high levels of weight.

In closing, the relationship between maternal weight gain and birth weight is complex. However, the growing use of information from population-based vital statistics will provide opportunities to examine the relationship more thoroughly.

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FIG.I: Distribution of Ethnicity by MWG Categories

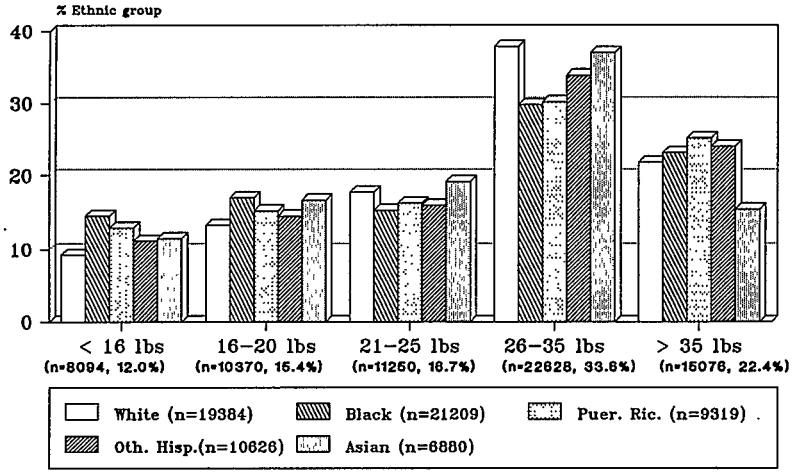


FIG II: Distribution of MWG Categories by Gestational Weeks

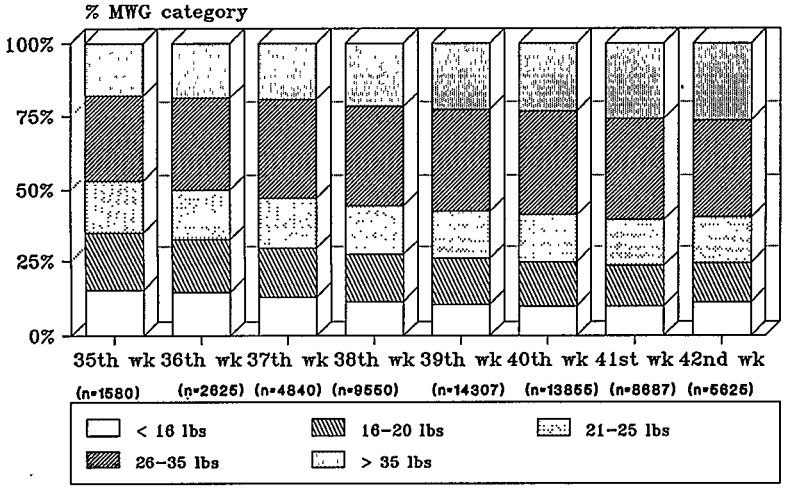


FIG III: MWG Category by Drug Use During Pregnancy

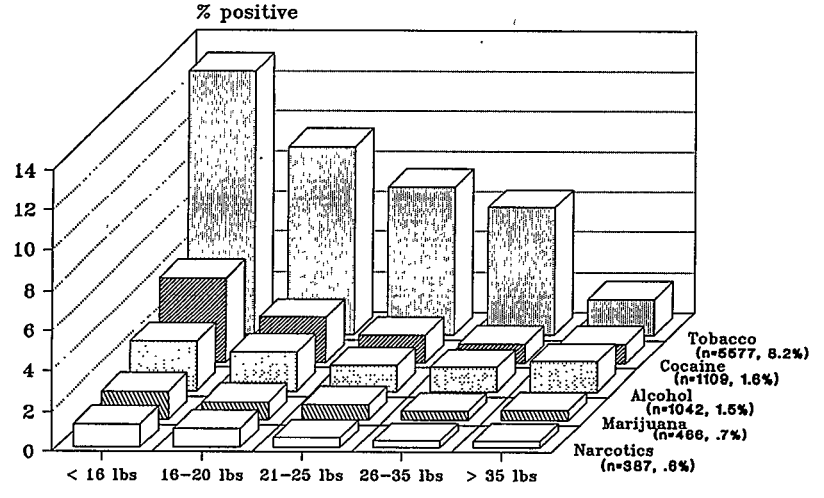
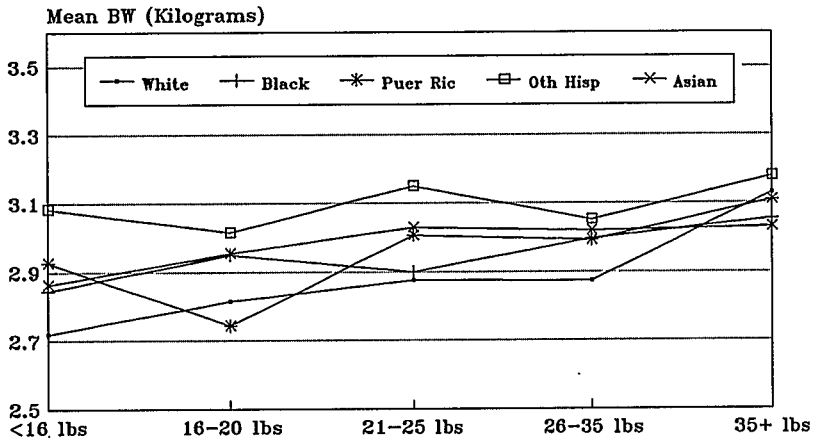
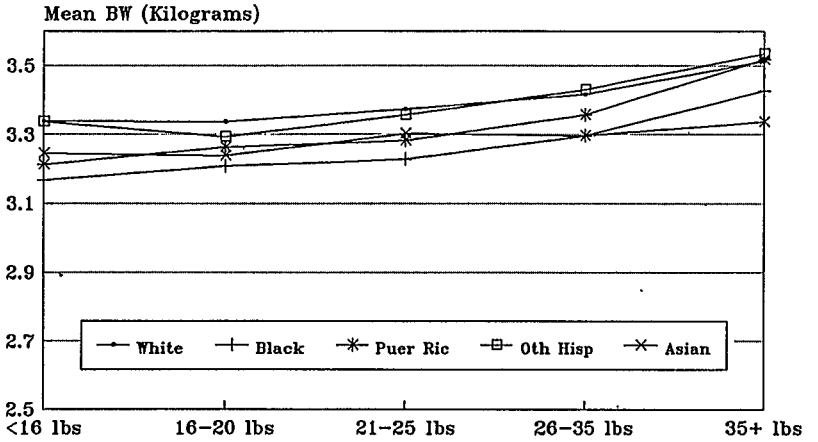


FIG IV: Mean Birth Weight for MWG by Ethnicity 35 wks Gestation



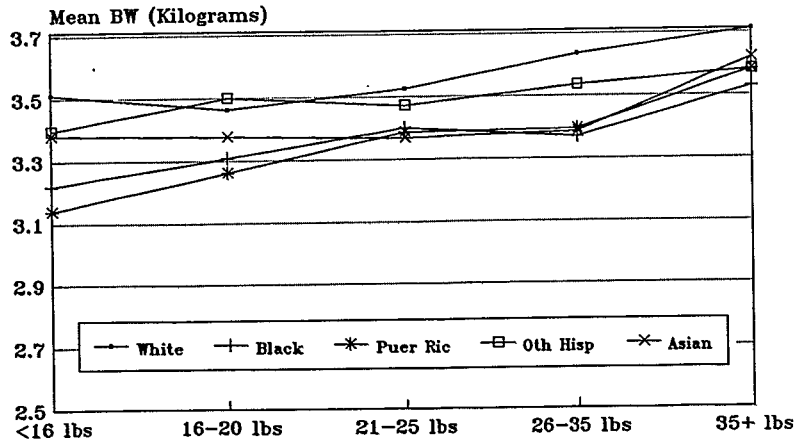
excl. drinkers, smokers; illicit drug users and high risk pregnancies

FIG V: Mean Birth Weight for MWG by Ethnicity 39 wks Gestation



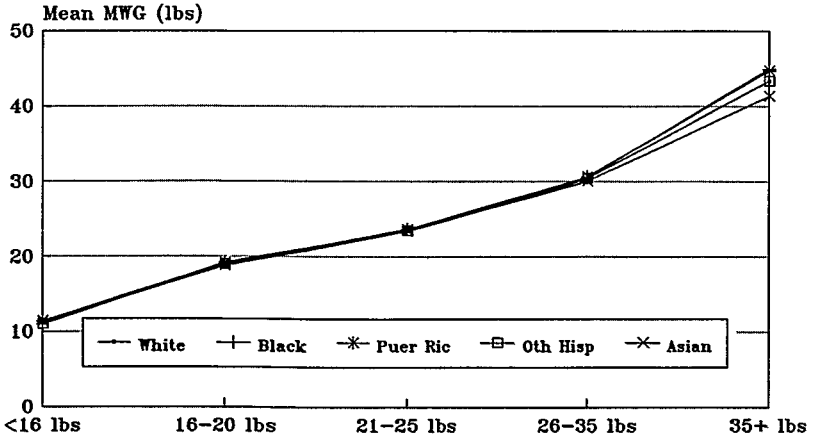
excl. smokers, drinkers, illicit drug users and high risk pregnancies

FIG. VI: Mean Birth Weight for MWG by Ethnicity 42 wks Gestation



excl. smokers, drinkers, illicit drug users and high risk pregnancies

FIG. VII: Mean Maternal Weight Gain Within Each Weight Gain Category by Ethnicity



excl. smokers, drinkers, illicit drug users and high risk pregnancies

A COMPARISON OF PREGNANCY OUTCOMES TO US AND FOREIGN-BORN BLACK WOMEN AT BOSTON CITY HOSPITAL

Jim Roeber, Boston (MA) Department of Health and Hospitals
Karen Power, Lois McCloskey, Micheal Schwartz

In 1989, Black mothers in the city of Boston had an almost two-fold higher rate of low-birthweight births than non-Black mothers (Table 1)[1]. This racial disparity in birthweight distribution is the starting point for many discussions of the problem of poor pregnancy outcome, as well as for discussions of where to focus preventative interventions.

Table 1. Rates and Relative Risks of Low Birthweight Pregnancy Outcomes, by Maternal Race/Ethnicity, Boston, 1989

Race/Ethnicity	Rate(+)	Relative Risk(*)	
Black	124	--	-- --
Non-Black	64	1.94	(1.71, 2.21)
White	53	2.35	(2.01, 2.75)
Hispanic	87	1.41	(1.19, 1.68)
Total	86	--	-- --

\+ Low Birthweight outcomes, per 1000 live births
* Black rate/non-Black rate (with 95% CI)

The current study investigates birthweight outcomes in a subset of births from the city of Boston, in order to address the question of whether this heightened risk of low birthweight outcomes is in fact uniform within the population of Black mothers. The intra-racial comparison chosen for attention was a comparison of U.S. to foreign-born Black mothers. This focus was motivated by the observation that in recent years the number of births to foreign-born Black women has been increasing in the city of Boston. From the point of view of informing the planning of services, it made sense to see if the needs of U.S. and foreign-born Black mothers were similar, as reflected in similarly poor birthweight outcomes and similarly high exposure to risks associated with poor outcomes.

The study sample chosen for this investigation was all births delivered to Boston residents at Boston City Hospital (n=2106) during a recent time period (3/22/89-8/22/90). Boston City Hospital was chosen in part because it is the cities major municipal hospital, serving the most ethnically diverse and statistically at-risk catchment area in the city. It was also chosen because of the availability, within the hospital, of a database which readily allows for investigation of the relationship between poor pregnancy outcomes and exposure to various risk factors. This database comprises all birth certificate data for all births delivered at the hospital since March of 1989. It was at that time that compilation of birth certificate data for Boston City Hospital births was automated using the Automated Vital Statistics System (AVSS)[2], operated by the cities Office of Health and Vital Statistics[3]. The sample and time frame of this study represent the first 17 months of data collection by this system. The birth certificate data used in this study included a range of socio-demographic, behavioral, and prenatal-care utilization measures, as well as measures of gestational age, maternal weight gain, and infant birthweight. A maternal country-of-birth variable included on the certificate was used to make the critical distinction between U.S. and foreign-born Black mothers, which was the basis for this particular investigation.

As shown in Table 2, the majority of women delivering at Boston City Hospital during the study period were Black. The remaining births were divided between Hispanic and White mothers. A look at the Black mothers by place-of-birth

Table 2. Maternal Race/Ethnicity for Births to Boston Residents, Boston City Hospital, 3/22/89-8/22/90

Race/Ethnicity	n	(%)
Black	1454	(69)
Hispanic	308	(15)
White	281	(13)
Other	63	(3)
Total	2106	(100)

(Table 3) shows that almost half (44%) of the Black mothers in the study sample were born outside the United States. The majority (59%) of these foreign-born mothers were born in Haiti, with Cape Verde, and Jamaica being the other major countries of origin.

The major findings of this study, reflecting the steps undertaken in the analysis, can be summarized as follows:

1) Like Black mothers city-wide, Black mothers delivering at Boston City Hospital during the study period were significantly more likely to have had low-birthweight babies than non-Black mothers (see Table 4).

Table 3. Maternal Place-of-Birth for Black Boston Resident Mothers, Boston City Hospital, 3/22/89-8/22/90

Place of Birth	n	(%)
United States	809	(56)
Haiti	381	(26)
Cape Verde	109	(7)
Jamaica	36	(2)
Other Caribbean	69	(5)
Africa	44	(3)
Other	6	(<1)
Total	1454	(100)

Table 4. Rates and Relative Risks of Low Birthweight Pregnancy Outcomes, by Maternal Race/Ethnicity, Boston Residents delivering at Boston City Hospital, 1989 3/22/89-8/22/90

Race/Ethnicity	Rate(+)	Relative Risk(*)
Black	160	-- -- --
Non-Black	103	1.55 (1.21, 2.01)
White	103	1.55 (1.08, 2.23)
Hispanic	104	1.54 (1.09, 2.19)
Total	142	-- -- --

+ Low Birthweight outcomes, per 1000 live births
* Black rate/non-Black rate (with 95% CI)

2) The risk of low-birthweight was not homogeneous within the Black sample, however: US-born Black mothers delivering at Boston City Hospital were two-and-a-half times more likely to have had a low-birthweight baby than foreign-born Black mothers (see Table 5). Another way of

Table 5. Rates and Relative Risk of Low Birthweight Pregnancy Outcomes, by Maternal Place-of-Birth, Black Boston Residents delivering at Boston City Hospital, 3/22/89-8/22/90

Race/Ethnicity	Rate(+)	Relative Risk(*)
US-born	218	-- -- --
Foreign-born	88	2.47 (1.86, 3.26)
Total	160	-- -- --

+ Low Birthweight outcomes, per 1000 live births
* US-born/foreign-born rate (with 95% CI)

stating this is that while Black women as a group were one-and-a-half times more likely to have low-birthweight babies than non-Black mothers (Table 4), foreign-born Black women as a sub-group were actually less likely to have low birthweight babies than non-Black mothers. US-born Black mothers, on the other hand, were more than two times more likely to have low birthweight babies than non-Black mothers (see Table 6).

Table 6. Rates and Relative Risk of Low Birthweight Pregnancy Outcomes, comparing Black Boston Residents, by Place-of-Birth, to Non-Black Boston residents delivering at Boston City Hospital, 3/22/89-8/22/90

Race/Ethnicity	Rate(+)	Relative Risk(*)
US-born Black	218	-- -- --
Non-Black	103	2.12 (1.46, 3.05)
Foreign-born Black/	88	-- -- --
Non-Black	103	0.85 (0.56, 1.31)

+ Low Birthweight outcomes, per 1000 live births
* Black/Non-Black rate (with 95% CI)

Clearly, the risk of the negative pregnancy outcome of low birthweight is not homogeneously distributed in the population of Black women delivering at Boston City Hospital.

3) This intra-racial disparity may be partly explained by differences between US and foreign-born Black women in exposure to the various risk factors for low-birthweight which are documented on the birth certificate. US-born Black women were found to have significantly more exposure to 10 of 14 risk factors for which information was available on the birth certificate. These risks included being teen-aged, being unmarried, having had less than a high school education, having ever smoked or drank during pregnancy, having had a short birth interval, having had low weight gain during the pregnancy, having had inadequate prenatal care, and having had a premature delivery (see Table 7).

4) On the other hand, the results of multivariate logistic modelling, simultaneously controlling for maternal place-of-birth (US vs foreign-born) as well as the above-mentioned risk factors, supports the conclusion that being US-born is an independent and significant risk factor for low-birthweight outcome, at least in this particular sample of Black Boston residents. Specifically, even after controlling for differences in exposure to all the potentially confounding risk factors for which data was available on the birth certificate, US-Born Black women were still 1.76 times more likely to have had a low-birthweight baby than foreign-born Black women (see Table 8).

These results suggest several conclusions. First, they suggest that it isn't really appropriate to speak of a "racial" disparity in birthweight outcomes, at least when discussing the catchment population of Boston City Hospital. The use of the phrase "racial disparity" implies that risk in this sample is somehow inevitably associated with being Black, or that it is homogeneously distributed within the "at-risk" (eg Black) population. The results of this study clearly show that risk is not uniform within the racial category. Instead, excess risk of low-birthweight outcomes seems to be distributed along ethnic lines, with some part of the African-American population ultimately bearing the excess burden of these poor pregnancy outcomes.

A second conclusion supported by this study is that there is something about being US-born and Black, above and beyond being more likely to be teen-aged, unmarried, a smoker, etc, which contributes to low-birthweight pregnancy outcomes. The converse statement is that there may be things about being a foreign-born Black which are associated with relatively better pregnancy outcomes. Unfortunately, no measure of the foreign-born mother's duration of residence in the US is included on the birth certificate. Otherwise we might be able to document the persistence or fragility of any ameliorative effects of being a foreign-born Black in the United States.

In the meantime, this study provides an estimate of the degree to which other aspects of being African-American, aspects which are not reported on the birth certificate, contribute to the excess risk of poor birthweight outcomes. Factors which were not controlled for in this

Table 7. Comparison of Risk Factors for Low Birthweight, by Mother's Place-of-Birth, Black Boston Residents delivering at Boston City Hospital, 3/22/89-8/22/90

Risk Factor	% at Risk US-born (n=809)	Foreign-born (n=645)	
Teen-age mother (≤ 18 years old)	15	3	*
Single mother	89	52	*
Mother has < high school education	46	38	*
Mother smoked during pregnancy	38	2	*
Mother drank during pregnancy	4	1	*
No method of payment for prenatal care	15	12	
Mother lives in neighborhood with high rate of low birthweight outcomes	88	86	
Short birth interval (≤ 1 year)	19	12	*
Low maternal weight gain (≤ 16 lbs)	30	23	*
Less than 9 prenatal care visits	58	44	*
Inadequate/no prenatal care (modified Kessner Index)	35	25	*
Premature delivery (gest age ≤ 36 weeks)	23	11	*

* significant difference (p<.01), based on chi-square comparison

Table 8. Results of Multivariate Logistic Analysis of Low-Birthweight: relation of mother's place-of-birth to low-birthweight outcome, controlling for 8 associated risk factors, Black Boston residents delivering at Boston City Hospital, 3/22/89-8/22/90

Variable	(description: mother...)	Adjusted Odds Ratio(+)	p
USBORN	(is US (vs foreign)-born)	1.76	.0106
AGELE18	(is age ≤ 18)	0.84	.6031
SINGLE	(is single)	1.32	.2446
LESSTHHS	(has < high school education)	1.06	.7635
SMOKES	(smoked during pregnancy)	1.31	.2103
DRINKS	(drank during pregnancy)	0.94	.8950
GAINLT16	(gained < 16 lbs during pregnancy)	2.10	.0001
INADEQUA	(had inadequate prenatal care)	1.14	.4853
PREMATUR	(delivery at gestational age ≤ 36 wks)	15.64	.0001

+ odds of low birthweight outcome to index group, adjusted for effects of other variables

study, which may be differentially distributed between US and foreign-born Blacks in the catchment area, and which may contribute to the observed difference in birthweight outcomes between these groups, include nutritional differences and substance use/exposure differences. They also include the accumulated physiological and psychological stresses of racism, poverty, and economic injustice, as they effect many African American mothers and the fathers of their children. Until we systematically collect data which adequately measure these various factors, we will be unable to control for them in our analyses, and hence unable to reliably estimate their contribution to poor birthweight outcomes.

Finally, just as this study warns us not to generalize about the risk of negative outcomes to Blacks, so it is important not to generalize about the risk to African-Americans. As we continue to explore the roots of negative pregnancy outcomes, in such studies as the Boston Department of Health and Hospital's Case-by-Case review of infant mortality, we should pay special attention to the experience of control groups, women whose pregnancies have not had poor outcomes. In this way we can learn from the lives of the healthy and the strong in the community, as well as the lives of the struggling and the at-risk, as we broaden our understanding of the personal, family, and environmental attributes which are associated with positive, as well as negative, pregnancy outcomes.

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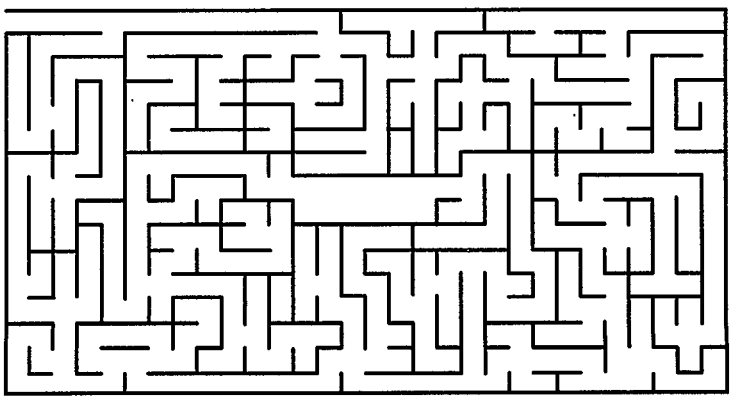
1. Boston Natality Report, 1989, Office of Health and Vital Statistics, Department of Health and Hospitals, Boston, MA, 1991.

2. AVSS Users Manual, Community Organization Research Institute, University of California, Santa Barbara, CA, 1987.

3. Births at Boston City Hospital: Data from the Automated Vital Statistics System (AVSS), Office of Health and Vital Statistics, Department of Health and Hospitals, Boston, MA, 1990.

Session W

Computer Assisted Survey Information Collection



CLASIC SOFTWARE

John S. Gardenier, National Center for Health Statistics

Introduction

The Federal Office of Management and Budget has a Federal Committee on Statistical Methodology. One of its subcommittees reported in May, 1990 that "Computer Assisted Survey Information Collection" (CASIC) can enhance the quality, speed, and flexibility of statistical data gathering.[1]

CASIC includes several different computer aided methods. Some require carrying computers into the field while others allow a single, centrally located computer system. When computers have to be carried into the field, weight and size become compelling features.

The software described herein is specifically designed for field data collection, hence we inserted L for laptop into the acronym. The result is "Computer/Laptop Assisted Survey Information Collection" (CLASIC) system.

The National Center for Health Statistics has sought to automate some of its most complex interview surveys, especially the National Health Interview Survey (NHIS) and the household interviews of the National Health and Nutrition Examination Survey (NHANES).

Computer Assisted Telephone Interviewing (CATI) just does not work. Apart from the fact that a substantial minority of households do not have telephones, few people will tolerate telephone surveys which often last from one to three hours.

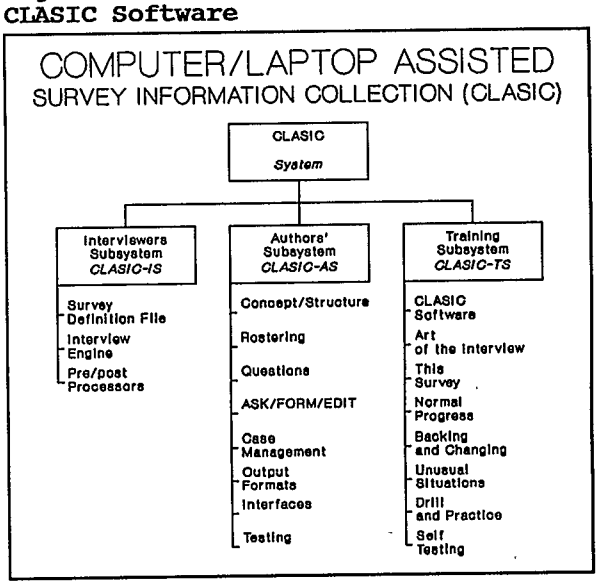
That is not to say that NCHS does not use CATI. It does, but only as a follow-up method for people who have already been interviewed in person.

The Make or Buy Decision

Given that the type of automation must be computer assisted personal interviewing (CAPI), can existing CAPI systems handle NCHS's most complex instruments? In the opinion of the promoters of most survey software systems, the answer is clearly, "Yes!"

An inhouse concept analysis of a suitable CAPI system[2] did not look like any of the existing systems, however. Figure 1. updates that concept.

Figure 1. Conceptual Summary of CLASIC Software



We proceeded to develop the software requirements specifications for an acceptable CAPI interviewing system.[3] Once these were in place, we could either build our own system or adapt one of the more powerful existing survey software systems to meet the full set of specifications.

Three additional considerations led to a decision to go ahead into the development of a new software system:

- The chance to design a software system to work on small computers without concern for the size or complexity of surveys. That is, we could design a CAPI system from the ground up, rather than adapt a CATI system to CAPI.

- The opportunity to design a generic software system to support many surveys using a common architecture for Survey Authoring, Interviewing, and Interviewer Training.

- The chance to optimize system maintainability and minimize risk through use of today's state of the art in programming languages and software engineering methods.

Goals for the Interviewers' Subsystem

The software requirements specifications for the first major subsystem, the Interviewers' Subsystem are quite extensive. The key needs are summarized in Table 1.

Table 1. Interviewers' Subsystem Goals

OPERATIONAL GOALS FOR CLASIC-IS
• Single Program to Run All NCHS CAPI Surveys (Of Any Size) on Laptop Computers
• Survey Text and Logic in Supplemental Files
• Back up and Change Answers Without Data Loss or Corruption
• Resume Interrupted Interview At or Near Point of Interrupt
• Allow Multi-Level Dynamic Rostering
• Keep Score on What Is Needed/Done in Interview

As of late 1990, no existing software system met all of these requirements. On the other hand, there are several excellent survey software packages which satisfy the needs of other complex surveys.

I want to emphasize most strongly that the NCHS decision to develop our own software system should not be interpreted as disparaging other CAPI software systems. Rather, we have some complexities in surveys such as the National Health Interview Survey (NHIS) which demand unique CAPI software features.

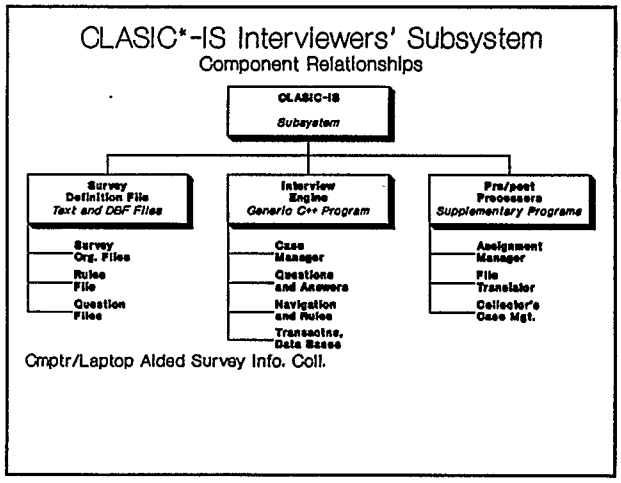
The Structure of CLASIC-IS

CLASIC-IS has three groups of software. Two of these groups are made up of computer programs; one group consists of data and text files.

The central feature of the interviewing subsystem is the Interview Engine. This is a complex computer program written in the C++ programming language. It is intended to be fully generic eventually. That is, the computer program will not contain any material specific to any one survey.

Figure 2. summarizes the subsystem.

Figure 2. CLASIC-IS Structure



Until we have implemented more than one survey, we cannot tell what features of individual case management are generic and which are survey specific. Thus, the Case Manager (CM) component of the Interview Engine is currently unique to the NHIS. It keeps score of what is required versus what has been completed. It allows the interviewer flexibility to move to different sections or to address different family members or other roster elements as needed. It also has sample adjustment and quit features. It writes to survey specific output data bases.

In contrast to CM mode, the remaining components make up the Automatic Questioning (Auto) mode. This mode governs normal navigation, question and answer handling, and temporary answer file management.

The Questions and Answers component governs the screen layouts for presenting questions along with either lists of potential answers or data entry fields for numbers, dates, or text. This same component controls the help feature and the question notes feature. This is the major generic user interface. (The Case Manager has its own user interface.)

The Navigation and Rules component controls all sequencing, question fills, editing of answers, and management of the temporary answer files. For navigation, it dynamically creates (or recreates) the roster structure at run time for each section of each survey. This allows efficient use of computer resources within the context of each interview regardless of the number and

Rules control which questions get asked of which respondents and when, the precise adjustment of question wording, and two levels of editing stringency - errors and warnings. Errors require a correction to the current answer before proceeding. Warnings suggest that an answer to the current (or some other) answer may be needed. The interviewer can override a warning and proceed.

The final component of the interview engine is a group of data base files which always have the same identification and structure regardless of which interview they are supporting. One of the most important of these is the "transaction file," which contains the non-rostered answers. (Rostered answers reside in survey-specific data base files.) Others include the question definition file and the rules file. The contents of these files change with the survey; their names and structures are generic.

CLASIC-IS has one "preprocessor" program and one or two "postprocessors". The Assignment Manager is a preprocessor which accepts data from a collection agency's communication to its interviewer. This tells each interviewer which interviews to conduct, with what sampling guidance or constraints. This component also provides any utilities needed for progress review, file handling, selection of which specific interview to conduct, and program or survey definition updates. It also invokes any postprocessors, as needed.

The File Translator is the postprocessor which translates the transaction file and survey specific data base contents into the output formats required for further processing after the interview.

Either as part of the File Translator or separately, the Collector's Case Management postprocessor prepares all data needed by the collection organization from the interview for purposes of receipt and control, data quality control, or re-interview comparison.

The Assignment Manager and the Collector's Case Management processors have to be specific to each data collection organization, if not to each survey. The File Translator can probably be made generic to respond to output format guidance expressed in the Survey Definition Files. That remains to be demonstrated.

The final major component of the CLASIC-IS subsystem is a set of survey specific files. The ID file defines the survey, the case numbering system, sampling particulars, summary completion codes, and other data for interfacing with the Assignment Manager. There are structural files which define the surveys sections and rosters.

The "Rules" file contains the sequencing, filling, and editing rules which constitute the logic of a specific survey instrument. This is a data base file of variables to be manipulated by the Interview Engine using a basic form of IF-THEN-ACTION logic.

The Question Files consist of two text files and one data base file. The two text files contain the permanent text (not the fill wording) of the help messages and the questions/edit messages respectively. The data base file is a question definition file, to specify the question type, field length for answer entry, any applicable rostering and a variety of options. One option is whether to allow entry of a range of numbers rather than a single number. Another is whether to allow entry of a season if the respondent cannot specify a more precise date.

Status and Outlook

As of this date (July 17, 1990), the software system has been developed adequately to support implementing the NHIS core questionnaire using the Interview Engine and Survey Definition Files only.

We will implement the supplements and program the pre- and post-processors later. We expect to turn over what we have now to the NCHS survey program staff for testing in August. Once they are satisfied that it is basically adequate, they will also provide it to Bureau of the Census (the data collection organization) for their testing as well.

We also plan to implement the household surveys of the Third National Health and Nutrition Examination Survey (NHANES III) this year. That will help us to draw a cleaner line between the generic and the survey specific elements of CLASIC-IS.

We will then turn our attention to developing the CLASIC-AS Survey Authors' Subsystem. The intent of that system is to allow professional survey designers to implement CLASIC surveys without any need for computer programming skills or

to implement CLASIC surveys without any need for computer programming skills or programmer assistance. Our expectation is for only partial success in meeting that goal initially.

Meanwhile, a separate development will soon be getting underway through the Office of Personnel Management for development of a generic computer-based instructional system for CLASIC interviewers.

Over the next three to five years, we expect to move ever closer to full implementation of the concept expressed in Figure 1.

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2. Gardenier, J. S., Kovar, M. G., Shumate, P., and Adams, C., CONCEPT DESIGN FOR THE NCHS COMPUTER ASSISTED PERSONAL INTERVIEWING (CAPI) SOFTWARE SYSTEM, Working Paper 34. Hyattsville, MD: National Center for Health Statistics, September, 1990.

3. Gardenier, J. S., Biggar, R. S., Adams, C., and Shumate, P., SOFTWARE REQUIREMENTS SPECIFICATIONS AND DESIGN OVERVIEW: COMPUTER/LAPTOP ASSISTED SURVEY INFORMATION COLLECTION (CLASIC) INTERVIEWERS' SUBSYSTEM, Working Paper 36. Hyattsville, MD: NCHS; January, 1991.

CAPI CASE MANAGEMENT AND COMMUNICATIONS

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and Karl K. Kindel

This paper presents a brief history, current assessment, and possible future vision of CAPI case management and communications as employed in national, household surveys.

Computer-assisted personal interviewing (CAPI) is a newly developing field. The Netherlands Central Bureau of Statistics (van Bastelaer, Kerssemakers, and Sikkel, 1988), together with Statistics Sweden (Lyberg and Dean, 1989; Statistics Sweden, 1989), have led European development, testing, and implementation of national CAPI surveys. The first national, household survey to use CAPI for all of its data collection, the Netherlands Labor Force Survey, began data collection in January 1987. Adoption of CAPI for the U.K. Labour Force Survey by the U.K. Office of Population Censuses and Surveys (Manners, 1990; and Blackshaw, Tembath, and Birnie, 1990); and for tests of the French Labor Force Survey by the Institut National de la Statistique et des Etudes Economiques (Bernard, 1990) has been based on the methods and software developed in the Netherlands.

In the U.S., the Nationwide Food Consumption Survey (NFCS) was the first national, household survey to use CAPI for at least part of its data collection. It was conducted by National Analysts in 1987 (Rothschild and Wilson, 1988). Concurrent development work by the Research Triangle Institute (RTI) for the Total Exposure Assessment Methodology Studies (Sebestik, et al., 1988) was followed by major tests of CAPI by the National Opinion Research Center (NORC) for the National Longitudinal Survey, Youth Panel (Speizer and Dougherty, 1991) and by Westat for the Medicare Current Beneficiaries Survey (Sperry, Bitner and Branden, 1991). The Census Bureau (Nicholls, 1988) has undertaken several CAPI tests and planned CAPI data collection for the National Health Interview Survey with the National Center for Health Statistics (Thornberry, Rowe, and Biggar, 1990) and for the Current Population Survey with the Bureau of Labor Statistics (Butz and Plewes, 1989). Details of the Census Bureau's current plans are presented in a companion paper by Kindel (1991).

Despite the newness of the field and the geographic dispersion of development, progress in CAPI case management and communications has been remarkably well coordinated through professional papers and informal exchanges among the developers. Progress has been largely cumulative; and a shared sense of the state of the art has begun to emerge.

1. Transmissions and Communications

Household interview surveys require a substantial flow of information to and from the geographically dispersed interviewing staff and the survey organization's central offices. Paper-and-pencil surveys typically mail out training materials, interviewing assignments, and blank interview forms or hand them out during group training sessions. The field staff mail back completed interview forms and reports on the disposition of incompleted cases. Last minute questionnaire changes and case reassignments are handled by special mailings and telephone calls.

Computer-assisted personal interviewing (CAPI) changes both what is transmitted to and from the field and how it is transmitted. The older methods -- training distribution, mail or delivery service, and voice telephone -- can still be used. But three new methods -- mailed or delivered diskettes, telecommunications via modems, and (perhaps in the future) wireless radio data networks -- become new options.

1.1 Hardware, Systems, & Questionnaire

The CAPI microcomputer, general CAPI software, and the CAPI questionnaire (application program) have typically been distributed at group training sessions or sometimes sent to the interviewers' homes shortly before training by a parcel delivery service. Hardware failures are rare but since they usually occur during the first few hours of use, group training is the ideal setting for diagnosis and replacement.

1.2 Assignments, Survey Data, and Dispositions

After the CAPI interviewers are equipped with the basic hardware and software, the primary information flow consists of interviewing assignments sent to the field and completed interview data and case dispositions returned to central offices. Increasingly sophisticated methods have been developed for these purposes in the few years since the first national CAPI survey.

Early CAPI systems often wrote their completed interview data to diskettes. The mailing of diskettes therefore replaced the familiar mailing of paper forms back to central offices. These procedures were followed by the Nationwide Food Consumption Survey (NFCS) and initial uses of CAPI in the National Health Interview Survey (NHIS).

Mailed diskettes have serious drawbacks, including:

1. Costs of the diskettes and of recycling them.
2. Problems of diskette handling, including occasional breakage and failure.
3. Interviewers confusing data, system, and backup diskettes, with occasional overwriting of files.
4 Delays and inconvenience of mailing or arranging for delivery services.
5. The difficulties of checking in, merging, and unduplicating data from multiple diskettes in central offices.

The last proved especially cumbersome in large surveys, such as the NHIS.

As experience with CAPI telecommunications increased, first in Europe and then in the United States, telephone transmissions via modems from interviewers' telephones became the preferred method of transmitting completed interview data back to central offices. A CAPI microcomputer is plugged into a modem (or has an internal modem) which is plugged into a telephone jack, usually in the interviewer's home. The interviewer may initiate the session or the micro may wake up at a scheduled time to begin a night transmission without further interviewer action.

The Dutch, British, and Swedish labor force surveys all use telecommunications to send completed interview data back to central offices as did the test of the French Labor Force Survey. In the U.S. CAPI telecommunications were pioneered by the Research Triangle Institute (Sebestik et al., 1988); and greatly enhanced by NORC developments for the National Longitudinal Survey (NLS). Based on the NLS experiences, Speizer and Dougherty (1991) concluded that telecommunications provide faster, more reliable, and less expensive means of transmitting CAPI data to central offices than do mailed diskettes.

The use of telecommunications to transmit interviewing assignments to the field has developed more slowly. Surveys which used both CAPI and paper forms in the same interview, such as the 1987 NFCS and the NHIS between 1988 and 1990, typically had the interviewer enter the case ID at the start of each CAPI interview. The Dutch and British labor force surveys initially sent interviewing assignments to the field staff on paper or diskettes. Recent tests by NORC, the Census Bureau, and Westat, all confirm the viability of sending interviewing assignments by telecommunications.

While interviewing assignments may consist of no more than a list of addresses to be interviewed, they may include extensive data on assigned cases from prior interviews or other records. Two-way telecommunications of interview data are especially attractive to panel surveys with closely spaced waves since they may make possible (or speed) incorporation of each wave's data in the next.

The current status or disposition of each assigned case also may be telecommunicated to central offices to provide concurrent field progress reports for survey supervisors and managers. The first fully automated telecommunications system for field disposition reporting was designed for the 1989 pilot of the National Household Seroprevalence Survey (O'Reilly et al., 1989). Although the NHSS used paper questionnaires rather than CAPI, the sensitive and complex nature of the field work required unusually prompt, accurate, and thorough field reporting.

The Research Triangle Institute equipped each NHSS interviewer and supervisor with a laptop microcomputer with an internal modem. Each interviewer entered information about each assigned case every night, prepared electronic mail messages for supervisors as necessary, and connected the laptop to a telephone line before midnight. Automatic transmissions occurred at preset times during the night. The survey sample control data base was automatically updated each night, ready to produce a daily progress report, while each local supervisor was sent reports and messages from the interviews they supervised.

1.3 Other Information Transmitted

Two-way electronic mail, as used in the NHSS pilot, is a high priority option for virtually all CAPI systems. Work is in progress to incorporate other unpredictable transmissions within the same system, such as: late corrections to the questionnaire; and reassignment of cases from one interviewer to another. These applications have been explored and tested by RTI and NORC and are being examined by the Census Bureau and Westat. (Sebestik et al., 1988; Speizer and Dougherty, 1990; and Kindel, 1991). Once established, the telecommunications system can be used, at least in principle, for a variety of other functions ranging from segment listing for field sampling to reporting of payroll hours and travel expenses.

1.4 Confidentiality, Security, and Data Integrity

The growth of CAPI telecommunications has been stimulated by technical solutions to potential problems in respondent confidentiality, computer security, and interrupted transmissions.

Since CAPI data files contain only the answers to survey questions, not the questions themselves, they would seem to

provide inherently better protection of respondent confidentiality than paper forms. Further protection is provided by encryption and compression of all files during transmission and by password access to CAPI equipment. At Statistics Sweden (Statistics Sweden, 1989) a variety of additional steps have been examined to ensure respondent confidentiality, such as separating names, addresses, and similar identifying information from survey answer files prior to their transmission. They are recombined at headquarters.

The security of central computer systems from unauthorized or inappropriate dial-in access is an equally important concern. These problems have generally been solved by password access, by writing transmissions to stand-alone systems, and by security filtering these data before they are copied to another system for processing and analysis. No direct connection is established between the remote CAPI microcomputers and the central computers.

Telephone transmissions may be disrupted by noise on the telephone line or by call waiting signals. Speizer and Dougherty (1991) report a transmission failure rate of 10 percent in the NLS. Fortunately, commercially available packages can detect interrupted transmissions, retry failed transmissions immediately without user intervention, and defer files which continue to fail for a later session. This process is becoming increasingly efficient. Early protocols required re-sending entire files if the transmission failed at any point. Newer protocols resume the transmission where it was interrupted and link the sections automatically.

1.5 Cost Effectiveness of Telecommunications

In the past, telecommunications were reserved for small files. Large files were distributed on mailed diskettes for reasons of cost and time. Sending a new questionnaire program of say 1.3 megabytes to one interviewer via 2400 baud modems would require about an hour and 15 minutes of transmission time. Even with 12 sending stations operating 24 hours a day, a full week would be required to reach all 1700 interviewers on the Census Bureau's Current Population Survey. But with compressed files and 14,400 baud modems, which the Census Bureau is planning to use, transmission of the same questionnaire is now estimated at about 2.7 minutes at a cost of roughly 30 cents in line charges. This is substantially less than mailing diskettes or paper forms.

The Census Bureau and NORC have compared the costs of public e-mail systems with dial-in connections to their organizations' own gateway PCs and servers. Both found the public "store and forward" e-mail systems more costly. For the NLS, Speizer and Dougherty (1991) estimated the cost of sending a 30,000 byte file at roughly two to three times the cost of dial-in to NORC's own equipment.

The efficiency of dial-in operations will depend in part on the cost of the central equipment required. The number of receiving ports can be reduced by high transmission speeds and by spreading the peak load. The Census Bureau plans to assign each interviewer a standard automatic transmission time during the night and early morning hours. Provision also has been made for occasional emergency transmission directly initiated by the interviewers.

1.6 Current Status and Future Visions

The design of CAPI communications has focussed to date on urgent production needs, containing costs, and timeliness. Their full impact on survey design lies in the future. Two visions of this future may be shared, although neither is likely within the next few years.

The first is the possibility of rapid response national personal interview surveys, that is, face-to-face surveys mounted in a few days. Computer-assisted telephone interviewing (CATI) helped make rapid response telephone surveys possible. CAPI telecommunications may make rapid response personal interviews possible. The main problems may lie in advance preparation of samples, faster authoring of CAPI questionnaires, and OMB clearance of Federally funded surveys.

The second vision of the future is replacement of telecommunications by wireless radio data networks. One such network was formed this year by IBM and Motorola and licensed by the FCC. It reportedly will permit one-way or interactive transmissions from almost any indoor or outdoor urban location 24 hours a day. Software controlled operations should permit seamless movement from data collection to data transmission. Other competitive networks are becoming available. It is uncertain whether these new networks will live up to their promises, prove cost effective, and provide sufficient protection for respondent confidentiality.

2. Interviewer Case Management

CAPI case management has two main components: (a) "interviewer" case management, that is, managing survey cases and related functions at the interviewer level; and (b) "general" case management at central and other offices.

The literature has much less to say about CAPI case management than about CAPI interviewing and communications. Since the Census Bureau has placed very high priority on case management development and automation, this and the following section of the paper will focus more frequently on the Census Bureau's plans. When we turn to backup systems, however, the broader experience of the field again becomes relevant.

2.1 Core Interviewer Case Management Functions

We can identify eight core functions of interviewer case management. These are:

1. Accept and store interviewing assignments.
2. Display a list of these assignments for the interviewer.
3. Select a case to interview.
4. Store the interview data for later retrieval when necessary.
5. Record the status or disposition of each case, such as complete, partial, appointment, untried.
6. Initiate telecommunications or prepare a diskette for mailing.
7. Provide electronic mail between interviewers and their supervisors.
8. Perform various system functions, such as logging in, setting and using passwords, and maintenance of core files.

These functions are called "core" both because they are central to what a CAPI interviewer must do and also because this is the current state of the art. Few interviewer case management systems presently do more than this, and some lack even a few of these functions.

2.2 Directions of Development

More elaborate interviewer case management systems are being planned with four common directions of development.

The first is core function enhancement. A fixed list of assigned addresses may be less than interviewers need to do their work. They may require options to update, edit, append, sort, and annotate the list. In panel surveys, they also may want to "preview" the household composition or review notes from the previous interviewer before calling at the address.

A second direction of development is fuller automation of both core and enhanced functions. Sending completed interview data to headquarters has sometimes been designed as a multi-step operation of identifying the cases to send, converting them to a new format, dialing the central office, starting the transmission, etc. A better design, employed by NORC, is one-touch operation with the computer performing all steps automatically.

The third -- and probably most significant -- direction of development is managing multiple surveys at the same time. All interviewer case management systems presently known to the authors are one-survey systems. Various organizations, including the Census Bureau, are working on multiple-survey systems, but they are currently somewhat beyond the state of the art. The easiest (although costly and awkward) solution is to have a duplicate system and duplicate hardware for each survey.

The fourth and final direction of development in interviewer case management is adding functions beyond basic interviewing. Top priority for the Census Bureau are training, reinterviewing, and cost and progress reporting. In time, updating maps of sampled areas, listing housing units in sampled blocks, and abstracting records at government offices may be added.

2.3 Backup Systems

Since computing hardware and software occasionally fail, large CAPI surveys prudently devote major attention to backup systems and procedures. For persons trained in traditional survey methods, paper forms seem the obvious backup medium, but paper backup systems have many disadvantages. For example, they cannot duplicate many of the new features increasingly used in CAPI surveys, such as dependent interviewing and complex branching.

Training CAPI interviewers in paper methods also is wasteful when most will never use paper forms or use them only after most of that training has been forgotten. Paper backup forms also may encourage some interviewers to revert to paper-and-pencil interviewing and use their CAPI microcomputers only as home key entry stations. Such patterns, which occurred in early uses of CAPI in the NHIS (Thornberry, Rowe and Biggar, 1990), circumvent the advantages of computer-assisted interviewing while adding costs through the interviewer double entry of answers on paper and then by keyboard. For these reasons, most survey organizations using CAPI have eliminated paper backup as an option.

The alternative is to build redundancy and recovery procedures into the new technology. Laptop or other CAPI hardware failures are rare and best solved by replacement from ready reserves by overnight delivery services. Faulty software is corrected by new self-installing programs distributed on diskettes or by telecommunications. Copies of interviewing assignments can be re-sent from central offices. Frequent (e.g., daily) transmission of

completed interview data to central offices (where files are easily copied) probably affords better protection from loss than batch mailing of paper forms. Interviewers also may be instructed to make and retain copies of data files for each day's interviewing on removable disks (Speizer and Dougherty, 1991).

3. General Case Management

A "general" CAPI case management system manages CAPI information at headquarters and at other offices involved in the design, supervision, processing, and administration of CAPI survey data. Since papers on CAPI have had relatively little to say about general case management, we will move directly to Census Bureau plans.

3.1 Main Components

We think of the general case management system as having three main components.

The first is a wide area communications network (WAN) which links all relevant parties in the survey process. It has three major subcomponents. One is an 800 number telephone dial-up link connecting the dispersed CAPI interviewing staff to a central host at headquarters. This network is isolated from the others for security reasons. The second component of the WAN provides basic telecommunications between Census Bureau headquarters, its twelve Regional Offices, and other centralized collection and processing units. The third consists of high speed data transmission links between the Bureau's telephone interviewing centers and headquarters.

The second component of the general data management system is a set of data bases to store information necessary for the conduct of the survey, including: (a) a sample control and check-in data base (b) a questionnaire data base holding current versions of the questionnaire and supplements; (c) a survey analysis data base; (d) interviewer data bases to develop interviewing assignments and accumulate interviewer performance measures; (e) payroll, personnel, and administrative data bases; and (g) an equipment and software data base to inventory components and log trouble reports.

The third component of the general case management system is a library of computer programs: to update and edit each data base; to move data (in full, in part, or in summary form) from one data base to another; to transmit information to appropriate staff; and to prepare summary reports for managers and supervisors.

A general case management system will undoubtedly reflect the unique structure of the organization that designs it, the types of surveys that organization conducts, and the functions it performs for clients and funding agencies.

The Census Bureau's general case management system must accommodate a very complex organizational structure that includes a headquarters unit, twelve regional offices, a processing unit in Jeffersonville, Indiana, roughly 2,400 interviewers and 400 senior interviewers/local supervisors.

This general case management system also must serve a variety of data collection methods the Census Bureau employs, not just CAPI. Several Census Bureau's surveys will employ a combination of CAPI and CATI, sharing the same sample, questionnaire, and final data set. Other surveys will combine CAPI or CATI with computer-assisted data entry of mailed forms, touch-tone data entry, or other data collection options.

Earlier paragraphs have been somewhat misleading, because the Census Bureau does not plan to construct a general case management system solely for CAPI. Rather it plans to include CAPI case management within a broader CASIC case management system. CASIC stands for "computer-assisted survey information collection" and encompasses all the above data collection technologies.

As should be apparent at this point, the design of CAPI case management quickly shades into much broader issues of organizational planning, especially in data processing. These plans must include maintenance (and sometimes even enhancement) of systems to support paper-and-pencil methods while they are being gradually replaced by CASIC.

A final complication is the potential need to design either a general or interviewer CAPI case management system that accommodates multiple CAPI-CATI interviewing systems concurrently. Not different questionnaires under the same system, but different CAPI-CATI systems, including such general systems as BLAISE, CASES, and AUTOQUEST, those designed by survey sponsors (e.g., the NCHS CLASIC system) as well as interviewing systems developed by the Census Bureau. Designing separate case management systems for each system, partitioning the field staff by system, and/or duplicating equipment at all levels might satisfy the requests of individual sponsors and survey managers, but these arrangements would prove costly and difficult to maintain. This problem is unsolved at this point. Technical, diplomatic, or organizational solutions must be found to simplify the design

task and, more importantly, avoid a bewildering array of different systems for the interviewers in the field.

To conclude, we point to one of the most neglected considerations in CAPI case management design -- the preferences and perceived needs of the interviewers themselves. In the rush to meet essential production requirements, to mount surveys quickly for contract purposes, and to choose software uniquely suited to specific surveys, the needs of the interviewers seem to be largely ignored. None of the papers in this field have yet mentioned interviewer contributions as a significant component of the design of a CAPI case management system.

As the field staff is presented with increasingly complex computer tasks to perform, we hope that the interviewers will be given a more significant role in developing the best means of expediting this work.

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CAPI: IMPACTS ON DATA QUALITY AND SURVEY COSTS

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INTRODUCTION

CAPI (computer-assisted personal interviewing) extends to face-to-face interviewing the CATI (computer-assisted telephone interviewing) technologies developed and deployed in the late 1970s and early 1980s. CAPI questionnaires are designed and implemented in software systems with all of the functionality now common to CATI (See for example, Nicholls and Groves, 1986). The software then is loaded onto a small, light, portable computer so that interviews can be conducted almost anywhere--in respondent's homes, in places of business, in public places such as hospitals, libraries, and restaurants, and even outdoors on porches, in backyards, and public parks.

Proponents of CAPI believe that it offers a number of important advantages over conventional paper and pencil (PAPI) techniques, most notably overall higher data quality and quicker turnaround of interview data at a lower cost. (For discussion, see Baker, 1990.) Although CATI technology has been widely used for over a decade, CAPI has been slower to emerge because of five basic concerns: technical feasibility, respondent acceptance, interviewer acceptance, effects on data quality, and costs. Steady improvements in both software and hardware and several years of international testing and research have put at least the first three of these to rest (Bradburn et al., 1991; NCHS, 1988; Lyberg, 1989; Keller et al., 1990; Foxon, 1988; and Bernard, 1989). There are now several commercially-available software systems which can meet most CAPI requirements. Portable computers weighing seven pounds and less are now on the market and have proven that they can withstand the demands of field interviewing with CAPI. Respondents are generally enthusiastic about CAPI. Interviewers can be trained to use it effectively and view it as a major advancement in their work.

Some questions remain, however, about the impact of CAPI on the quality of survey data and about its cost. This paper focuses on these two critical issues. It describes a controlled experiment to detect mode effects and measure costs on a nationwide CAPI survey. The analysis it presents is very preliminary, but, we believe, provides an interesting overview of the types of benefits which CAPI surveys are likely to realize and the problems they may encounter.

CAPI at NORC

NORC began developing CAPI as early as 1984. After several years of software development and testing, NORC undertook in 1989 a series of field tests aimed at establishing the feasibility of CAPI with then-current hardware and software. We conducted five tests over an eleven month period ranging in size from a small test of five interviewers and 25 respondents to a larger test using 20 interviewers and 300 respondents (Ingels et al., 1989; and Bradburn et al., 1991a). These tests employed then state-of-the-art laptop computers weighing around 10 pounds.

These tests confirmed what other CAPI developers throughout the world were also discovering. While the hardware we were using was less than ideal (too heavy at a little over 10 pounds), CAPI was technically feasible. We found little evidence to support frequently-voiced concerns about interviewer and respondent acceptance. Indeed, both interviewers and respondents embraced the new method of data collection enthusiastically. Still, we remained concerned about possible mode effects and CAPI's cost effectiveness.

CAPI on the NLS/Y

The National Longitudinal Survey of Labor Market Experience/Youth Cohort (NLS/Y) is a longitudinal face-to-face survey now in its 13th year. The survey is funded by the Bureau of Labor Statistics (BLS). The Center for Human Resources Research (CHRR) at Ohio State University is the prime contractor and NORC is the data collection subcontractor. The sample consists of 11,464 people who were aged 14-21 as of January 1,1979 and who have been interviewed every year since. The sample was stratified by sex, race, ethnicity and poverty status with oversampling of blacks, hispanics, white youths in poverty and equal numbers of men and women in each group. The questionnaire is primarily oriented toward labor market participation, education and fertility. It is an extremely complex questionnaire with many skip patterns and extensive rostering. The complexity of the questionnaire and the difficulties that interviewers have in making their way through it make it an ideal candidate for a computer-assisted administration.

Three of the NORC feasibility tests described above focussed on the NLS/Y. In the largest of these tests, half of the Ohio sample for the 1989 round (Round 11), randomly selected from all Ohio cases, was interviewed using CAPI. In all, 301 cases were completed by CAPI (completion rate of 91.8 percent) and 264 cases were completed by PAPI (completion rate of 95.6 percent).

The success of the Round 11 pilot led BLS to consider using CAPI for the full 1990 round (Round 12). Still, they felt they needed answers to three central questions:

- What are the key operational issues for carrying out CAPI on a national scale?
- What are the likely impacts on the data of a change in collection method?
- What are the likely costs of the survey with CAPI?

Additional research clearly was required. Cost considerations mandated that this research be conducted in a live-production framework. BLS agreed to fund a carefully controlled experiment on Round 12 to collect the information needed to answer each of the three questions posed above.

Design of the Experiment

The Round 12 experiment was designed with two constraints. First, it was to be a true experiment and strict procedures were developed to insure that there was no contamination between the experimental and control groups. Second, the experiment could not compromise the quality of the data for the study as a whole, including the overall completion rate target of 92 percent, a completion rate which was necessary to maintain the integrity of the survey panel.

The experimental design called for division of the NLS/Y sample into three subsamples:

- Twenty-five percent of the respondents were to be

interviewed using CAPI

- An additional 25 percent were designated as Control cases to be interviewed using PAPI

- The remaining 50 percent were regular NLS/Y cases, interviewed using PAPI but not part of the experiment.

Data from the CAPI and Control cases will be compared in the analyses of mode effects. The design serves as a substitute for overlapping samples which one might use in a repeated cross-sectional survey. Thus, any mode effects from CAPI which cannot be corrected can be controlled for in any future use of the data.

Because random selection of cases into the two groups would not result in cost efficient clustering of cases for interviewer assignment, mode selection was based on the attributes of the interviewers and their assignment characteristics, for example, geographical location and previous NLS/Y experience. Twenty-five percent (77) of the Round 12 interviewers were randomly assigned to the CAPI condition, 25 percent (77) were assigned to the control condition and the remaining 170 interviewers were assigned to the remaining cases which were also done PAPI.

CHRR develped the interviewing software for the survey. NORC developed the management system, including the telecommunications component that interviewers used to transmit their cases to the NORC central office (Speizer and Dougherty, 1991). NORC Interviewers used Compaq LTE notebook computers, each equipped with a 20 MB hard disk and weighing about seven pounds.

Sample Selection

Field Managers assigned NLS/Y cases to interviewers as in any normal round. Interviewers were characterized by assignment size and complexity, urban versus rural case load, assignment type (regular versus regular-plus-conversion cases), and ethnicity (black, white, or Hispanic). Interviewers with Spanish language cases and cases outside the 48 contiguous states were excluded from the experiment for cost reasons, the anticipated difficulty with international phone transmission of cases, and the cost of providing interviewer support by international long distance. These types of cases are a very small portion of the NLS/Y sample and excluding them from the experiment was judged to have little adverse impact on the generalizability of the experimental findings.

Interviewers were randomly assigned to conditions by using procedures which balanced the conditions on the basis of interviewer type: regular interviewer versus converter; ethnicity; geographic region; and metropolitan/non-metropolitan areas. This was accomplished by sorting the interviewers with respect to these four variables and then forming groups of four "matched" interviewers. Within each matched group, interviewers were randomly distributed among four groups: one CAPI group, one control group, and two regular groups.

Cases belonging to a CAPI condition interviewer were done in the CAPI mode, those belonging to a control interviewer were in the control condition and done PAPI. The remaining cases were "other" and done PAPI. To maintain experimental integrity interviewers and cases could not cross mode, that is a CAPI interviewer could not interview a respondent in any other condition as long as the interviewer was participating in the experiment. No Control interviewers were allowed to do cases using CAPI.

The total number of cases assigned to the CAPI mode was 2814. The Control sample had 2715 cases (See Table 1).

TABLE 1

The NLS/Y Round 12 Experimental Design

	CAPI	Controls	Other
Interviewers	77	77	170
Assigned cases	2814	2715	5935
Completions	2306	2287	N/A
Completion rate	81.9%	84.2%	N/A

Control of the Sample Design

NORC's automated Field Management System (FMS) is designed to track, on a case by case basis, production, cost and sample information. We modified the the system for Round 12 to allow tracking of the experiment so that no contamination occurred between experimental conditions.

Near the end of the field period it became clear that, within the constraints of the budget, we could not achieve the targeted completion rate for the entire study and still maintain strict adherence to the experimental conditions. Thus, for cost reasons, we stopped the experiment after we had reached a completion rate of at least 80 percent each for the CAPI (81.9 percent) and the Control (84.2 percent) conditions. Interviewers completed the remaining cases by whatever method was convenient. The overall completion rate for all of Round 12 was 91.6 percent.

Data for Evaluating the Experiment

A great variety of data were gathered as part of the experiment which will enable us to analyze for mode effects. In addition to the data collected with the main NLS/Y questionnaire, CAPI respondents were asked to complete a brief self-administered paper questionnaire after the interview recording their reactions to being interviewed by computer. Interviewers filled out Interviewer Feedback Forms on each case. Problem Report Forms were used when problems were encountered as well as a lengthy 15th Case Questionnaire and an Exit Questionnaire. The cost of both the CAPI and Control cases was carefully tracked.

DATA QUALITY

While waiting for the Round 12 experimental data to become available we undertook an analysis of the Round 11 feasibility study (Bradburn et al., 1991a). This work suggested three areas for initial hypothesis testing in Round 12: levels of missing data, responses to sensitive questions, and interviewer handling of a series of questions about rates of pay. Because of the great interest of BLS, the experiment's sponsor, in a battery of questions drawn from the Current Population Survey (CPS) we also looked at those questions.

Missing Data

A central feature of computer-assisted interviewing is that it can help prevent interviewers from making mistakes. The most obvious example is following the skip pattern of the questionnaire. Properly programmed CAPI software ensures that the interviewer always follows the correct skip pattern; items cannot be skipped or left blank.

The research record seems to bear this out. For example, a small-scale CAPI feasibility study conducted by Research Triangle Institute in 1987 researchers found that over 90 percent of the errors made by paper and pencil interviewers were failures to record an answer; CAPI interviewers made no such errors (Sebestik et al., 1988). Groves and Mathiowetz (1984) demonstrated that CATI interviewers were able to follow complex skip logic virtually flawlessly, while paper and pencil interviewers made a great many mistakes, almost five times as many as with CATI. Presumably, this same finding applies to CAPI.

TABLE 2
Mean Percent of Items Coded as Refused, Don't Know and Illegal Skip in NLS/Y

	Rounds 1-10	CAPI
Refused	.053%	.045%
Don't Know	.368%	.380%
Illegal Skip	.994%	

Source: Olsen (1991)

Our analysis looked at the three kinds of missing data—incorrect skips, refusals, and don't know responses. Table 2 shows the average rate of incorrect skips, refusals, and don't knows for the first ten rounds of the NLS/Y. It compares these means with similarly computed means for rounds 11 and 12 but using only the data collected with CAPI. While CAPI has no apparent effect on refusals and don't know responses, it completely eliminates illegal skips which account for the overwhelming proportion of missing data in the NLS/Y.

Sensitive Questions

One of the most interesting mode differences among face-to-face, self-administered and telephone interviewing found by Sudman and Bradburn (1974) in their review of response effects was on sensitive questions. They found that in more private modes of administration, such as self-administration, respondents were more likely to report negative behavior. While it is not apparent that CAPI would be viewed as more anonymous that PAPI, since both are face-to-face, it is possible that because the interviewer is entering the responses into a computer rather than writing them down on a form that has the respondent's identifying information on it, respondents feel more anonymous, which encourages them to report more of what they might consider to be negative or sensitive information.

One of the most oft-cited research findings in the CAPI literature is Waterton and Duffy's (1984) study of Scottish drinking habits in which it was reported that self-administered computer-assisted interviews yielded higher estimates of alcohol consumption, a behavior which is traditionally underreported. Our analysis of the NLS/Y Round 11 feasibility test data showed a similar effect. Twenty-three of 26 questions about alcohol-related problems had higher frequencies for CAPI than for PAPI, although only two were statistically significant (Bradburn et al., 1991a). One hypothesis for these findings is that respondents perceive computer-assisted interviews as being more confidential and therefore are more likely to report truthfully.

Unfortunately, the Round 12 questionnaire did not carry over the questions on drinking from Round 11. However, there are a number of questions on use of contraceptives which we examined to see whether there were differences between the two modes. In one series of questions males were asked first whether they or their partner have used any birth control methods in the last month.

TABLE 3

During the last month have you or your partner/spouse used any form of birth control?	Males		Females	
	CAPI	Control	CAPI	Control
Yes	66.1%	58.5%	72.4%	68.3%
No	33.9%	41.5%	27.6%	31.7%
	N=1899	X^2=11.41	N=2168	X^2=4.44

TABLE 4

In the past month, how often have you or your partner/spouse used birth control?	Males		Females	
	CAPI	Control	CAPI	Control
Always	89.5%	93.0%	94.7%	95.0%
Sometimes or Never	10.5%	7.0%	5.3%	5.0%
	N=1170	X^2=4.30	N=1513	X^2=.08

Those responding yes were asked how often. Respondents who said they had used a method were asked which of 15 different methods they used. These same questions were repeated for females.

Frequencies on these items suggest some mode effect. Sixty-six percent of the male CAPI respondents report having used some form of birth control in the previous month compared to 58.5 percent for controls. When males reporting having used a method in the last month were asked how often they used it, 89.5 percent of the CAPI respondents reported that they always used it compared to 93 percent for the controls (Tables 3 and 4). While the differences in both cases are small, they are statistically significant. On the question about specific methods, there were no clear

differences between modes. Seventy-two percent of the female CAPI respondents report having used birth control in the last month as compared to 68 percent of the controls. This difference is statistically significant. Unlike males, females show no reporting differences across mode when asked how often. Similar to the males, there are no apparent differences in reports on the specific methods used.

In addition to these questions on birth control, females also are asked a large number of questions on current and former pregnancies, including questions about health-related behavior such as smoking, drinking, and drug use during pregnancy. While we have yet to analyze these data in detail, our preliminary analysis has not uncovered any mode differences, although for many of these items the skip pattern results in very few cases for analysis.

The hypothesis that respondents perceive computer-assisted interviewing as more confidential and therefore are more likely to report sensitive information is partially born out in the results of a self-administered interview of CAPI respondents immediately after the main interview. Respondents were asked to compare the experience of being interviewed by computer with the experience of the previous eleven rounds of interview by paper and pencil and to indicate which they felt was the more confidential. Forty-seven percent felt that the CAPI interview was more confidential with only five percent favoring paper and pencil. The remaining 48 percent felt that the two modes were equally confidential.

Interviewer Behavior

Although there has been considerable research on interviewer reactions to CAPI, it has mostly been directed at their willingness and ability to adopt to new interviewing technology. There has been relatively little attention paid to how interviewers change their behavior in the actual interview situation. Some proponents of CAPI emphasize that the technology will bring greater control of interviewers and thereby eliminate undesirable features of interviewer behavior, while others argue its major benefit is to give interviewers an improved tool for doing what they always have done.

Our analysis has uncovered one potential change in how interviewers present questions to respondents. The questionnaire has a sequence of questions aimed at establishing wage rates for employed persons. In a multi-part question respondents are first asked how much they earn at their current job. Then they are asked the unit of pay (per hour, per week, and so forth) for the just reported wage. Those who report a unit of pay other than hourly are routed to a question which asks if they are paid by the hour, and if so, how much they earn per hour. All of these questions are on a single page of the questionnaire.

Analysis of the data collected in this set of questions suggests a very interesting phenomenon. The control interviews show significantly more respondents reporting being paid by the hour in the first question in the series than do CAPI interviews, although overall there is no difference across mode in the percent of workers who eventually report being paid by the hour (Table 5). At another point in the questionnaire this identical series of questions is asked about the respondent's spouse with similar results.

One possible explanation for this difference rests in the ways in which questions are presented first to PAPI and CAPI interviewers and then in turn to respondents. With PAPI (and especially with these questions being all on one page) questions may appear in a more obvious context than with PAPI. The interviewer can see the entire sequence, is aware of their purpose (to establish an hourly wage for

TABLE 5

Respondent Unit of Pay

	CAPI	Controls
Identified as hourly in the first question	38.2%	46.5%
Identified as hourly in the second question	25.5%	17.4%
Total Hourly	63.7%	63.9%
Total N	1845	1793

respondents being paid by the hour) and in some cases may probe for an hourly rate in the first question. In the CAPI system used on the NLS/Y, the CAPI interviewer can see only one question at a time, may miss some of the context of the questions, and is less likely to "freelance" in the way a PAPI interviewer sometimes does. This phenomenon of question isolation in CAPI may be gratifying to some and disturbing to others, depending on their feelings about the latitude which interviewers should have in administering a questionnaire.

The CPS Questions

A major area of interest for the experiment's sponsor, BLS, is a group of about 65 questions on current labor force status drawn with some modification from the CPS. Our preliminary analysis of that data from this section of the questionnaire uncovered few differences across mode, with perhaps the most interesting being that on the first and central question of this section: What were you doing most of last week?

In this question the interviewer is instructed first to record the respondent's verbatim answer and then code it to one of

TABLE 6

What were you doing most of last week?	CAPI	Control
Working	69.5%	69.4%
With a job but not at work	3.1%	5.1%
Looking for work	2.0%	2.7%
Keeping house	16.6%	15.7%
Going to school	1.5%	1.5%
Unable to work	1.2%	1.4%
Other	6.1%	4.2%
Total N	2091	2048
X^2=21.49		

the categories in Table 6. Even though the differences in the resulting distribution are small, they are statistically significant. The CAPI cases have more responses to this question in the "Other" category than do the Controls. The

Controls have more responses in the "With a job but not at work" category.

Two hypotheses suggest themselves. The first has to do with the way in which the questionnaire functions in CAPI. The interviewer is given the basic question to read and then records the verbatim. Then the verbatim disappears from the screen and the interviewer is asked to code it to one of the seven categories. It is possible that the interviewer, without being able to see the verbatim, has difficulty fitting it into a category, and simply codes it as "Other."

The second hypothesis relates to how Control cases were processed prior to data entry. Long-standing NLS/Y coding procedures in this section instruct coders to look ahead to other questions directed at respondents who report working less than 35 hours during the report week. These questions establish what the respondent was doing. If the respondent was not working that week but still employed (for example, on vacation or on sick leave) the coder is to return to the first question, check its coding, and correct it if necessary. No parallel procedure exists in CAPI.

We need to explore this issue further, testing both of these hypotheses by looking at Control cases as they came in from the field. Regardless of which proves correct, both teach us something important about CAPI. The first instructs us in the importance of considering software design very carefully. The second alerts us to the importance of reviewing and understanding our traditional procedures very carefully before converting a survey to CAPI.

THE COST OF CAPI

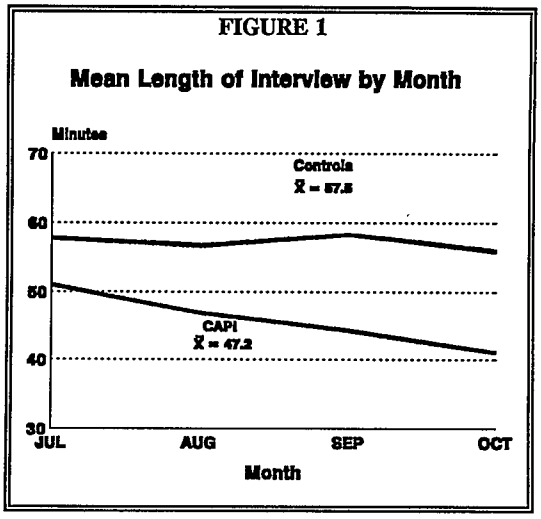
Reducing survey costs is often cited as a likely benefit of CAPI. In theory at least, CAPI eliminates the need for all of the post-interview processing required by paper-and-pencil interviewing, thereby saving the not insignificant costs of keying, machine-editing, and programming to set up and perform these tasks. Skeptics argue that any savings in post processing are offset or even exceeded by the increased cost of interviewing and by pre-field costs such as software design, increased training, and hardware acquisition.

Unfortunately, research on CAPI has not always focussed on cost, preferring instead to look at overall feasibility, respondent acceptance, interviewer acceptance, and so forth. One exception is the previously-cited RTI test (Sebestik, et al., 1988) in which they reported that the costs of fielding their survey with CAPI were higher than paper and pencil (even though they excluded hardware and software costs), largely because the hoped-for savings in processing did not materialize while the cost of interviewing rose. The experience on NLS/Y was somewhat different. The NLS/Y training costs ran about 70 percent higher for CAPI than for PAPI; this compares to about an 18 percent increase reported by RTI. The actual field interviewing costs on NLS/Y were about 12 percent higher, compared to 17 percent for RTI. Unlike the RTI experience, however, the NLS/Y data processing costs—including the hardware—were much lower for CAPI than for PAPI, although the overall cost of the NLS/Y CAPI cases was about 12 percent higher than for the Controls.

It should be noted that the higher field costs are not due to increased interviewing time, but rather to an added support burden the transition to CAPI requires and, in the case of the NLS/Y, allocation of the hardware costs to the field effort rather than data processing. In fact, the actual length of the interview on the Round 12 NLS/Y was much shorter with CAPI than with PAPI.

Figure 1 plots the average length of the interviews conducted each month of the Round 12 field period by mode of administration. The timings for the CAPI interviews are based on two time stamps generated by the software. The starting time is logged at the first question after the household enumeration has been completed and verified; the ending time is generated after the last question, before the locating and interviewer remarks sections. In the Control cases, interviewers recorded the time in those locations.

FIGURE 1



In the first month of interviewing, the timings for CAPI were about six minutes less than those for the Controls. Over the entire field period, as interviewers became more adept at CAPI the average length of the CAPI interviews declined to a point where by the last month of interviewing the CAPI interviewers were on average almost 15 minutes shorter than those conducted with paper and pencil. Over the entire field period, the control interviews lasted about 57 minutes while the CAPI interviews averaged only 47 minutes.

Should this finding cause us to rejoice or to wring our hands in dismay? Should we see here the potential for CAPI to save time (and therefore interviewing costs) as well as to lighten respondent burden? Or is this the much-feared pacing problem of CAPI where the interview moves at break-neck speed, controlled by a machine rather than the human pace of conversation?

We think the former. The NLS/Y questionnaire is an extremely complicated one which requires the interviewer to do a good deal more than read questions, record answers, and follow skip instructions. There are over 60 different instructions to the interviewer to go back to a complex facesheet, find a specific bit of information, record it in the questionnaire, and then use this information in a question. There are almost 30 occasions when the interviewer must refer to an answer other than that to the current question in order to determine the next question to be asked. There are nine questions which require that the interviewer perform a calculation. All of this, of course, is done automatically, instantly, and correctly by the CAPI software. The same probably is not always true where interviewers must do these things manually, under the unique pressures of the interview situation.

We need to be cautious in generalizing the NLS/Y experience to other surveys. The NLS/Y incurs very large data processing costs (relative to other costs) by virtue of a good deal of materials generation—assignment lists, complex facesheets, locating information, and so forth—prior to field and an extremely rigorous post-data-entry batch cleaning. As we have just seen, the questionnaire is very complicated, the sort that can be administered more efficiently by computer than by traditional PAPI methods. More generally, we also should expect that several key cost elements—need for

interviewer training, interviewer field support, and the cost of hardware—will decline as organizations gain experience and hardware costs continue to fall. In the end, the final cost differences between modes will depend on the mix of elements in a given survey.

CONCLUSION

Our assessment of the NLS/Y CAPI experiment is that is was a great success, both operationally and in the database that it has produced. As our analysis moves forward and we are able to look more closely at the issues discussed here and others as well, we feel sure that we will be able to fill in a number of missing pieces in our understanding of CAPI, its benefits and its costs. Thus far, we believe that we have learned a number of important things:

- Nationwide CAPI surveys clearly are feasible; interviewers can make the transition and respondents like it.
- Some respondents view computer-assisted interviews as more confidential than traditional face-to-face methods and may be more forthcoming in response to sensitive questions.
- In this early phase at least, interviewers may ask questions differently with CAPI than with paper and pencil.
- While initial CAPI efforts may be somewhat more expensive that PAPI, we expect it to become cost neutral quickly. Still, the cost benefits will vary depending on the design of a given survey.

We should stress again that the findings here are very preliminary. The experimental data is an enormously rich resource, and we have only scratched its surface in this brief report. We remain confident, however, that there are no major flaws in CAPI that have gone undetected. There simply are advantages and disadvantages which we must understand better so that we can use this promising new data collection technology appropriately.

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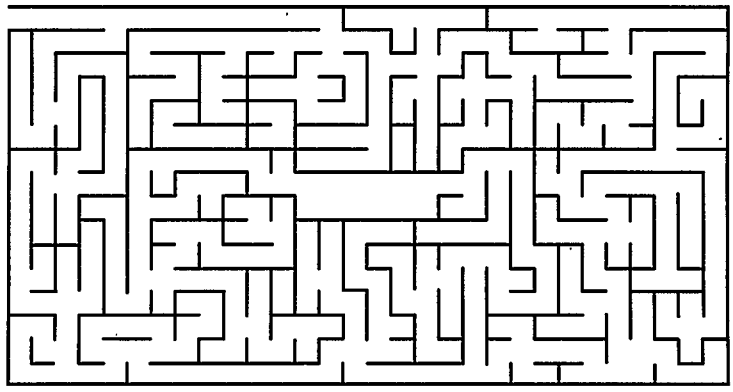
Session X

Small Area Data Needs



MODEL-BASED INFERENCE FOR SMALL AREAS FOR BINARY VARIABLES IN THE NATIONAL HEALTH INTERVIEW SURVEY

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(Not available for publication)

BEHAVIORAL, PSYCHOSOCIAL, DEMOGRAPHIC, AND HEALTH FACTORS ASSOCIATED WITH RESIDENCE IN HIGH SMR ZIP CODES

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Introduction

Observations of the unequal distribution of disease by geographic location are not new, providing one of the foundations of modern public health and epidemiology. Both before and after John Snow's mid-nineteenth century investigation of the causes of cholera in London, investigators have searched for the equivalent of the "Broad Street Pump" with which to explain non-random occurrences of the location of disease. Interest in this subject remains strong today as evidenced by a recent national conference on clustering of health events devoted to the public demands, methodologic pitfalls, and statistical complications involved in the study of the clustering of health events (National Conference on Clustering of Health Events, 1990).

Since 1965, the Alameda County Study of the California Department of Health Services has been following the health of almost 7,000 persons, investigating the association between behavioral, social, psychological, and demographic factors and health outcomes (Berkman and Breslow, 1983). In the process of conducting this work, we have repeatedly noticed substantial geographic variation in rates of all-cause mortality and other causes of death. For example, in one study the 9-year mortality experience of residents of Oakland, California, the largest city in Alameda County, was examined as a function of whether or not they lived in federally-designated poverty areas in Oakland. Residence in the poverty area was associated with more than a 70% increase in the 9-year risk of death even when there was adjustment for a large number of important covariates (Haan, Kaplan & Camacho, 1987). Similarly, in another study, a number of factor analytically-derived scales based on Alameda County census tract characteristics were found to be independently associated with risk of death, and census tracts which were high on these scales were clustered together (Haan, Kaplan & Syme, 1989).

The present study investigates, in greater detail, factors associated with these high risk areas. The approach is somewhat different from that taken in our previous cohort-based studies. In this study we calculated the standardized mortality ratios (SMR) for all-cause mortality for Alameda County zip codes, conducted a large telephone survey which collected of a wide variety of information including zip code of the respondents, and then brought these two sources of data together. Our analyses were directed at examining the factors associated with residence in high, medium, or low SMR zip codes. Thus, we are not examining factors associated with health status but, instead, with residence in areas which differ in health status as reflected by all-cause SMRs. While this is clearly an ecologic outcome which does not reflect the health status of the respondents, we are interested in understanding variations in the health of areas. Importantly, an informal review suggested that high SMR areas in Alameda County have remained high over relatively long periods of time, regardless of the births, deaths, and relocations which characterize any geographic area over time.

Methods

Estimation of SMRs

Standardized mortality ratios (SMRs) for deaths from all-causes for both sexes combined were calculated for 43 sub-areas of Alameda county defined by postal zip code. The SMR for a zip code was calculated by dividing the observed number of deaths by the number expected if age specific mortality rates for the entire county applied to the population of the zip code.

Records of deaths by census tract for 1984-1988 were obtained from the Alameda County Department of Health. The census tract totals were then allocated to zip codes based on the work of Gould et.al., (1985). These investigators combined information on 1980 census tract boundaries, 1985 proprietary zip code boundary files, and other sources, coupled with manual review to allocate the population of a census tract to one or more zip codes.

To calculate expected deaths for each zip code, population estimates by age and sex for each area for 1984-1988 were required. To simplify the calculation, a mid-period (1986) age and sex-specific estimate was derived for each zip code using a linear interpolation of 1980 and 1989 data obtained from the National Planning Data Corporation. These 1986 estimates were then adjusted so that when summed over zip codes they equaled age and sex-specific estimates for the entire county produced by the California Department of Finance (1990). The estimated age-sex populations in each zip code were then multiplied by age-sex- specific mortality rates for the entire county for 1984-1988 to obtain the expected numbers of deaths in each zip code.

Survey Data

Between April 1988, and June 1990, data were collected from 3,047 adult residents of Alameda County using a Waksberg random digit dialing technique with one adult resident of each household being randomly selected. Data from additional Black and Hispanic residents were obtained in the same way using a stratified sampling technique which sampled more heavily from telephone exchanges which contained higher proportions of Blacks and Hispanics. Analysis weights were calculated by a two step process which involved the calculation of a crude weight for each person in the sample approximately proportional to the reciprocal of that individual's selection probability and post stratification adjustment of the set of crude weights to match the distribution of the county population by age, race and sex.

Information was obtained on a wide variety of variables including: self-reported health conditions and disabilities, behavioral factors, social networks and support, race/ethnicity, socioeconomic position and education, preventive health services use, health care coverage,

socioenvironmental demands and control, and disadvantage.

Statistical Methods

A series of age- and sex-adjusted polytomous logistic models were evaluated in which three outcomes were used: high SMR, medium SMR, and low SMR zip code. The high and low zip codes corresponded to the approximate upper and lower quintiles of the distribution of zip code SMRs. SAS PROC CATMOD was used to fit the multinomial logistic model to all observations in the sample using the WEIGHT option to incorporate the analysis weights (SAS Institute Inc.). The regression coefficients and odds ratios from this fit are those reported. To estimate variances and covariances for the coefficients that reflect the complex design of the sample, a half-sample replication method, suggested by B.V. Shah (personal communication) was used. This method was employed because available software either did not calculate variances for complex survey designs (SAS) or did not accommodate the multinomial logistic model (SUDAAN, Research Triangle Institute).

The half-sample replication method utilizes a series of 50 weighted logistic analyses carried out on 50 simple random samples, without replacement, of one-half the PSUs in the sample. The empirical variances and covariances of the coefficients from the 50 replications, calculated using SAS PROC CORR, provided estimates of the variances of the coefficients obtained from the model fit to the full sample. To test the significance of the logistic regression coefficients, the ratio of the coefficient to its standard error was treated as a Student's t statistic with 49 degrees of freedom (1 less than the number of replications).

Results

Standardized Mortality Ratios

There was considerable variation between the 43 zip code areas, with SMR's ranging from 0.54 to 1.42 (Figure 1). Zip codes were assigned to three categories in order to examine factors associated with residence in high SMR (SMR= 1.13-1.42, N=7), Medium SMR (SMR= 0.75-1.12, N=28), and low SMR areas (SMR= 0.54-0.74, N=8).

Polytomous Logistic Analyses

There was a strong association between health status measures and residence in high SMR zip codes. A one unit increase in an index which measures the number of chronic diseases reported (1-11) was associated with increased odds of residence in high vs. low SMR zip codes (OR= 1.24, 95% C.I.=1.03-1.49) and medium vs low SMR zip codes (OR=1.11, 95% C.I.= 0.95-1.20). The number of activity of daily living (ADL) and instrumental activity of daily living (IADL) problems (1-12) was also associated with area of residence ($OR_{HIGH\ vs.\ LOW}$=1.26, 95% C.I.=1.10-1.45; $OR_{MEDIUM\ vs.\ LOW}$=1.17, 95% C.I.=1.03-1.33), as was reporting fair/poor vs. good/excellent perceived health ($OR_{HIGH\ vs.\ LOW}$=3.00, 95% C.I.=1.78-5.04; $OR_{MEDIUM\ vs.\ LOW}$=1.52, 95% C.I.=0.96-2.42). Higher prevalence of high blood pressure, vision trouble, hearing trouble, back pain, muscle pain, and headache was found in the high vs. low SMR areas as well. Table 1 indicates the strong associations between Race/Ethnicity and socioeconomic variables and area of residence. Blacks are more than nine times more likely than whites to live in a high SMR vs. low SMR area, and Hispanics compared have over three times the odds of whites. Family income and education both show a graded association with residence in high vs. low SMR area. Residence in high SMR zip codes was also associated with respondent's reports of the frequency of having inadequate money for food/month and inadequate money to fill a prescription/year.

Levels of smoking, alcohol consumption, body mass index (BMI)[weight (lbs.)/height^2(inches)], and exercise were also associated with SMR area (Table 2). High SMR areas had increased prevalence of current smoking ($OR_{HIGH\ vs.\ LOW}$=1.58, 95% C.I.=0.98-2.55; $OR_{MEDIUM\ vs.\ LOW}$=1.42, 95% C.I.=0.94-2.14), and past smoking ($OR_{HIGH\ vs.\ LOW}$=1.48, 95% C.I.=0.92-2.36; $OR_{MEDIUM\ vs.\ LOW}$=1.55, 95% C.I.=0.98-2.43). Respondents who live in high SMR areas had increased frequency of reporting no exercise in the last month ($OR_{HIGH\ vs.\ LOW}$=2.34, 95% C.I.=1.69-2.34; $OR_{MEDIUM\ vs.\ LOW}$=1.29, 95% C.I.=0.94-1.76), and were more likely to be in the 5th quintile of BMI ($OR_{HIGH\ vs.\ LOW}$=3.07, 95% C.I.=1.54-6.11; $OR_{MEDIUM\ vs.\ LOW}$=1.81, 95% C.I.=0.95-3.44). Residents of high areas were also more likely to report abstaining from alcohol consumption ($OR_{HIGH\ vs.\ LOW}$=1.69, 95% C.I.=1.06-2.68).

Substantial differences between areas were also seen with respect to medical and preventive care access (Table 3). Lack of health insurance (including Medicare and Medicaid) was elevated in high, but not medium, areas (Table 3) ($OR_{HIGH\ vs.\ LOW}$=2.24, 95% C.I.=1.16-4.33). Not having a check-up within the last 2 years was reported more frequently by those in high SMR areas ($OR_{HIGH\ vs.\ LOW}$=1.41, 95% C.I.=0.90-2.20), as was not having a Pap test (for women) during the last 12 months ($OR_{HIGH\ vs.\ LOW}$=1.83, 95% C.I.=0.91-3.68; $OR_{MEDIUM\ vs.\ LOW}$=1.60, 95% C.I.=0.89-2.85). There was some indication that having "ever" had a cholesterol check was more prevalent in high than in low SMR areas.

Different levels of social network participation and social support were also reported in the high, medium, and low SMR areas (Table 4). Those who reported fewer than three close friends and relatives were three times more likely to live in high vs low areas (95% C.I.=1.38-6.53). Low emotional support was also more prevalent in high risk areas. Those who reported no persons available at least some of the time to listen or to confide in about emotional problems were more likeley to live in high or medium vs. low SMR areas ($OR_{HIGH\ vs.\ LOW}$=4.84, 95% C.I.=1.75-13.34; $OR_{MEDIUM\ vs.\ LOW}$=2.42, 95% C.I.=0.98-5.96).

Table 5 presents the results for socioenvironmental factors. A summative demands index was generated based on three items in which respondents agreed or strongly agreed that their work or usual daily activity, if not working, involved working "hard," "fast," or "repetitively." Those who reported 2 or more demands were 1.75 times more likely to live in a high or medium SMR zip code than those who reported no demands ($OR_{HIGH\ vs.\ LOW}$=1.75, 95% C.I.=1.13-2.70; $OR_{MEDIUM\ vs.\ LOW}$=1.74, 95% C.I.=1.09-2.77). A resources index was based on five questions which asked if respondents agreed or strongly agreed that in their work or usual daily activity, if not working, they were free

to make a lot of decisions, could decide how to do things, were able to be creative, were able to learn new things, and were appreciated. Those who reported fewer than four resources tended to be more likely to reside in high vs. low SMR zip codes ($OR_{HIGH vs. LOW}$=1.40, 95% C.I.=0.91-2.13). A socioenvironmental strain variable was also associated with zip code residence. The odds of living in high vs. low SMR zip codes was examined in those who reported high demands and low resources vs. those who reported low demands vs. high resources ($OR_{HIGH vs. LOW}$=1.99, 95% C.I.=1.08-3.67). Variables which reflect safety were also associated with residence in high vs. low SMR zip codes. Respondents who reported that their neighborhood was unsafe or very unsafe from crime were almost three times more likely to live in high vs. low SMR zip codes ($OR_{HIGH vs. LOW}$=2.72, 95% C.I.=1.52-4.86). Similarly, there was a tendency for reports of having been a victim of a violent crime to be more prevalent in the high SMR areas (($OR_{HIGH vs. LOW}$=2.24, 95% C.I.=0.85-5.87).

Conclusions

There is considerable variation in all-cause SMR's between zip codes in Alameda County, and a wide variety of sociodemographic, behavioral, social, medical care, and socioenvironmental differences are associated with the variations. It is appropriate to point out a number of methodological and conceptual issues which need to be considered in interpreting these results. The design of this study might be considered a "mixed" ecological analysis, with risk factors measured at the individual level and health outcomes measured at the ecologic level. While this design benefits over the usual ecological analysis in that it collects information from individuals, thereby allowing an examination of confounding, effect modification, and other aspects which cannot be addressed in data which includes risks factors and outcomes which are both measured ecologically, it does have certain limitations. The biggest limitation is that, properly speaking, the analyses do not model a health outcome. Instead they model residence in areas which differ in a summary measure of health, all-cause mortality. While this creates interpretive problems, other observations and analyses (not shown) are somewhat reassuring in that they indicate that the pattern of elevated SMR's has remained relatively constant over several decades, and that the risk factors measured in this study are, in this data set, related cross-sectionally to measures of health status.

The methodologies used in converting from census tracts to zip codes and estimating denominators may be subject to error, but it is not possible to determine, at this time, how large or in what direction. Similarly, the proper analysis of a complex survey design requires population information which is not always available, and we had to rely on proprietary information, the validity of which is unknown. With the continuing release of information from the 1990 census, it should be possible to address many of these data quality issues. Finally, the collection of self-reported information over the telephone must, by necessity, exclude those without telephones, is undoubtedly biased against the inclusion of the very poor or the socially marginal, and suffers from the limitations of self-reported data.

While these are not inconsequential conceptual and methodologic problems, they should not detract from the major conclusion, which is that there are substantial small area variations in health status in Alameda County, and that an extremely wide variety of risk factors seem to be associated with these geographic variations. The implication of this pattern of results is that broad-based interventions involving behavioral, social, socio-environmental, medical, and economic foci may be required in order to reduce geographic inequalities in health.

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Table 1
Association Between Race/Ethnicity and Socioeconomic Variables and Residence in High/Medium/Low SMR Zip Codes Age and Sex-adjusted: Alameda County California, 1984-1988

Variable	High vs. Low		Medium vs. Low	
	OR	95% CI	OR	95% CI
Race				
Black	9.26	5.10-16.81	1.26	0.77-2.05
Hispanic	3.42	1.95-6.00	1.04	0.69-1.57
White (ref)	1.00		1.00	
Income Quintile				
1	2.33	1.17-4.63	0.70	0.41-1.20
2	2.13	1.11-4.07	0.94	0.59-1.52
3	1.35	0.66-2.75	0.97	0.58-1.61
4	0.86	0.42-1.80	1.12	0.68-1.83
5 (ref)	1.00		1.00	
Education				
< High School	4.29	2.41-7.64	1.58	0.95-2.63
High School/GED	2.81	1.69-4.67	1.76	1.11-2.80
> High School (ref)	1.00		1.00	
Inadequate $ for Food				
≥ 1/month	1.68	0.87-3.26	0.92	0.51-1.65
0/month (ref)	1.00		1.00	
Inadequate $ for R.				
≥ 1/year	4.03	1.63-9.95	1.55	0.64-3.77
0/year (ref)	1.00		1.00	

Table 2
Association Between Behavioral Variables and Residence in High/Medium/Low SMR Zip Codes Age and Sex-adjusted: Alameda County California, 1984-1988

Variable	High vs. Low		Medium vs. Low	
	OR	95% CI	OR	95% CI
Smoking Status				
Current smoker	1.58	0.98-2.55	1.42	0.94-2.14
Past smoker	1.48	0.92-2.36	1.55	0.98-2.43
Never smoked (ref)	1.00		1.00	
Alcohol Consumption				
Abstainers	1.69	1.06-2.69	0.86	0.58-1.27
>45 drinks/month	1.06	0.59-1.88	1.17	0.68-1.99
1-45 drinks/month (ref)	1.00		1.00	
Body Mass Quintile				
1	0.97	0.50-1.89	1.33	0.73-2.40
2	1.25	0.67-2.34	1.10	0.64-1.88
3 (ref)	1.00		1.00	
4	1.74	0.83-3.65	1.40	0.71-2.77
5	3.07	1.54-6.11	1.81	0.95-3.44
Exercise				
None	2.34	1.69-3.24	1.29	0.94-1.76
≥1/month (ref)	1.00		1.00	

Table 3
Association Between Preventative Care Variables and Residence in High/Medium/Low SMR Zip Codes Age and Sex-adjusted: Alameda County California, 1984-1988

Variable	High vs. Low		Medium vs. Low	
	OR	95% CI	OR	95% CI
High Blood Pressure				
Yes	3.04	1.65-5.62	2.18	1.30-3.65
No (ref)	1.00		1.00	
Cholesterol Check				
Yes	1.33	0.84-2.11	1.31	0.87-1.98
No (ref)	1.00		1.00	
Last Pap Smear				
>1 year	0.55	0.27-1.10	0.63	0.35-1.12
≤1 year (ref)	1.00		1.00	
Last General Checkup				
>2 years	0.71	0.45-1.11	0.90	0.60-1.33
≤2 years (ref)	1.00		1.00	

Table 4
Association Between Social Variables and Residence in High/Medium/Low SMR Zip Codes Age and Sex-adjusted: Alameda County California, 1984-1988

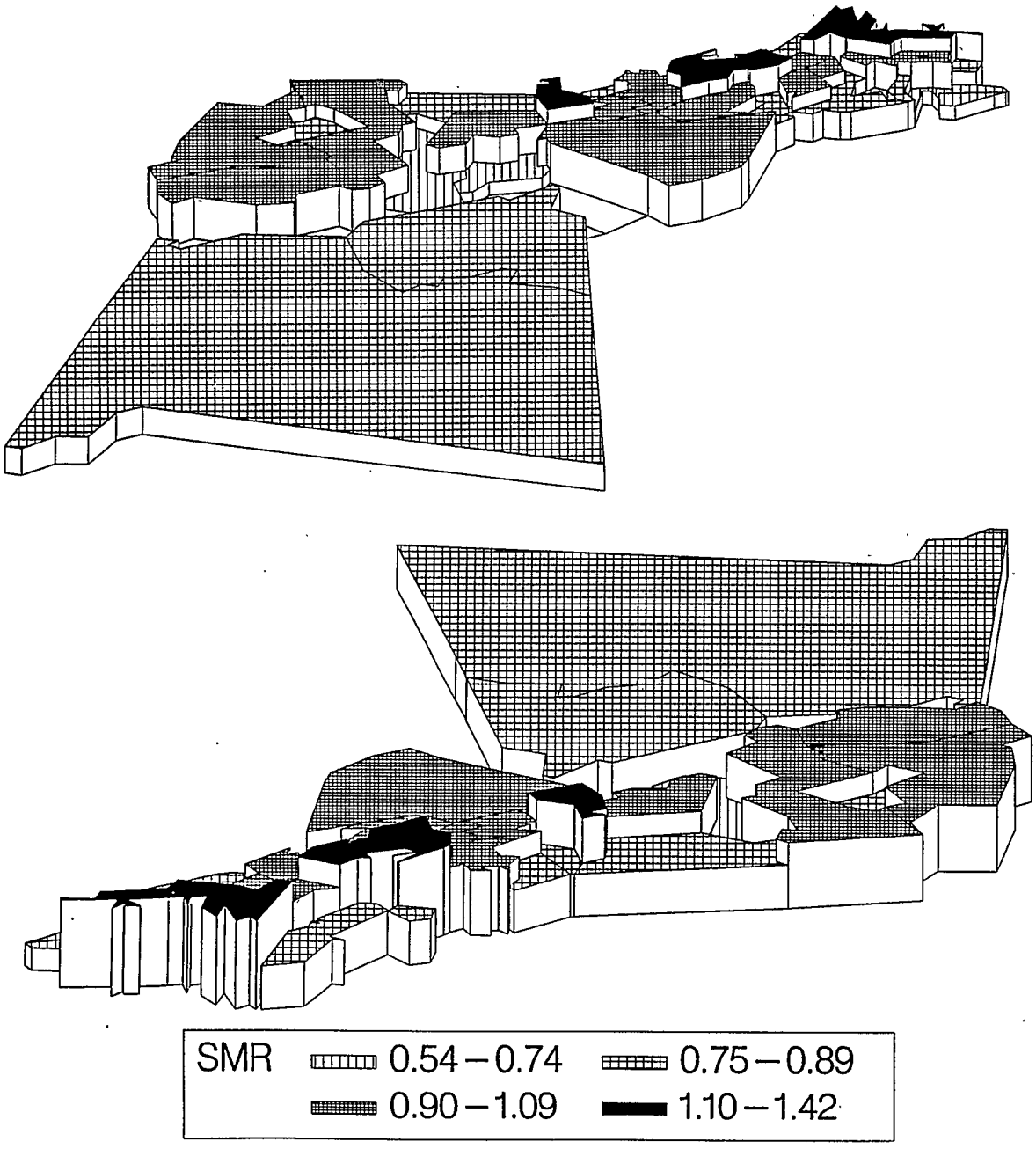
Variable	High vs. Low		Medium vs. Low	
	OR	95% CI	OR	95% CI
Friends Index				
≤2	3.00	1.38-6.53	1.54	0.75-3.18
≥3 (ref)	1.00		1.00	
Emotional Support Index				
0	4.84	1.75-13.35	2.42	0.98-5.96
1	1.89	0.68-5.24	1.30	0.54-3.16
2 (ref)	1.00		1.00	
Tangible Support Index				
0≤index<2	2.59	0.66-10.13	1.10	0.29-4.22
2≤index<4	1.27	0.77-2.10	0.86	0.53-1.42
4 (ref)	1.00		1.00	

Table 5
Association Between Socio-environmental Variables and Residence in High/Medium/Low SMR Zip Codes Age and Sex-adjusted: Alameda County California, 1984-1988

Variable	High vs. Low		Medium vs. Low	
	OR	95% CI	OR	95% CI
Neighborhood				
Unsafe/very unsafe	2.72	1.52-4.86	0.65	0.41-1.05
Safe/very safe (ref)	1.00		1.00	
Victim of Crime				
Yes	2.24	0.85-5.87	1.17	0.47-2.91
No (ref)	1.00		1.00	
Demands Index				
>2	1.75	1.13-2.70	1.74	1.09-2.77
1<index≤2	1.16	0.72-1.85	1.25	0.81-1.93
<=1 (ref)	1.00		1.00	
Resources Index				
≤4	1.40	0.92-2.13	1.10	0.78-1.55
>4 (ref)	1.00		1.00	
Strain Index				
High/Low	1.99	1.08-3.67	1.51	0.89-2.57
High/High	2.14	1.13-4.04	1.80	1.09-2.97
Low/Low	1.64	1.02-2.63	1.17	0.77-1.80
Low/High (ref)	1.00		1.00	

Figure 1

SMRs for All Cause Mortality by Zip code
Alameda County, California: 1984-1988



LOCAL RATES ADJUSTMENT EMPLOYING GEOGRAPHIC SIMILARITIES AND EMPIRICAL BAYS

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INTRODUCTION

When the mortality rates of certain rare disease are to be estimated for small areas, the estimates are subject to high variabilities. This variability is caused by the rarity of disease and the sparcity of the population. Hence single cases within sparse areas can appear as unusual and might attract more attention than they deserve. Data which for fixed periods of time can be modeled with the Poisson distribution and which have counts in the neighborhood of zero, can also be found to demonstrate instabilities over extended epochs. Such instability is sometimes referred to as hyper-Poisson variability and is signaled by its variance over several periods being larger than its mean count. Empirical Bayes (EB) estimation of mortality rates has been employed in various ways with useful results. Tsutakawa, et al. (1985) used EB approach to generate stable estimates for comparison and prediction of cacer mortality rates. Clayton and Kaldor (1987) proposed four different models; independent gamma, log-normal with and without spatial correlation, and nonparametric model. Manton, et al. (1989) presented two-stage EB procedure for geographic mapping of cancer mortality rates. In the present study, EB was employed with two objectives. The first is to produce stable estimates of mortality (and other) rates in sparsely populated areas, and the second is to produce a relatively simple statistical method for that purpose. If the parameter in the Poisson probability mass function (PMF) has a gamma density, then rate, for counties of geographic similarity as a single intity, has the negative binomial as its probability mass function. Data from geographically similar counties, not necessarily adjacent, are used to estimate the parameters of the negative binomial. The posterior density of the Poisson parameter is also a gamma augmented by the observation of the incident county. The Bayes estimater, the mean of the posterior, is straightforward as are its standard error and confidence intervals. Data from the North Carolina central cancer registry were used to illustrate this method. Geographic similarity is defined by varibles other than those recorded by the cancer registry.

METHODS

A region is an aggregation of geographically similar counties. These similar counties are those with common geographical factors that might be associated with the occurrence of the disease of interest. For example, the degree of urbanization or age distribution of population can be used for this purpose. Hence, mortality rates of a disease are assumed to be nearly homogeneous across the counties which comprise the region.

The occurrence of deaths due to a certain disease in a population can be assumed to follow binomial distribution with expected number being equal to NR, where N is the number of the people exposed, and R is the mortality rate of the disease of interest. Then, the Poisson approximation to binomial distribution says that, when N is very large and R is very small, in such a way that NR is equal to θ, the binomial is approximately the Poisson distribution with mean θ. Thus, any rare disease such as cancer or birth defect, can be modeled by Poisson distribution. Cancer will be used as the generic rare disease. The reader is invited to substitute its favorite rare disease wherever cancer occurs.

Let X_{ijk} be the observed number of deaths due to cancer in region i, county j, and time period k, where $i = 1,\ldots,L$, $j = 1,\ldots,M_i$, and $k = 1,\ldots,N$. The L regions are expected to have different number of counties within them. Then, X_{ijk} has a Poisson distribution with mean θ_{ijk}, that is,

$$f_1(x_{ijk}) = \frac{\exp(-\theta_{ijk})\,\theta_{ijk}^{x_{ijk}}}{x_{ijk}!}, \qquad (1)$$

where $X_{ijk} = 0, 1, 2, \ldots$

Furthermore, for region i and a given interval of time k, the sum of the observed number of deaths due to cancer also has a Poisson distribution. This can be easily shown by using moment generating function for Poisson distribution.

Let $x_{i1k}, x_{i2k}, \ldots, x_{iMk}$ be observed number of deaths for region i and time k. Then, the likelihood function of θ_{ijk} is given by,

$$L(\theta_{ijk}|x_{ijk}) = \frac{EXP(-\sum_{j=1}^{M_i} N_{ijk}R_{ijk}) \prod_{j=1}^{M_i} (N_{ijk}R_{ijk})^{x_i}}{\prod_{j=1}^{M_i} x_{ijk}!} \qquad (2)$$

where N_{ijk} is the size of the midyear population, and R_{ijk} is the mortality rate

of the cancer.

The MLE of R_{ijk} can be obtained by maximizing (2) with respect to R_{ijk}. Hence, under the assumption of the homogeneity of mortality rates within a region, the MLE of R_{ijk} for region i and time k is

$$\hat{R}_{i.k} = \frac{X_{i.k}}{N_{i.k}} \qquad (3a)$$

and

$$\hat{\theta}_{i.k} = X_{i.k}, \qquad (3b)$$

where the absence of subscript (.) indicates a summation has been made over all possible values of the missing subscript.

If this model is extended to include several periods of time, the mortality rates may also prove to be highly unstable over time, especially when the incident county is sparse. In this case, time should also be adjusted by employing a compound distribution for x_{ijk}. Since the gamma distribution is the preferred probability model for waiting time until a case takes place, it is assumed that the prior distribution of the Poisson parameter θ_{ijk} has a gamma distribution. Hence,

$$f_2(\theta_{ijk}|\alpha_{ijk},\beta_{ijk}) = \frac{\theta_{ijk}^{\alpha_{ijk}-1}EXP(-\theta_{ijk}/\beta_{ijk})}{\Gamma(\alpha_{ijk})\beta_{ijk}^{\alpha_{ijk}}} \qquad (4)$$

Then, the joint distribution of X_{ijk} and θ_{ijk} conditioning on α_{ijk} and β_{ijk} is derived from (1) and (4). Without loss of continuity or generality, the subscripts can and will be omitted. Thus,

$$f_{12}(x,\theta|\alpha,\beta) = \frac{\theta^{x+\alpha-1}EXP(-(1+1/\beta)\theta)}{x!\Gamma(\alpha)\beta^{\alpha}} \qquad (5)$$

The marginal distribution of X conditioning on α and β can be obtained from (5) by integrating over the range of θ.

$$f_3(X|\alpha,\beta) = \frac{\Gamma(x+\alpha)\beta^x}{\Gamma(x+1)\Gamma(\alpha)}\left(\frac{1}{1+\beta}\right)^{\alpha+x}. \qquad (6)$$

This is the negative binomial distribution. Therefore, the occurrence of deaths in a region for extended periods of time can be modeled by the negative binomial distribution.

The posterior distribution of θ, given x, α, and β, can be easily obtained from (5) and (6) using Bayes rule :

$$g(\theta|x,\alpha,\beta) = \frac{\theta^{x+\alpha-1}EXP\left(-\theta/\frac{\beta}{1+\beta}\right)}{\Gamma(x+\alpha)\left[(\beta/(1+\beta)\right]^{x+\alpha}}. \qquad (7)$$

Equation (7) is that of a gamma density with shape and scale parameter being equal to $x+\alpha$ and $\beta/(1+\beta)$, respectively. Hence, the Bayes estimator, θ_B, of θ is given by

$$\theta_B = \frac{\alpha\beta}{1+\beta} + \frac{\beta}{1+\beta}x. \qquad (8)$$

Estimation of Parameters using EB and Method of Moments

The EB estimates are the same as the Bayes estimates except that the numerical values of α and β, the shape and scale parameters of the negative binomial distribution, respectively, are not specified a'priori. Instead, the EB estimates of θ require that α and β be estimated from data other than x. Therefore, α and β in equation (8) are replaced by their ML estimates obtained by combining data across several time periods.

From the likelihood function of α and β, given n iid observations, $X_1,\ldots,X_n$, the following relations between α and β can be derived.

$$\alpha\beta = \frac{\sum_{j=1}^{n} x_j}{n} \qquad (9)$$

and

$$\sum_{j=1}^{\infty} n_j \sum_{i=1}^{j} \frac{1}{\alpha+(i-1)} = n\ LOG(1+\beta), \qquad (10)$$

where n_j are the number of the observations equal to j.

If (9) and (10) are solved for α,

$$\sum_{j=1}^{\infty} n_j \sum_{i=1}^{j} \frac{1}{\alpha+(i-1)} = nLOG\left(1+\frac{\bar{x}}{\alpha}\right). \qquad (11)$$

Equation (11) can now be solved by using an iterative numerical method.

The negative binomial parameters, α and β, can also be estimated by using the method of moments. In general, this method is easy to apply, but is not preferred over MLE. In this study, the method of moments is applied only to generate an initial value for equation (11). These estimates can also be used when the equation does not converge. The moment estimators of α and β are,

$$\alpha^* = \frac{\bar{X}^2}{S^2-\bar{X}} \qquad (12)$$

and

$$\beta^* = \frac{S^2 - \bar{X}}{\bar{X}}. \quad (13)$$

Since α^*, $\beta^* > 0$ by definition, S^2 should be larger than X to have α^* and β^* be valid estimates.

The MLE of α and β, when applied to equation (8), yield the EB estimator of θ, i.e.,

$$\theta_{EB} = E(\theta|x, \hat{\alpha}, \hat{\beta})$$

$$= \frac{\hat{\alpha}\hat{\beta}}{1+\hat{\beta}} + \frac{\hat{\beta}}{1+\hat{\beta}}x \quad (14)$$

Since equation (14) involves with all x's, θ_{EB} should be a good estimator. When α approaches zero and β increased without bound with the restriction that $\alpha\beta = X$, then, θ_{EB} is equivalent to MLE of θ. It can also be shown that θ_{EB} is always closer to θ in probability than is any x's. This can be done by showing that θ_{EB} has smaller mean square error (MSE) than any x's for all θ.

Confidence Intervals for Estimates

The 95% confidence interval for θ_{EB} can be estimated by integrating equation (9). Let L and U denote lower and upper limits, respectively. Then,

$$\int_L^U f_4(\theta_{EB}|x, \hat{\alpha}, \hat{\beta})\, d\theta_{EB} = 0.95. \quad (15)$$

The lower tail integration of equation (15) is the Pearson's incomplete gamma function and this can be approximated chi-square distribution with degrees of freedom equal to $2(\alpha+x)$. Hence,

$$P\{\chi^2_{2(\hat{\alpha}+x)} \leq 2L(\frac{\hat{\beta}+1}{\hat{\beta}})\} = 0.025. \quad (16)$$

Similarly, from the upper tail integration of equation (15),

$$P\{\chi^2_{2(\hat{\alpha}+x)} \leq 2U(\frac{\hat{\beta}+1}{\hat{\beta}})\} = 0.975. \quad (17)$$

Finally, from (16) and (17), the lower and upper limits of θ_{EB} can be estimated.

Choosing the Best Model

The null model in this study is based on Poisson distribution. In this model, there is no compounding, and the whole state is regarded as one region. Hence, it is assumed that there are no differences in mortality rates due to geographical or temporal variations for each county. The mortality rates for each county is the ratio of the total number of deaths and the number of midyear population of those at risk. When calculating this ratio, all counties are included.

The alternative models are composed of two or more regions, where each region includes similar counties. Compounding the Poisson leads to the negative binomial distribution. There are three kinds of variations to be modeled.

i. Geographical,
ii. Temporal, and
III. Both geographical and temporal.

Model i and ii can be tested by summing over all observations by county and time, respectively, within a region. The third model is simply an extension wherein both time and area are used to develop estimates of the parameters of the negative binomial. The posterior remains a gamma. Since the negative binomial is obtained by compounding the Poisson, it can be tested against the Poisson using likelihood ratio test.

Let us attempt to choose between the Poisson and negative binomial. Then

H_0 : Poisson (θ) is the distribution of choice.

H_1 : Negative binomial (α, β) model is better.

suppose n_x denote number of observations at value x, where x = 0,..., m. Then, under H_0, the likelihood function for θ is

$$EXP[L(\theta)] = \prod_{x=0}^{m} [P(X|\theta)]^{n_x}, \quad (18)$$

where $P(X|\theta)$ is given in (1). Under H_1, the likelihood function for α and β is

$$EXP[L(\alpha,\beta)] = \prod_{x=0}^{m} [f(X|\alpha,\beta)]^{n_x}, \quad (19)$$

where $f(X|\alpha,\beta)$ is given in (6). Let

$$\Lambda = EXP[L(\theta)]/EXP[L(\alpha,\beta)]. \quad (20)$$

Then, -2 times the logarithm of (20) has a chi-square with one degree of freedom. Whether summing counties or years or both, the test applies equally.

EXAMPLE

The EB estimators of rates derived in the previous chapter were applied to the colon cancer data in the state of North Carolina for the period 1985-1989. There are 100 counties in North Carolina and they are grouped into regions by the degree of urbanization. The degree of urbanization was determined by the percentage of urban areas in a given county. The resulting five regions, region 1 to region 5, are composed of counties with 0%, 1-25%, 26-50%, 51-75%, and 76-100% of urban areas, respectively. Table 1 show mean and variance of mortality rates for each region. Region 1 has the highest variabilities as

Table 1
Observed Mortality Rates
(per 100,000)

Region	Mean	Var	Var/ Mean
I	25.5	62.4	2.4
II	22.3	27.0	1.2
III	21.0	44.9	2.1
IV	19.2	18.5	1.0
V	20.1	26.0	1.3

Table 2
Parameter Estimates

Region	Moment Estimator		MLE	
	α	β	α	β
I	5.8	3.3	6.0	3.2
II	5.7	8.2	6.8	6.9
III	4.3	14.3	4.4	14.1
IV	3.2	41.0	4.2	31.9
V	5.9	43.4	7.2	35.3

expected, since it consist of sparse counties where the number of observed death and population at risk is smallest among regions.

Table 2 show moment estimators and MLE of α and β, the negative binomial parameters in (6). When the moment estimators were used as initial values for the Newton-Raphson procedures, it converged in 3 iterations in most cases.

Table 3 show mortality rates for selected counties. Two extreme cases for each region are listed. For the county Graham, mortality rate is increased from 19.7 to 27.8, since the observed number of death is smaller than mean number. On the otherhand, the rate is decreased from 28.3 to 24.5 for Perquimans for the opposite reason. These changes in rates are smaller as the degree of urbanization increase from region 1 to region 5. Region 1 which is the aggregation of rural counties have the largest differences between observed and adjusted mortality rates. Region 4 and 5 which contain relatively large counties have no substantial differences between observed and adjusted mortality rates.

Table 4 show 95% confidence intervals of estimated number of deaths for counties appeared in table 3. The confidence intervals for estimated number of deaths are obtained from (16) and (17). Since degrees of freedom for chi-square

Table 3
Mortality Rates

County	Pop.	Observed		Estimated	
		Num	Rate	Num	Rate
Region I (N=27; Num=18.9)					
Graham	7,106	7	19.7	10	27.8
Perquimans	30,389	43	28.3	37	24.5
Region II (N=27; Num=46.9)					
Henderson	68,072	113	33.2	105	30.7
Pender	26,168	28	21.4	30	23.2
Region III (N=30; Num=61.8)					
Cleveland	86,579	100	23.1	98	22.5
Lee	41,573	37	17.8	39	18.6
Region IV (N=10; Num=132.7)					
Buncombe	171,548	205	23.9	203	23.6
Onslow	126,126	70	11.1	72	11.4
Region V (N=6; Num=254.2)					
Durham	168,182	185	22.0	187	22.2
Guilford	332,420	364	21.9	361	21.7

Table 4
Confidence Intervals
for Estimated Deaths

Region	County	Num (Est.)	95% C.I.
I	Graham	10	(5.2, 15.7)
	Perquimans	37	(27.0, 47.5)
II	Henderson	105	(86.9, 124.4)
	Pender	30	(21.1, 41.4)
III	Cleveland	98	(79.5, 116.9)
	Lee	39	(27.6, 51.1)
IV	Buncombe	203	(175.9, 230.8)
	Onslow	72	(56.1, 88.8)
V	Durham	187	(161.2, 214.0)
	Guilford	361	(324.8, 398.2)

distributions are greater than 30 for all cases, the chi-square statistic can be approximated by standard normal distribution.

$$\chi^2 = \frac{(Z_p+\sqrt{2v-1})^2}{2}, \qquad (21)$$

where v is α + x and Z_p is the p-th fractile of the standard normal.
The confidence intervals of estimated mortality rates can be obtained by dividing by the total midyear populations of corresponding counties.

The hypothesis testing regarding whether negative binomial model is better than Poisson model is carried out for each region using (20). Table 5 show these chi-square statistics and these values are highly significant. Hence it can be concluded that the negative binomial models are better for all regions.

Table 5
Hypothesis Testing
(Poisson vs. Negative Binomial)

Region	Chi-square statistic
I	38.2
II	130.2
III	330.2
IV	296.3
V	191.6

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ESTIMATING THE NUMBER OF THE UNINSURED BY SMALL AREA

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The number of people without health insurance generally is unknown by small area. The best data available are from the Current Population Survey of the U.S. Census[1], which provides data on health insurance status at the state and metropolitan statistical area level, but not by individual counties. Knowing the number of uninsured for smaller areas would be valuable. For example, those who are grappling with universal insurance proposals, as we are in New York State, could make good use of the information for estimating the geographic distribution of the uninsured. Also, when presenting universal insurance proposals to legislators, it is helpful to know how many of their constituents are uninsured.

Those who are doing small area studies of hospital use could make use of this information as well. Insurance status of patients is a variable that may account for some of the observed variation in discharge rates. However, in order to investigate hospital discharge rates by insurance status, it is necessary first to estimate the population of small areas by insurance status for the rate denominators.

Presented here is a method of estimating the number of the uninsured by small area. The method is general; it can be used to estimate any social variable for which appropriate data are available. The method is based on hospital discharge data. The ratio of the uninsured to total population is estimated from the ratio of uninsured discharges to total discharges. The estimate is adjusted to account for the fact that the discharge rate of the uninsured tends to be disproportionately low compared to their proportion in the population. Data to adjust the discharge rate of the uninsured are available at the statewide level; an adjustment factor computed at the statewide level is applied at the county level. Discharges are limited to causes of admission for which there is a high degree of consensus among providers regarding hospitalization.

Discharge data by county are available from the Statewide Planning And Research Cooperative System (SPARCS), a New York State Department of Health system that collects data on all hospital discharges in New York State. The assumption is made that discharges with an expected primary payor of self-pay or no charge are a good proxy variable for uninsured patients.

Since the ratio of the uninsured among hospital discharges in a given county can be determined from discharge data, the number of the uninsured in that county can be computed with the following formula:

$$\frac{\text{County Population: Uninsured (Unknown)}}{\text{Total (From Census)}} \simeq \frac{\text{County Hospital Discharges: Uninsured (From Discharge Records)}}{\text{Total (From Discharge Records)}} \times C \text{ (Adjustment)}$$

The adjustment factor, C, is necessary because it is well documented that the uninsured are less likely to go to the hospi-

tal than the insured, since they are less able to afford hospital care. Thus, the uninsured's share of hospital discharges will be less than their share in the total population. It is necessary to correct for this by multiplying the ratio among hospital discharges by an adjustment factor.

"C" derived at the state level will be applicable at the county level only if the discharge rates are relatively stable from area to area. However, Wennberg and others have produced many studies of the extent to which discharge rates vary from area to area.[2] They have developed a statistic, the systematic component of variance[3], which quantifies this variation. They focus on groups of DRGs with a high systematic component of variance--DRGs with discharge rates that vary widely from area to area. These are DRGs for which there is a lack of consensus among physicians about appropriate treatment. If discharge rates vary from area to area, the implication is that either too much money is being spent on medical care in high rate areas, or people are being underserved in low rate areas. This variation also presents a problem for the equation being considered. If discharge rates vary widely, then the equation cannot be expected to yield consistently accurate results of the uninsured by area.

A solution is available that builds upon the work of the small area analysis school. The solution uses the systematic component of variance. However, instead of focusing on DRGs with a high systematic component of variance, the method focuses on DRGs with a low systematic component of variance, DRGs that are consistent from area to area. Presumably, these are DRGs for which there is a high consensus among physicians about appropriate treatment, and for which medical indications for treatment are clear. If this consensus about treatment holds from area to area, presumably it also will hold from payment source to payment source. Based on this assumption it is possible to estimate "C" at the state level and apply it at the county level.

Several criteria were used to pick low variance DRGs. They had to have a low systematic component of variance, be plausible as the type of procedures for which a medical consensus exists, and have high correlations with known data when used to predict two independent data sets, Medicaid eligibles and the uninsured among Standard Metropolitan Areas in New York State. Following are the DRGs that were used in the initial work.

Selected Low Variance DRGs

DRG	DESCRIPTION
14	Specific cerebrovascular disorder except transient ischemic attacks
174	Gastrointestinal hemorrhage age>69 and/or complication and/or comorbidity
219	Lower extremity and humerus procedure except hip, foot, femur age 18-65 without complications
123	Circulatory disorders with acute myocardial infarction, expired

DRG 14 is a serious stroke. DRG 174 is gastrointestinal hemorrhage with complications. DRG 219 consists of operations on the leg. DRG 123 is a heart attack resulting in death. These are all serious conditions. There is consensus among physicians about what to do when a patient has one of these conditions--the patient is admitted to the hospital. Wennberg specifically mentioned two of these conditions, heart attack and stroke, as conditions with extremely low patterns of variation.[4]

Discharges from these low variance DRGs when combined can be used to solve for C at the statewide level. Since the ratio

of the uninsured among discharges is based on DRGs that vary little from area to area, the result should be relatively accurate when applied to counties.

In the following example, the number of uninsured for the state as a whole and the population of New York State are taken from the Current Population Survey. The ratio of the uninsured among these low-variance DRG discharges is computed from SPARCS discharge data. Therefore, the equation can be solved for C. In this case, C equals 2.0.

$$\frac{\text{New York State Uninsured (2,121,357)}}{\text{New York State Total (17,951,667)}} \simeq \frac{\text{New York State Low Variance DRG Discharges: Uninsured (Self-pay/No charge) (16,977)}}{\text{New York State Low Variance DRG Discharges: Total (288,205)}} \times C$$

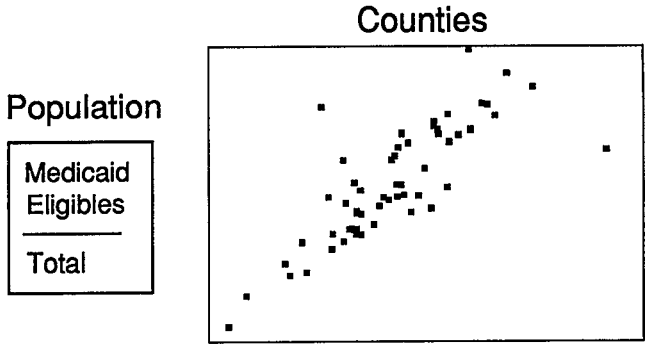
$$C \simeq 2.0$$

Once C is known, it can be used to solve for the uninsured in a specific county. For example, in Albany County, the population is 283,400. Total SPARCS discharges with the four low-variance DRGs were 4,541, of which 269 were uninsured. Substituting these values into the equation, the number of persons estimated to be uninsured in Albany County is 33,576.

How accurate is this estimate? One way of addressing this question is to use the method to predict known data. For example, the proportion of Medicaid eligibles can be predicted from the proportion of discharges that have Medicaid as a payor. SPARCS discharges with Medicaid as either the primary or secondary payor were used, since Medicaid eligibles over 65 would have Medicare as their primary payor. This estimate was compared with data from the New York State Department of Social Services on the number of Medicaid eligibles in counties outside New York City, divided by county populations.[5] The correlation coefficient between the percent of Medicaid eligibles and estimates based on the method is .81. A scatter plot of the two data sets is presented in Figure 1.

Note that discharges are from DRG 373, normal childbirth. This DRG has a very low systematic component of variance. In addition, there is consistency about hospitalization during childbirth. Ninety-nine percent of births in New York State occur in hospitals.

Figure 1



Another set of known data that can be used to test the method is the number of uninsured by metropolitan statistical

area, available from the Current Population Survey. Figure 2 is a scatter plot of the rate of uninsured estimated from low variance DRG discharge data for the four low-variance DRGs from SPARCS against the rate of uninsured from the Current Population Survey. Were it not for one outlier, the correlation would be very high; as it is, the correlation coefficient is .79.

Using the four low-variance DRGs results in an estimate that is an improvement on the use of all discharges. Using all discharges produces a .52 correlation coefficient.

Figure 3 presents percents of the uninsured in the boroughs of New York City and surrounding counties based on 1983-87 SPARCS discharges for the four low variance DRGs. Percents are grouped into four ranges. The results are as expected. The percents of the uninsured are high in the central city, low in surrounding suburbs, and high again in more rural areas. The low percent in Dutchess County may be due to the fact that state facilities and IBM are major employers in the county. Both provide health insurance to employees. As a test of the consistency of the method, two sets of percents were generated for these counties based on the low variance DRG data for odd and even years. The correlation between the two sets of percents is .84.

Figure 2

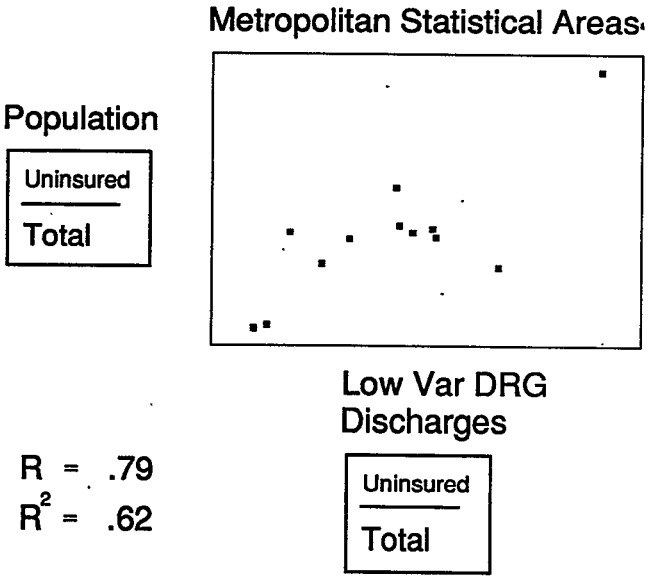


Figure 3

Percents of Uninsured

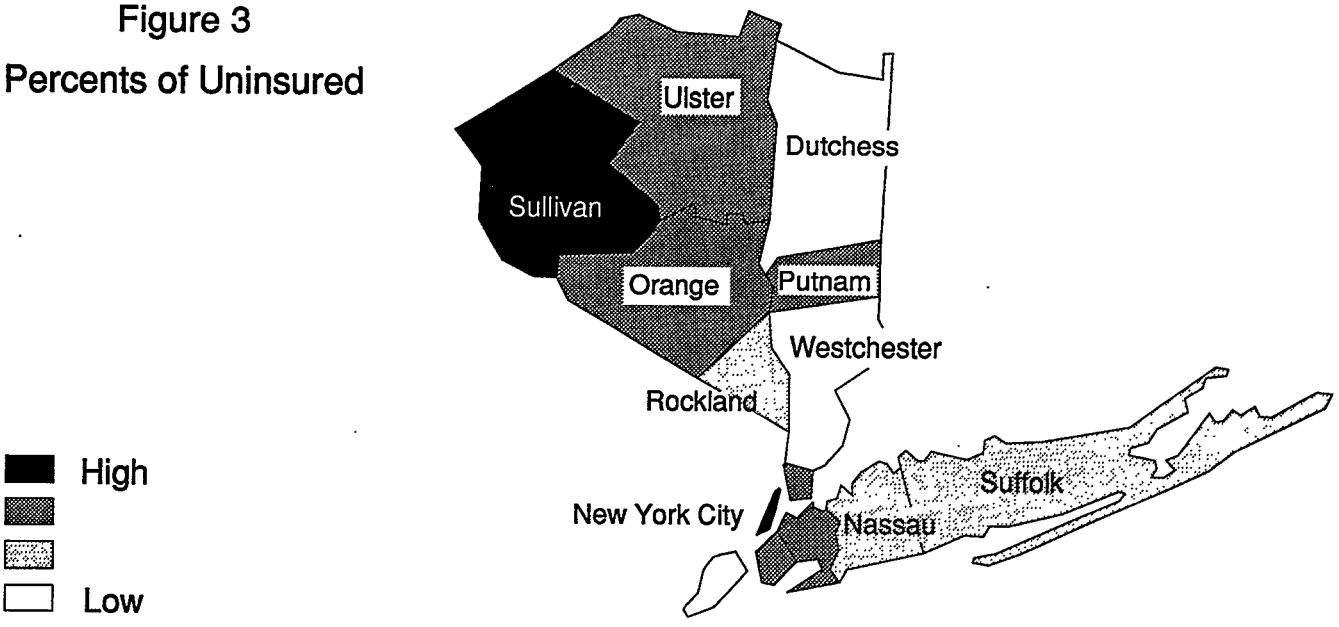
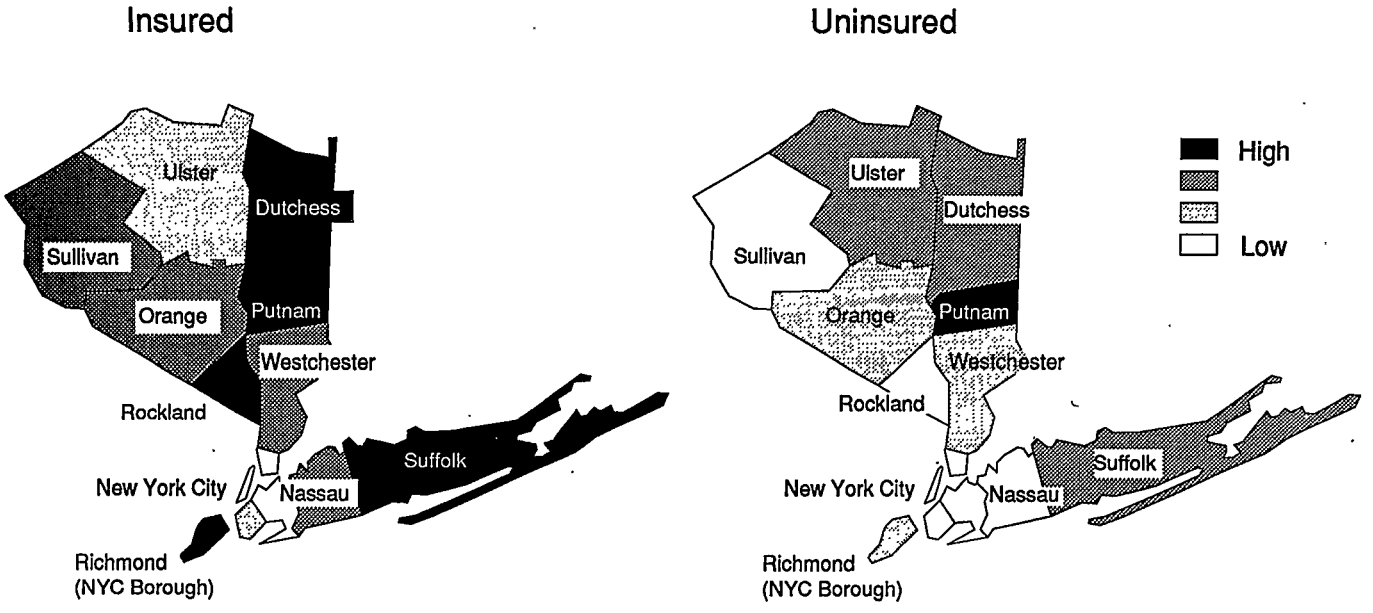


Figure 4 illustrates how these estimates of the uninsured can be used to extend small area analysis to explore effects of insurance coverage on hospital discharges. Tonsillectomy rates are presented for the insured and uninsured. These rates could not be calculated were it not for this method, since there would be no data for the rate denominator.

The results show patterns of access to hospitals which are the same across insurance status in some counties, but different in others. The central city has low tonsillectomy rates for both the insured and the uninsured. Dutchess, Putnam, and Suffolk Counties have high rates for both groups. Patients are treated consistently in these areas regardless of insurance status. On the other hand, Rockland County shows a different pattern. In Rockland County, tonsillectomy is treated at a high rate for the insured but at a low rate for the uninsured. There are several counties and boroughs that also show wide differences by insurance status--Sullivan, Richmond, and Nassau. In these areas, a major determinant of whether or not one is treated for tonsillectomy is whether or not one has insurance.[6]

This work is preliminary. One next step is to identify more low variance DRGS to increase sample size and improve estimates in the smaller counties. Furthermore, the estimates can be adjusted by applying other county data that are indicators for the uninsured, data such as the percent unemployed, the percent of businesses that are small businesses, and the percent of the population between 100% and 200% of poverty.

Figure 4
Tonsillectomy Rates



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2 Wennberg, an author of the original and several subsequent studies, is commonly mentioned in connection with the small area analysis school, but many others are involved as well. A good review of small area studies is available in Sherman Folland and Miron Stano, "Small Area Variations: A Critical Review of Propositions, Methods, and Evidence," Medical Care Review, Winter 1990, Vol. 47 No. 4, pgs 419-465.

3 The systematic component of variance is a form of variance which adjusts for differences in population denominators and prevailing rates among areas. It is described in Klim McPherson, John E. Wennberg, Ole B. Hovind, and Peter Clifford, "Small-Area Variations in the Use of Common Surgical Procedures: An International Comparison of New England, England, and Norway," New England Journal of Medicine, Nov 18, 1982, Vol. 307 No. 21, pgs 1210-1314.

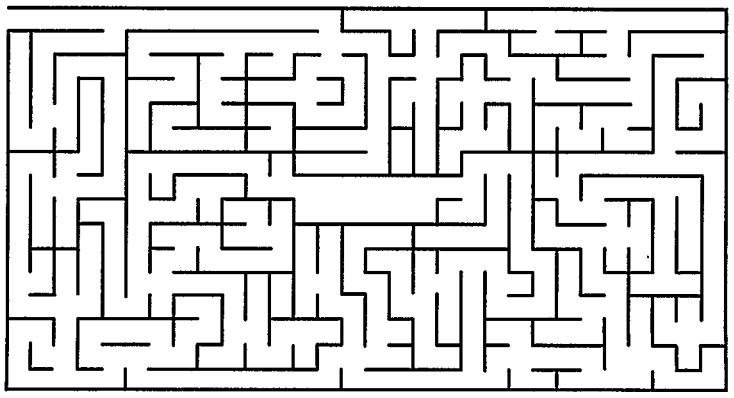
4 John E. Wennberg, "Population Illness Rates Do Not Explain Population Hospitalization Rates," Medical Care, April 1987, Vol. 25 No. 4, p. 355.

5 Medicaid data were combined from the Statistical Supplement to the 1986 Annual Report of the New York State Department of Social Services, Table 30; and the Statistical Supplement to the 1987 Annual Report of the New York State Department of Social Services, Table 30.

6 Sample sizes were smaller for the uninsured because there are fewer uninsured in the population. This could increase the variance for the uninsured and contribute to the observed result. This effect should be controlled in future studies.

Session Y

Medical Service Areas



CRITERIA FOR SELECTING AN APPROACH TO MEDICAL SERVICE AREA DEFINITION

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Introduction

When evaluating variations in provider behavior and health outcomes across different geographic areas, one must define medical service areas (MSA) carefully. Three approaches are commonly used for defining spatial boundaries for service areas. They are 1) the geopolitical definition (GP), 2) geographic distance assessment (GD), 3) and market area assessment based on patient origin data (PO). These approaches are not interchangeable. The choice of approach, and of method within each approach, should be based on several factors, including type of service funding, type of dependent variable, population density, sample size, and the availability of "denominator data". The issues and trade-offs involved in choosing an approach will be discussed in this paper, and then illustrated by several examples.

Background

The use of ecologic analysis is becoming of increasing interest to many researchers. We all know the danger of ecologic fallacy, where one draws inferences from aggregate data to behaviors or impacts on the individual level. The use of groups or populations as the unit of analysis may, however, be the only practical method to answer important questions regarding certain types of policy decisions. We expect that research of this type will increase in the coming years because we may discover variations in cost, access, effectiveness, or quality of care by looking at differences between defined populations. Also, ecologic analysis may indicate to us the size of the gap between the efficacy of an intervention, as reported in a randomized study, and the effectiveness of this intervention when used in true practice conditions in communities.

MSAs must be carefully defined in order to be useful for analysis. Each of the methods of defining areas that is currently used is based on a different underlying reality of the consumption/utilization of care, and each is appropriate only for certain situations and services. When we select a MSA we must make trade-offs, because no method will provide us with the perfect set of boundaries for the population of interest.

There are three different ways of defining MSAs:

1. GEO-POLITICAL BOUNDARIES
2. GEOGRAPHIC DISTANCE FROM PATIENTS TO PLACE OF SERVICE
3. PATIENT ORIGIN DISTRIBUTION OF THOSE PATIENTS USING A PARTICULAR SOURCE OF CARE

Geopolitical Boundaries

The first type of MSA we will discuss is that defined by geo-political boundaries. These may be: countries, states, regions, counties or aggregations of such units. This definition is perhaps the oldest.

The use of geo-political boundaries for defining a population or area is appropriate if the areas of interest can be defined by words such as American, North Carolinian, County resident, etc. The definition of the unit, e.g. state, region, county would depend on where authority for administrative and fiscal decisions rest. You would try to get (at least) one level lower than the unit of authority that controls resources. If you can't do this (e.g., a county may be the only level for which data are categorized), then you might try to assess variations by population characteristics within your analysis, (i.e., variations across races, sexes, or socioeconomic groups within the county).

A number of authors have used geopolitical boundaries in research. For example, McLafferty (1986) used census tracts in her analysis of the characteristics of closure hospitals in New York City; Pasley (1987) used counties to examine surgical discharge rate variations in N.Y. State; McLaughlin (1989) used counties and hospital market communities to assess if variations in discharge rates and procedures would hold up to adjustment for socioeconomic variations; Makuc (1985) used county aggregations in her study of physician market areas; and Morrisey (1989) examined SMSAs in his study of hospital anti-trust issues and price effects on patient willingness to travel. One of us (Simpson, 1988) has used counties to examine impact of funding levels for WIC, prenatal care (PNC), and Food Stamps on low birth weight rates in North Carolina; also Simpson and Veney (1988) have examined variations in health status across countries for the WHO Health For All project.

Geographic Distance

The geographic distance from patients to their place of service may be defined as either the distance from their residence or the distance from their work place to a source of care. The assumptions when using this approach are the following:

- utilization decreases by the cube or higher power of the distance (in time or miles) that a patient has to travel.
- the choice of provider is based on convenience (distance or time minimization).

Geographic distances from patients to places of service are often used by health planners, and have also been used in research but, less frequently. The research by Gittleson (1984) is an example of insightful use of this type of medical service area definition. He used distances within Baltimore to examine variations in rates for spinal punctures and bone marrow biopsies in patients in the city, with special emphasis on the relationship between the Johns Hopkins Hospitals and variations in population use rates.

Patient Origin

The approach that uses the origin distribution of those patients using a particular source of care to define MSAs assumes that the distribution of patients among providers is stable over time within a fairly large geographic area. The analyst looks at concentric areas around an institution, as defined by percentage of people living in each geographic area that use a given hospital, and/or the geographic areas where a hospital has at least a specified level of the population using that provider. Griffith (1972) defines this institution-population relationship using two measures. His index of commitment measures the proportion of persons living in a defined geographic area who use the target institution as a source of care, while his index of relevance measures the proportion of a hospital's admissions that come from that defined geographic area.

The patient origin distribution for those using a particular source of care has been used by many researchers. Wennberg's (1984) studies of small area variations in admissions rates in Maine, Massachusetts and Iowa are perhaps the best known. He found that the incidence of (age and sex adjusted) discharge rates for various DRGs varies among populations, and these studies have been replicated by others. Wennberg and his group use hospital discharge ZIP codes aggregated by plurality as the basis for defining a hospital market area. Others, such as Garnick (1987), have used a somewhat less stringent criterion, i.e., ZIP codes comprising 60% of a hospital's discharges. Each researcher has found that variations in age and sex adjusted discharge rates among areas are clearly identifiable. How much of this variation is due to physician practice patterns, how much of it is due to socioeconomic differences in populations, or how much is due to the interaction between practice patterns and socioeconomic differences is not clear.

McLaughlin (1989) demonstrated, in her research on Michigan service areas, that at least some of the variation between areas is explained by socioeconomic factors such as poverty, education, race, unemployment, and access to medical resources. Both she and McMahon (1989) found, however, that discharges for DRGs with high variations remained high - providing support for the influence of medical uncertainty on variations in hospitalization incidence. Garnick (1987) used California hospital market areas defined by travel distance (15 miles), patient origin, and SMSAs for the purpose of clarifying the level of competition within an area.

Diehr (1990) identifies several issues that must be considered when the patient origin method is used to define MSAs. Her research indicates that the homogeneity of the size and age of the population used to calculate rates may strongly affect any hypothesis tested. She has also found the chi-square statistic to be the one that is most robust for this type of analysis.

Which Approach To Use?

The choice of which approach to use depends on the following seven factors:

1. THE PURPOSE OF THE STUDY is the first important factor to consider. If the purpose is to analyze the economic exchange decisions of patients, then the geographic distance method would give the best result, all else being equal. If the MSA will be used to define populations that are served by specific programs or providers, then the geopolitical boundary or patient origin methods would work better.

2. ECONOMIC & ADMINISTRATIVE CHARACTERISTICS OF THE PROGRAMS INVOLVED should be considered. If the money for paying for services follows the individual, i.e. it is based on individual eligibility, and services can be provided by either private and public providers, then the patient origin method may work best. If money follows a program, the geopolitical or distance method may yield the better MSA definition.

3. ANALYTIC ADEQUACY (POWER) is an important consideration for any inferential study and predictive validity is essential for accurate forecasting. The three methods may behave very differently on these dimensions and the performance of each method should be considered before a final choice is made. Distance based MSAs have been more common in predictive studies. To maximize the power of a study we must trade off increases in power generated by defining MSAs to include a large number of patients, against decreases in power resulting from the inevitable dilution of the population of interest as the MSAs increase in size.

4. MAJOR ISSUES RELATED TO BARRIERS TO ACCESS must be considered in the selection of a method for defining MSAs. The validity of MSAs that are based on distance measures may be influenced by the availability of public transportation and the presence of major road systems, mountains, lakes or rivers. MSAs that are defined by patient origin may not reflect recent shifts in markets, and their inclusion of charity/no pay regions will depend on such patients being treated administratively the same way as paying patients. If this

is not consistently the case across institutions then the resulting variations in the MSAs may influence the conclusion validity of a study.

5. THE STRUCTURE OF EXISTING REFERRAL PATTERNS are especially important to consider if the purpose of the study is related to the evaluation of an innovation aimed at integrating care, improving access and utilization, or managing resource consumptions. In such studies it would be desirable to use geopolitically defined MSAs to reflect administrative/funding realities, or to use geographic distance to incorporate patient convenience preferences. Neither method will, however, perform well if the decision on where to get care is made by referring physicians through well established channels that do not coincide with distance criteria or geopolitical boundaries.

6. DIFFERENCES IN USE PATTERNS AMONG SUB-POPULATIONS should be considered when use patterns may differ among patients of different age, race, income, socioeconomic level, educational level. Each of the three methods should be assessed separately to clarify how expected differences in population use patterns would influence the validity of the MSAs definition, given the purpose of the study.

7. DIFFERENCES IN USE PATTERNS ACROSS PROCEDURES must also be considered. Some procedures may be termed "convenience goods", i.e. routine general care. Most patients will go to the nearest facility to get such interventions. Other procedures fall in the category of "shopping goods"; patients shop around until they find a price-feature combination that satisfies them, i.e. deliveries. A third type of procedures may be classified as "specialty goods" i.e. coronary artery bypass operations, and generally patients seek such procedures from recognized expert providers, often upon the advice of generalist providers.

Three Illustrations

In example A the MSA specification must be appropriate for predicting care utilization by AIDS patients. Example B considers issues related to the evaluation of the impact of public funding for prenatal care on low birthweight rates. Example C considers the MSA specification related to an assessment of the effect of hospital closures on outcomes for vulnerable populations in their service areas.

Example A

PURPOSE: SITE SELECTION TO MAXIMIZE ACCESS FOR AIDS PATIENTS

APPROACH: Use geographic distance (GD) from patient to place of service. Rationale: This method is the most satisfactory based on the analysis below.

1. PURPOSE OF STUDY: find locations that maximize the utilization and minimize the cost of travel. Therefore select GD approach.

2. ECONOMIC & ADMINISTRATIVE CHARACTERISTICS OF THE PROGRAMS INVOLVED: The sources of funds and authority is mixed for such programs. This criterion is of little importance here.

3. ANALYTIC ADEQUACY (POWER): This type of project is predictive not inferential, so the issue of statistical power does not arise. Because we have few data available for predicting utilization by AIDS patients, a simple method of minimizing time and travel costs for patients would lead us toward the GD approach.

4. MAJOR ISSUES RELATED TO BARRIERS TO ACCESS: Indigent and minority patients have severe barriers to access to care in most communities. These sub-groups are also of high risk for HIV infection. The GD approach will allow us to define the MSAs to specifically minimize the influence of these barriers to access if we weigh access by high-risk groups heavily in the MSA formulation.

5. STRUCTURE OF EXISTING REFERRAL PATTERNS: AIDS care for the majority of patients at this stage of the epidemic consists of primary care. Primary care decisions are generally made by patients or their families, who, in most cases would try to minimize travel time and cost. The GD assumptions fit well here.

6. DIFFERENCES IN USE PATTERNS AMONG SUB-POPULATIONS: There are major differences in use patterns among sub-populations of AIDS patients. Many middle class patients purposely seek care outside their community to prevent information from "leaking" about their HIV status. Poor and homeless AIDS patients seek the closest source that is willing to care for them. The most inclusive service area definition for wealthy patients is based on patient origin, but many poor and homeless patients could be excluded if this method were used. The geopolitically defined MSA fits neither the patients who flee to seek care, nor those who seek care close to where they live. Thus, the GD method is the best choice based on this criteria.

7. DIFFERENCES IN USE PATTERNS ACROSS PROCEDURES: AIDS patients use different types of services during the course of the disease. Those in the late stages need more high-technology support and more specialist care. For this group the most appropriate MSA definition would be that based on patient origin. AIDS patients who are IV drug users may need Methadone support, for such patients distance minimization is important. This criterion indicates that the analyst must decide on the relative importance of these two groups in the study.

Example B

PURPOSE: TO DETERMINE THE IMPACT OF PUBLIC FUNDING OF PRENATAL CARE ON RATES OF LOW BIRTHWEIGHT (LBW)

APPROACH: Compare rates using geo-politically (GP) defined MSAs (counties). Rationale: Many of the data required are aggregated at the level of the county. The most consistent unit for administrative authority, reporting, and eligibility determination is the county.

1. PURPOSE OF STUDY: To determine if high rates of funding result in lower rates of LBW births, ceteris paribus.

2. ECONOMIC & ADMINISTRATIVE CHARACTERISTICS OF THE PROGRAMS INVOLVED: County Health Departments are the traditional providers of prenatal care for poor women. They use federal, state, and local funds for programs, with the county as the most common base level of administrative authority. Increasingly Medicaid pays for similar care, and services are available through private providers. However, data on these services can be aggregated by county. Therefore select the GP approach.

3. ANALYTIC ADEQUACY (POWER): This type of analysis requires the researcher to use statistical means of controlling for differences in risk of LBW. Most of the important control variables are available for county level aggregations. It would be close to impossible to get information on community level risk factors for distance or patient origin MSAs.

4. MAJOR ISSUES RELATED TO BARRIERS TO ACCESS: High risk of LBW is correlated with minority, teen-age, and poverty status. Many teens, poor, and minority women depend on public clinics in their county for care. This leads us towards the GP approach.

5. STRUCTURE OF EXISTING REFERRAL PATTERNS: High-risk pregnant women often receive care at special regional clinics. They are, however, usually referred by local providers, and data on them may be allocated to their county of residence. MSA specification by the patient origin method would be the selection of choice for such women, and the GP method would be the second best choice.

6. DIFFERENCES IN USE PATTERNS AMONG SUB-POPULATIONS: The use of publicly funded PNC is unequally distributed across communities and populations. Convenience and cost of care will affect a woman's utilization of care. This leads us to suggest MSA definition by PO for self pay or insured women, MSA definition by GD for women who get care in free clinics, and MSA definition by GP for women who seek care in county clinics.

7. DIFFERENCES IN USE PATTERNS ACROSS PROCEDURES: PNC uses mainly low technology procedures, leading us to expect few differences across procedures. This criterion therefore provides little guidance for MSA definition in the case of PNC.

Example C

PURPOSE: TO EXAMINE THE IMPACT OF HOSPITAL CLOSURE IN RURAL AREAS ON VULNERABLE MEDICARE SUB-GROUPS

APPROACH: Use patient origin data to aggregate ZIP codes by the DRG market share for the hospitals of interest. Rationale: This approach fits the purpose of the study well. It allows us to maximize statistical power and is the method of choice based on most of the other criteria examined.

1. PURPOSE OF STUDY: To determine if local hospital access change the use and outcomes of care for Medicare patients with multiple diagnoses of psychiatric, alcohol and drug related problems. The PO approach is most closely linked to an individual institution's historical service area, and is therefore the method of choice.

2. ECONOMIC & ADMINISTRATIVE CHARACTERISTICS OF THE PROGRAMS INVOLVED: Medicare patients can receive care anywhere and the program is nationally administered. Therefor this criteria provides no specific guidance for specifying MSAs.

3. ANALYTIC ADEQUACY (POWER): The statistical power in this study is maximized if the MSAs are defined so that they have the greatest number of Medicare eligibles, and the least dilution of this population by Medicare patients who receive care in a competing hospital. Therefore select the PO approach.

4. MAJOR ISSUES RELATED TO BARRIERS TO ACCESS: Medicare patients who need hospitalization for psychiatric/alcohol/drug related conditions can get care anywhere. They would be expected to follow the local hospital market pattern in seeking care. Therefore the PO approach is the most appropriate for this study.

5. STRUCTURE OF EXISTING REFERRAL PATTERNS: Most of these patients are treated locally, again supporting the use of the PO method for MSA definition.

6. DIFFERENCES IN USE PATTERNS AMONG SUB-POPULATIONS are specific for Medicare patients and vary by diagnosis within this group. MSA specification should therefore be based on Medicare data on patient origin for Psychiatric, Alcohol, and Drug Use related DRGs.

7. DIFFERENCES IN USE PATTERNS ACROSS PROCEDURES: There would be minimal variation in use patterns across procedures. This criteria is not very useful for guiding MSA definition in the case of Medicare hospitalizations.

Conclusion

The question remains: Which approach to use? The answer is: IT ALL DEPENDS!! We have discussed a set of criteria that should be used as a framework for analyzing and selecting a method for defining MSAs. It is clear that a perfect method for defining MSAs does not exist, and that researchers must make trade-offs between the three methods based on many factors that influence the individual study. The use of the seven criteria presented in this paper will make such trade-off between methods explicit and thereby help the analyst in making the decision.

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IMPACT OF HOSPITAL CLOSURES ON ACCESS TO CARE

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INTRODUCTION

When a hospital closes, concerns are raised about the availability and accessibility of alternative sources of inpatient and emergency care. Two recent studies by the Office of the Inspector General (OIG) found little or no effect of rural hospital closures on access to care. Through interviews with local officials, the OIG (1989) found that few patients were affected by the hospital closures and that other hospitals were located nearby. Moreover, in many cases, physicians and patients were bypassing the local hospital in favor of other nearby facilities.

According to a household survey in rural communities with hospital closures, the OIG (1990) found that the perceptions of access problems were strongly related to the distance to the nearest hospital: 40 percent of those without a hospital nearby (more than ten miles) expressed a serious concern about access, compared to only 11 percent of those with a nearby hospital (less than ten miles). In addition, the low income or elderly were more likely than others to express a serious concern about access.

Reardon et al. (1991) compared potential access in counties where the only hospital closed (OHC) versus counties that never had a hospital (NHH). They found that residents of OHC counties had access to more healthcare providers than residents of NHH counties, with the exception of ambulance services. However, travel distances and times were slightly longer for OHC residents than NHH residents (although the differences were not statistically significantly).

None of these studies examined actual utilization patterns pre- and post-closure to determine the impact of hospital closures on hospital use. This study uses Medicare claims data to examine the effect of a hospital closure on travel patterns for inpatient care. This study takes a population-based approach, that is, by constructing service areas for each of the closing hospitals and following the hospital utilization patterns of the population pre- and post-closure. Hospital service areas have been defined on the basis of discharge patterns for each hospital.

SAMPLE SELECTION

This study includes hospital closures in nine states for which complete Medicare (Part A and Part B) claims data were available from 1985-1989: Alabama, Georgia, Kansas, New Jersey, Oklahoma, Oregon, Pennsylvania, Washington, and Wisconsin. The eligibility criteria for the hospital cloures were as follows: hospitals had to be Medicare-certified, short-term, general acute care facilities which closed in either 1986 or 1987. Hospitals that converted from acute care to non-acute care status were included, for example, conversions to a psychiatric or rehabilitation facility. Mergers that resulted in a conversion to a non-acute care facility (e.g., psychiatric, outpatient department, or office space) were also included.

The final study sample includes 23 hospital closures in the nine states. Twelve of the 23 were urban and 11 rural (Table 1). Sixteen of the 23 closures took place in 1987. Fourteen of the hospitals closed permanently, while nine were converted into a non-acute care health facility (mostly urban hospitals). Ten of the fourteen permanent closures were in rural areas; only one rural hospital had a status change rather than a permanent closure.

TABLE 1

SAMPLE DESCRIPTION

	TOTAL	URBAN	RURAL
Number of Hospitals	23	12	11
Year of Event			
1986	7	4	3
1987	16	8	8
Type of Event			
Permanent Closure	14	4	10
Termination of Acute Care	9	8	1

Urban closures averaged 84 beds, compared with 49 beds in the rural closures (Table 2). Occupancy rates were slightly higher on average in rural hospitals (48 percent) than urban hospitals (43 percent). Rural hospitals were also slightly more dependent on Medicare patients than those in urban areas (46 percent versus 40 percent).

TABLE 2

HOSPITAL CHARACTERISTICS, 1984

	TOTAL	URBAN	RURAL
Bed Size	67	84	49
Occupancy	45%	43%	48%
Medicare Share	43%	40%	46%

DEFINITION OF HOSPITAL SERVICE AREAS

Analytic Approach

The primary unit of analysis for this study is the hospital service area. Hospital service areas focus on realized access (those who actually use the hospital) instead of potential access (i.e., the target population). This concept was developed in the small area analysis literature and is typically defined by a collection of ZIP codes, census tracts or other geographic areas for which the residents rarely depart for hospital care (Rohrer, 1987). Hospital service areas are frequently developed on the basis of patient origin data, namely ZIP code level admission or discharge data (Wright and Marlor, 1990).

Griffith (1972) proposes two measures of the importance of a hospital to a given area:

Relevance index: reflecting the proportion of an area's discharges accounted for by a given hospital; and

Commitment index: indicating the proportion of a hospital's discharges from a given area.

Algebraically, these two measures are as follows:

$$RI_i = \frac{DISCH_{ij}}{TOTZIP_j}$$

$$CI_i = \frac{DISCH_{ij}}{TOTHOSP_i}$$

where:

RI_i = relevance index for hospital i;

$DISCH_{ij}$ = the number of discharges from hospital i in area j;

$TOTZIP_j$ = total discharges from area j;

CI_i = commitment index for hospital i; and

$TOTHOSP_i$ = total discharges from hospital i.

As can be seen from the above formulas, the numerators in the two equations are identical: the number of discharges from a given hospital for a specific ZIP code. What differs are the denominators. In the relevance index, the number of discharges in the ZIP code is the denominator. The relevance index can be interpreted, therefore, as the importance of the hospital to the ZIP code (i.e., the population residing in the ZIP code). The denominator for the commitment index is the total number of hospital discharges. This index measures the importance of the ZIP code to the hospital.

Method

Hospital service areas were created for each of the 23 hospitals based on a patient origin study. Discharge patterns prior to hospital closure were analyzed using the 100 percent Medicare Part A claims files for 1984 and 1985. These files contain all Medicare discharges in the U.S., not just in the selected states.

We considered both the importance of the hospital to the community (relevance index) and the reliance of the hospital on the community for patients (commitment index). First, ZIP code areas were ranked by the relevance index, i.e., the number of discharges from the closed hospitals as a proportion of all discharges for patients living in the ZIP code area. ZIP code areas for which the hospital provided at least 5 percent of the discharges were included.

In the second step, ZIP code areas were added in cases where the commitment index summed to less than 60 percent of total hospital discharges. However, a minimum of one percent of discharges from each individual ZIP code area was required for inclusion.

Results

Two examples demonstrate how the method was implemented. The service area for the Riverside Hospital is comprised of nine ZIP codes representing 74.2 percent of all Medicare discharges from the hospital (Table 3). Four of the ZIP codes each accounted for less than 5 percent of total discharges. However, in all cases the relevance index is above 5 percent. In fact, one ZIP code 07082, accounted for only 3.2 percent of all discharges from Riverside Hospital, yet this hospital accounted for one-fourth of all discharges in the ZIP code.

TABLE 3

HOSPITAL SERVICE AREA: Riverside Hospital, New Jersey

ZIPcodes	Commitment Index	Relevance Index
07005	31.9%	39.1%
07054	15.4	19.0
07035	8.6	12.8
07034	5.6	22.5
07045	5.0	33.8
07082	3.2	24.5
07058	1.7	14.0
07046	1.5	16.2
07981	1.3	6.3
Total	74.2%	

South Bergen Hospital provides another example (Table 4). Seven ZIP codes accounted for 62.8 percent of the hospital discharges. In none of the cases was the relevance index above 5 percent. However, these ZIP codes were selected to achieve a minimum of 60 percent on the commitment index.

We had originally proposed an 85 percent threshold for the hospital service areas. Only 8 of the 23 hospital service areas reached this minimum. Two were urban hospitals and six were rural hospitals. Instead we chose a 60 percent threshold so as not to create service areas

TABLE 4

HOSPITAL SERVICE AREA: South Bergen Hospital, New Jersey

ZIPcodes	Commitment Index	Relevance Index
07604	15.2%	*
07644	13.2	*
07070	10.9	*
07073	8.0	*
07075	7.8	*
07071	4.0	*
07072	3.7	*
Total	62.8%	

*less than 5 percent.

that were so large and diffuse that we would dilute all potential effects of the hospital closure. Following the lead of Garnick et al. (1987), we also set a minimum of one percent on the commitment index. One hospital service area fell just short of the 60 percent threshold. None of the 25 ZIP codes in the service area had a relevance index greater than 5 percent and only one ZIP code had a commitment index above 5 percent.

An additional issue arose for hospitals which had overlapping hospital service areas. This occurred in two states, Oklahoma and Washington. In both cases, two hospitals serving the same ZIP code closed during 1986 or 1987. One option for handling overlapping ZIP codes was to assign the ZIP code to the area which relied most on the hospital. However, because the beneficiaries in these ZIP code areas depended on two closing hospitals to some extent, they were potentially subject to more limited access to hospital care. As a result, separate hospital service areas were created containing only the overlapping ZIP codes. In this way, the effect of the dual closures on these populations can be measured. Three overlapping service areas were formed, with one occurring in rural Oklahoma and two in Seattle.

Thus, we constructed 26 hospital service areas for the 23 closing hospitals, including three overlapping areas that were served by two of the closing hospitals. Fourteen of the service areas are urban and twelve are rural (Table 5). Rural service areas typically include fewer ZIP codes (2 to 9) with a mean of six. In contrast, the number of ZIP codes required to create urban hospital service areas ranges from 1 to 25 with an average of nine.

Another difference between urban and rural hospitals was noted in the number of ZIP codes in which the closed hospital provided 5 percent or more of the inpatient care: the relevance index exceeds five percent for 85 percent of the rural ZIP codes, versus 51 percent of the urban ZIP codes.

The percent of discharges accounted for by each of the hospital service areas ranges from 58 to 90 percent (mean = 75 percent). Hospital service areas for rural hospitals account for a greater proportion of discharges, ranging from 61 to 90 percent and averaging 81 percent of the hospital's discharges. In contrast, service areas for urban hospitals include 70 percent of discharges on average.

TABLE 5

CHARACTERISTICS OF HOSPITAL SERVICE AREAS

	TOTAL	URBAN	RURAL
Number of Closures	23	12	11
Number of Areas	26	14	12
Number of ZIPcodes			
Mean	7	9	6
Range	1-25	1-25	2-9
Percent of ZIPcodes with Relevance Index > 5%	56%	51%	84%
Percent of Admissions Included in Service Area			
Mean	75%	70%	81%
Range	58-90%	58-88%	61-90%

MARKET SHARE OF CLOSING HOSPITALS

How important are the closing hospitals to their respective service areas? Figure 1 shows the market share of closing hospitals in 1984 relative to all other hospitals serving the service area. In 14 service areas, the closing hospital accounted for less than 10 percent of Medicare discharges in the service area, suggesting that these hospitals had a relatively low level of significance to the population. This could lend support to the hypothesis that many residents were "voting with their feet" prior to the hospital's closure.

In another seven service areas, the closing hospitals accounted for 11-20 percent of the inpatient discharges in 1984. In only four of the areas was the hospital responsible for more than 20 percent of Medicare discharges.

As shown in Figure 1, the majority of closing hospitals in urban areas had less than a 10 percent market share. Rural hospitals had a higher market share on average, with the majority in the 11-20 percent range.

FIGURE 1
Market Share of Closing Hospitals, 1984

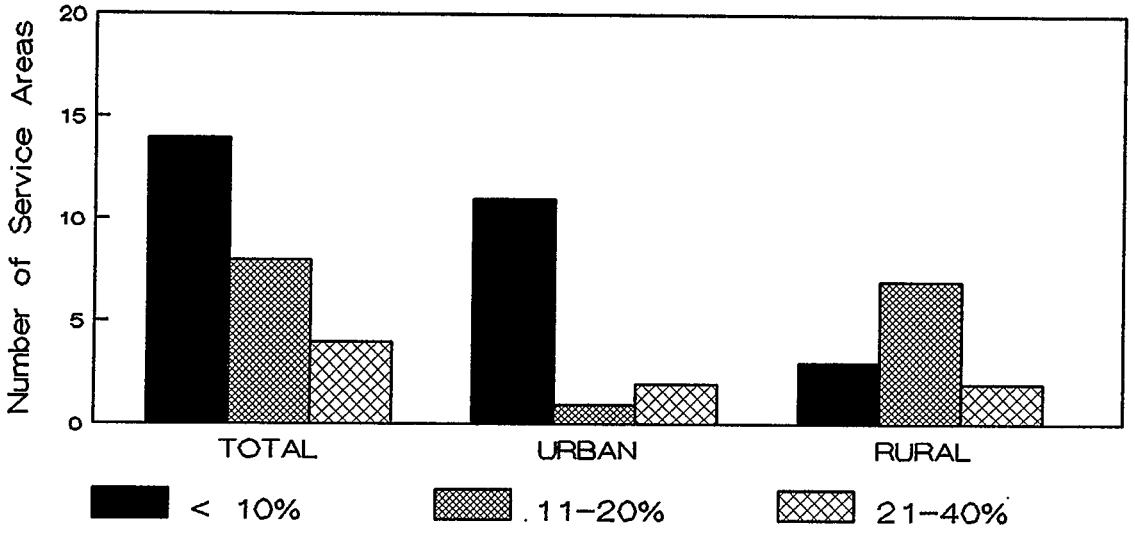
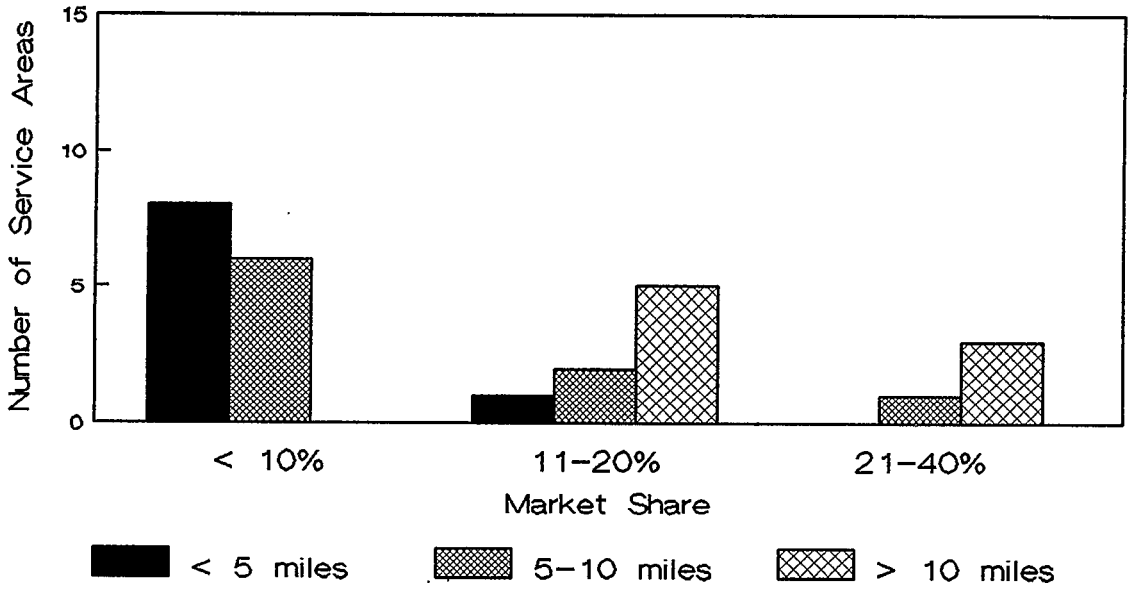


FIGURE 2
Distance to Nearest Hospital by Market Share



The market share of the closing hospital is clearly a function of the distance to the next-nearest hospital (Figure 2). All of the service areas with a market share of 10 percent or less had other hospitals within 10 miles. Where the closing hospital had a relatively high market share pre-closure, travel distances to the nearest hospital were higher post-closure (often greater than 10 miles).

IMPLICATIONS

Based on the analysis of hospital distances and discharge patterns pre- and post-closure, three access scenarios were devised. Under the first scenario, the closing hospital had an insignificant share of Medicare discharges prior to closure (10 percent or less) and thus, the closure was unlikely to result in any dislocation or changes in discharge patterns. Fourteen service areas are included in this category, including 11 in urban areas and 3 in rural areas.

Under the second scenario, the closing hospital had a significant share of the market (in excess of 10 percent), but another facility within 15 miles (or perhaps multiple facilities) has clearly taken over the share of the market following the closure. In some cases, the facility that replaces the closing hospital may be related to the hospital closure as a result of a merger and then conversion of the "closing" hospital to a non-acute care service. In other cases, it may be a separate entity located within 15 miles of the closing hospital. Five service areas are included in this category based on the evidence that another nearby facility has assumed the share of discharges previously represented by the closing hospital (two urban and three rural).

Under the third scenario, seven hospitals (one urban and six rural) were significant providers in their service area, accounting for 15 percent or more of discharges in 1984. In addition, descriptive analyses of nearby hospital facilities indicate that there were no emergency facilities within 15 miles of the closing hospital or that the nearby facility was at high risk of financial instability (e.g., low occupancy, small size, high Medicare dependence). These service areas will be the focus of future work, in terms of hospital utilization rates, Medicare expenditures, and out-of-pocket expenses for health care.

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HOSPITAL SERVICE AREAS AND UTILIZATION RATES IN A COMPLEX MARKET

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Introduction

Variation in hospital medical and surgical rates have been widely studied, pioneered by the works of Wennberg[1,2]. Many others have followed his lead and documented that the variation in these rates is due to many factors including clinical judgment, sociodemographic factors, availability of resources (beds, personnel, etc.), prevailing custom, and random variation[3]. These studies require that for a given geographical area of study there must be complete coverage of hospitalization data using a common coding system. In addition, the geographic universe must be divided into meaningful areas for the comparison of rates.

The analysis of small-area variations in hospital utilization rates has been most informative when applied to regions dominated by single-hospital service areas, such as rural areas, or isolated towns, and small cities. In metropolitan areas with many hospitals, the complexity of the hospital market has prevented researchers from specifying hospital service areas and associating rates in those areas with specific facilities. The most common solution has been to treat the entire metropolitan area as a single service area served by all hospitals in the area.

Most studies use areas that are predefined based on political boundaries (e.g., cities/towns, counties, etc.). For example, in a study by Perrin, et al comparisons were made between New Haven, Boston, and Rochester[4]. McPherson[3], in a study comparing rates from Canada, U.S. and England points out that the data from Canada, using Provinces as the sub areas, and U.S., using regions as the sub areas, the differences in rates "are largely statistical fictions, possessing a more geographic than social significance". Studies conducted in Maine and Vermont by Wennberg and others use areas defined by a combination of political boundaries and service areas[5].

This study demonstrates that areas defined on the basis of hospital service patterns provide a basis for comparisons that is stable over time and useful for the planning and evaluation of medical care in predominantly urban settings. Hospital market shares, calculated at the census tract level provide the basic measure that is used for aggregating the census tracts into hospital service areas. Cluster analysis techniques are used to define the aggregation process such that the final service area definitions are not controlled by political boundaries.

Political boundaries (cities/towns) have been used in Rhode Island to define secondary health planning areas[6]. These areas had two primary deficiencies. First, the City of Providence was included in one service area. This service area included all socioeconomic levels and was served by several hospitals. Thus variation within this area could not be partitioned and examined with respect to clinical judgment or sociodemographic characteristics. Second, some of the other areas had such a small population base that the calculations of hospital utilization rates were not stable. The use of the census tract as the basic building block in the definition of service areas corrects both of the deficiencies.

Methods

Rhode Island is completely covered by 213 census tracts defined for use in the 1970 and 1980 U.S. Census. Uniform hospital discharge data is available for these census tracts from 1974 to the present. There are about 4,500 individuals in each census tract and about 135,000 discharges from the state's community hospitals per year.

Discharge data from 1979, 1980, and 1981 was combined to calculate the market share for each community hospital in each census tract. Market share is defined as the number of discharges for the three year period from a given hospital divided by the number of discharges from all community hospitals for a particular census tract. A market share matrix of 213 rows (census tracts) by 15 columns (hospitals) is the input matrix for clustering. Ward's method of

hierarchical clustering was used which is included in the Statistical Analysis System (SAS) software package. The procedure groups those census tracts together that have similar utilization patterns based on hospital market shares. The details are given elsewhere[7,8]. The primary objective is to group census tracts together such that the variation in market share patterns within the clusters is minimized relative to the variation among the clusters. The final solution is determined based both on empirical methods and inspection.

After the service areas are defined, the utilization rates of all hospitals for each service area are examined. Each hospital is classified as either a contributor to that service area or a non-contributor based on the percentage of discharges from a particular hospital for a given service area. For the purposes of this study, if that percentage is greater than 25% for a given hospital then the hospital is considered a contributor to that service area.

The stability of these service areas was assessed by calculating the percentage of utilization from non-service area hospitals for each service area for the periods 1974-1976, 1979-1981, and 1983-1985. The choice of these time periods was based on availability of denominator or population data and consistent numerator data.

In addition to service area stability over time is the question of variability among the service areas for specific diagnostic and procedure groups. Other investigators have have examined large numbers of diagnostic and procedure groups and classified them into high, medium, and low categories based on the amount of geographic variability they exhibit[9]. The diagnoses and procedures selected for this study were based on consistency of definition over the time periods selected (despite coding changes from H-ICDA-2 to ICD-9-CM) and sufficient number of discharges for analysis. These diagnostic groups and surgical procedures are given below:

DIAGNOSIS	VARIATION
Acute Myocardial Infarction	Low
Adult Gastroenteritis	Very High
Chest Pain	Very High
Chronic Obstructive Lung Disease	Very High
Pediatric Bronchitis and Asthma	Very High
Adult Bronchitis and Asthma	Very High
PROCEDURE	
Choleocystectomy	Low
Hysterectomy	High
Back and Neck Operations	Very High

The diagnostic and procedure specific hospital discharge rates were calculated for each service area and for each of the three time periods (74-76, 79-81, 83-85). Using the Rhode Island rate as the expected, a one degree of freedom Chi Square test was used to determine if the rate for a particular service area was significantly ($\alpha = .05$) above or below the state average. To facilitate comparisons among the service areas, the percentage above or below the state average was determined.

Results

The hierarchical clustering of the 213 census tracts based on the market share from 15 community hospitals or hospital units resulted in 10 service areas for Rhode Island. The clustering pattern resulted in the Providence area being composed of four clusters and the remainder of the state decomposing into six clusters. These service areas are primarily composed of contiguous census tracts though this was not a clustering criterion.

The Providence clusters are dominated by two hospitals with each area except East Bay having one additional contributing hospital (Table 1). Thus the Providence Clusters are multi hospital service areas while the remainder of the state is partitioned into single hospital service areas. The populations in these service areas range from 21,220 to 178,806 with annual discharge rates per 1,000 of 79 to 165.

The percentage of discharges to non service area hospitals (Table 2), demonstrates that, for the periods selected, there is remarkable stability. The range in these percentages is relatively small in the metropolitan areas and larger in the outlying areas. These

Table 1. Population, Discharges, Annual Discharge Rate, and Primary Hopitals for the Ten Hopital Service Areas in Rhode Island.

SERVICE AREA	POPULATION (1980)	DISCHARGES (1979 - 1981)	ANNUAL DISCHARGE RATE*1,000 (1979 - 1981)	PRIMARY HOSPITAL(S) *
PROVIDENCE WEST	124,153	48,611	131	Rhode Island Women and Infants St. Joes Providence
PROVIDENCE NORTH	142,856	47,237	110	Rhode Island Women and Infants Roger Williams
EAST BAY	150,944	35,716	79	Rhode Island Women and Infants
EAST SIDE	21,220	7,161	112	Rhode Island Women and Infants Miriam
PAWTUCKET	102,443	41,795	136	Memorial
NORTHERN	73,767	36,422	165	Woonsocket Fogarty
KENT	178,806	61,191	114	Kent County Memorial
ISLAND	66,834	25,552	127	Newport
WEST	34,425	14,983	145	Westerly
SOUTH	51,706	20,763	134	South County

* Hospitals not appearing in any service area: Cranston General, Saint Joseph (Fatima Unit), and Notre Dame.

Table 2. Percent of Discharges to Non-Service area Hospitals for Three Time Periods and Ten Service Areas.

	PERCENT USE OF NON-PRIMARY HOSPITALS		
SERVICE AREA	1974-1976	1979-1981	1983-1985
PROVIDENCE WEST	37	35	34
PROVIDENCE NORTH	42	41	42
EAST BAY	42	41	43
EAST SIDE	22	19	20
PAWTUCKET	42	45	47
NORTHERN	16	18	22
KENT	44	45	43
ISLAND	6	8	11
WEST	21	21	23
SOUTH	36	35	41

Table3. Percent of Discharges Above or Below the State Average in Three Time Periods and Ten Service Areas in Rhode Island for Selected Diagnoses.

SERVICE AREA	ADULT MYOCARDIAL INFARCTION	ADULT GASTRO-ENTERITIS	CHEST PAIN	CHRONIC OBSTRUCTIVE LUNG DISEASE	PEDIATRIC BRONCHITIS AND ASTHMA	ADULT BRONCHITIS AND ASTHMA
			1974 - 1976			
PROVIDENCE WEST	0.09	-0.09	0.27	0.27	-0.06	0.00
PROVIDENCE NORTH	0.05	-0.15	0.15	0.07	-0.40*	-0.07
EAST BAY	-0.27*	-0.39*	-0.29	-0.18	-0.66*	-0.44*
EAST SIDE	0.19*	0.02	0.48*	-0.31	-0.43*	-0.08
PAWTUCKET	0.12	-0.16	0.21	0.31	0.72*	-0.04
NORTHERN	0.08	0.40*	-0.46*	0.38*	0.50*	0.64*
KENT	0.14	-0.07	0.18	-0.23	0.21	-0.15
ISLAND	-0.20*	0.85*	-0.45*	-0.30	-0.08	0.55*
WEST	-0.43*	0.52*	0.54*	-0.03	0.24	0.74*
SOUTH	0.00	0.43*	-0.69*	-0.30	0.40*	0.06
MAX-MIN	0.61	1.23	1.23	0.69	1.37	1.18
			1979 - 1981			
PROVIDENCE WEST	-0.18	-0.06	-0.19	-0.44*	-0.51*	-0.26
PROVIDENCE NORTH	-0.04	0.03	-0.04	-0.34	0.08	0.01
EAST BAY	0.23*	0.35*	0.32	0.11	0.59*	0.30
EAST SIDE	-0.29	0.13	0.16	0.26	0.42	-0.13
PAWTUCKET	-0.19	0.22	0.10	-0.20	-0.06	-0.05
NORTHERN	-0.14	-0.57*	0.15	0.10	-0.62*	-0.44*
KENT	0.02	0.07	-0.25	0.16	-0.10	0.15
ISLAND	0.14	-0.23	0.22	0.72*	0.42	0.09
WEST	0.08	-0.69*	-0.88*	0.06	0.14	-0.44*
SOUTH	0.26*	-0.12	0.33	0.31	-0.20	0.16
MAX-MIN	0.55	1.04	1.21	1.16	1.21	0.74
			1983 - 1985			
PROVIDENCE WEST	-0.04	0.02	-0.13	-0.20	-0.46*	-0.19
PROVIDENCE NORTH	-0.03	0.10	-0.22	-0.13	0.02	0.12
EAST BAY	0.18	0.32*	0.24	0.26	0.48*	0.32*
EAST SIDE	-0.01	0.21	0.12	0.26	0.58*	-0.17
PAWTUCKET	-0.31*	-0.05	0.04	-0.08	0.09	-0.21
NORTHERN	-0.15	-0.54*	0.13	-1.23*	-0.41	-0.91*
KENT	-0.10	-0.04	-0.18	0.22	-0.30	-0.01
ISLAND	0.29*	0.08	0.32*	0.63*	0.60*	0.49*
WEST	0.28*	-0.43*	-0.21	0.24	0.16	-0.03
SOUTH	0.24*	-0.15	0.27	0.14	-0.05	0.38*
MAX-MIN	0.60	0.86	0.54	1.86	1.06	1.40

*: significantly different from state average at $\alpha = .05$

Table 4. Percent of Discharges Above or Below the State Average in Three Time Periods and Ten Service Areas in Rhode Island for Selected Proceddures.

SERVICE AREA	CHOLEOCYSTECTOMY	HYSTERECTOMY	BACK AND NECK OPERATIONS
		1974 - 1976	
PROVIDENCE WEST	0.11	0.12	0.06
PROVIDENCE NORTH	0.03	0.08	-0.05
EAST BAY	-0.22	-0.20	-0.11
EAST SIDE	-0.03	-0.09	0.23
PAWTUCKET	0.24*	0.19	-0.01
NORTHERN	0.19	0.13	0.60*
KENT	0.07	0.13	0.04
ISLAND	-0.30*	-0.47*	0.00
WEST	-0.24*	-0.16	-0.65*
SOUTH	-0.26*	-0.29*	-0.52*
MAX-MIN	0.54	0.66	1.25
		1979 - 1981	
PROVIDENCE WEST	0.11	0.15	0.10
PROVIDENCE NORTH	0.12	0.11	-0.07
EAST BAY	-0.20	-0.18	-0.11
EAST SIDE	-0.19	-0.09	-0.05
PAWTUCKET	0.21	0.10	-0.02
NORTHERN	0.18	0.13	0.19
KENT	-0.01	0.13	0.05
ISLAND	-0.21	-0.39*	0.41*
WEST	-0.13	-0.25*	-0.67*
SOUTH	-0.20	-0.24	-0.19
MAX-MIN	0.41	0.54	1.08
		1983 - 1985	
PROVIDENCE WEST	0.10	0.08	0.06
PROVIDENCE NORTH	0.06	0.09	0.02
EAST BAY	-0.13	-0.23	-0.09
EAST SIDE	-0.19	-0.04	-0.30
PAWTUCKET	0.17	0.24	0.05
NORTHERN	0.12	0.03	-0.08
KENT	0.11	0.21	0.24
ISLAND	-0.35*	-0.34*	0.00
WEST	-0.05	-0.43*	-0.63*
SOUTH	-0.32*	-0.22	-0.20
MAX-MIN	0.53	0.67	0.87

*: significantly different than state average at $\alpha = .05$

outlying areas are growth areas in the state and these patterns may also reflect retention of medical care providers from a previous residence or increasing competition for this market.

The range in variation for the selected diagnoses (Table 3) follows the pattern predicted from the other investigators. The variation for AMI is low compared to the other diagnostic groups over the three time periods but Chest pain is lowest in the 83-85 period and COLD is almost as low as AMI in the 74-76 period. Also, the variation in COLD increases over the three time periods. There is no discernible pattern among the service areas except that "Kent" is consistently not different from the state average for all the time periods. These patterns in variation follow those reported in the literature.

The range in variation for procedures (Table 4) is also consistent with that found by other investigators. Choleocystectomy has low variation over all time periods, Hysterectomy is high, and Back and Neck Operations are very high. Unlike the diagnoses selected, there is a pattern for the procedures over the service areas. All the Providence service areas ("Providence West", "Providence North", "East Bay", and "East Side") and "Kent" are not significantly different from the state average. Also, "Island", "West", and "South" service areas tend to have discharge rates below the state average.

Conclusions

The service areas defined by clustering market shares provides relatively uniform provider specific service areas. In this study a complex metropolitan market area (Providence) is subdivided on non-political boundaries such that variation in rates among these areas can be more easily attributed to clinical choice, socioeconomic status, custom, and other factors. The stability of these areas over time makes the temporal evaluation of rates more compelling and meaningful.

The general variability patterns found here conforms to those of other investigators and suggests that utilization rates based on clusters exhibit the same characteristics as those found in studies using service areas that are simple and defined on political areas. Thus these service areas are useful in the same way as the others, but have the advantage of allowing for the subdivision of metropolitan areas that has been a problem in small area analysis.

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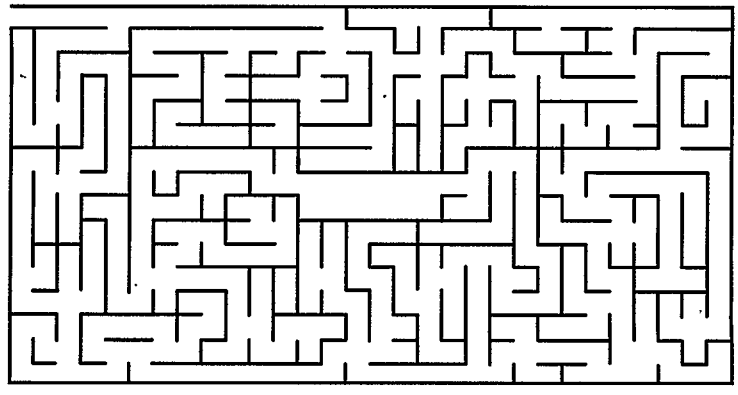
Session Z

Detecting Aberrations Application to Surveillance



SURVEILLANCE FROM A CENTRAL CANCER REGISTRY: I. A DENOMINATOR-FREE STRATEGY

J. Wanzer Drane, University of South Carolina
and Tim E. Aldrich

This paper presents a design of a surveillance system to be used within a central cancer registry. The statistical methodologies employed do not require sizes of populations at risk. Therefore the strategy is denominator-free.

On examining the records of a cancer register one will notice a small number of variables, typically: 1. ID, 2. Address, 3. State if other, 4. Race, 5. Sex, 6. Primary site, 7. Age at Dx., 8. Dx. Date, 9. Morphology, and 10. Grade. Through the use of the TIGER (Topologically integrated geographic encoding and referencing) system of the Bureau of the Census, or even a set of maps and a simple ruler or scale, addresses can be converted into (X,Y) coordinates, absolute or relative, within the state. Thus each case can be located precisely in both space and time of diagnosis. Location (X,Y), date of Dx, site or morphology and grade are the essential elements to monitor the occurrence of cancer in a state.

CLUSTER (ATSDR, 1990) contains twelve windows and thirteen subprograms (SP) used to analyze data which are either location or time specific or both. Each SP was written for the application of a specific statistical method. Here, we propose to use three of those subprograms in tandem with a common subset of the variables typically collected and stored by a central cancer registry. The initial SP is KNOX (1964) which requires Longitude (X), Latitude (Y), and Date or Time (T). The second SP is BARTON (Barton,and David, 1965) which also uses (X,Y,T) but differently than does KNOX. The third subprogram is SCAN (Naus, 1965) which needs only T. Using these three SPs in tandem one is able to detect 1) The formation of spatial clusters of cases within time, 2) Alterations of spatial patterns of cases over designated intervals of time, and 3) Increases in the incidence of cases over short intervals of time. Anyone of these could signal an investigation. Together they constitute a substantial data filter against missing occurrences of unwanted increases in either spatial or temporal frequencies. A schematic of their use in a surveillance program is illustrated in Figure 1.

HOW IT WORKS

Data covering a particular epoch, say the previous twelve months, are read into FILEMAKER. FILEMAKER presents several questions to the user. The user responds to questions about age, sex, counties, and sites or morphologies to be used to select records for processing. Files are then created according to the answers to those questions. The files are then sorted by Dx Date because both SPs, BARTON and SCAN, require it. KNOX does not.

KNOX calculates distance and elapsed time between all N(N-1)/2 pairings of a sample of size N. By some criteria closeness in distance and elapsed time are defined. A 2x2 table is created as in figure 2. The count, n^{11}, is the KNOX statistic and is presumed to be distributed as a Poisson random variable. The parameter of the Poisson probability mass function (PMF) is estimated by $n_{1.}n_{.1}/[N(N-1)/2]$. If $P(X \geq n_{11}) \leq \alpha$, a space by time cluster is inferred, and this result is FLAGGED. A FLAG is a message identifying particular subset of data which identifies a cluster.

		T-I-M-E Close	Not Close	Total
S P A C E	Close	n_{11}	n_{12}	$n_{1.}$
	Not Close	n_{21}	n_{22}	$n_{2.}$
	Total	$n_{.1}$	$n_{.2}$	N(N-1)/2

Table 2: The 2x2 table constructed by KNOX. n_{11} is the KNOX statistic.

The data are passed to BARTON which divides the epoch into time cells, usually months. This method is somewhat akin to the analysis of variance. The BARTON statistic is Q, where

$$Q = \left[\frac{N-1}{N-n}\right]\left[1 - \frac{\textit{Mean square within}}{\textit{Mean square bet.}}\right],$$

with expectation equal one. After a two transformations a Z and an F statistic result. If significance is obtained, a FLAG is printed along with the coordinates of the mean locations for each time interval. A FLAG signals the movement of the spatial distribution of points over time. It does not signal the presence of a cluster.

Only the temporal cell counts N(I), for $I \in [1,T]$, where T is the number of time

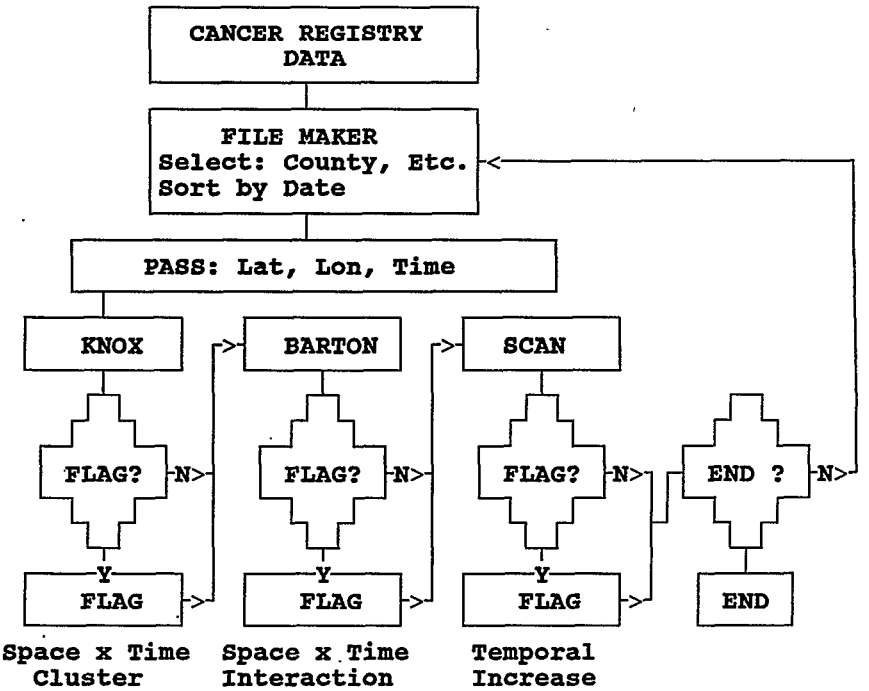


Figure 1. Schematic of a surveillance program employing KNOX, BARTON and SCAN in tandem. Lat = latitude. Lon = longitude.

cells, are passed to SCAN. Windows of widths 1, 2, 3, and 4 are used to scan the T cells. The largest number of cases in a window among all T+1-W windows is the SCAN statistic. The PMF of this statistic is obtained through a complicated set of convolutions of binomial PMFs. If $P(X \geq MaxCases) \leq \alpha$, an inference that a local (pulse) increase has occurred is appropriate, and a FLAG is printed.

DISCUSSION

To be sure, we are interested in sets of cancer cases which are rare and when found are close in distance and elapsed time. Such a set of cases, rare or not, constitute a cluster. But our interest should not end there. We ought to be also interested in how and why spatial patterns change over time. This is the reason for adding BARTON to KNOX. When compared to suggested latencies of cases a few months or even a year could be considered a short while. But a discernable spike or pulse, a temporally local increase in incidence, could signal a temporally local exposure to an identifiable cause of the cancer so registered.

Thus, we have included three different statistical methods, all of which are denominator free. Together they are capable of detecting clusters, spatial changes over time, and temporal spikes, any one of which could trigger an investigation. At this writing programming is twenty percent complete. Each algorithm is programmed and working. An objective over the next year is to complete the programming and validate this combination of methodologies through sensitivity analysis and actual data from North Carolina and Tennessee.

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AN EVALUATION OF A METHOD FOR DETECTING ABERRATIONS IN PUBLIC HEALTH SURVEILLANCE DATA

Donna F. Stroup
Centers for Disease Control

(Not available for publication)

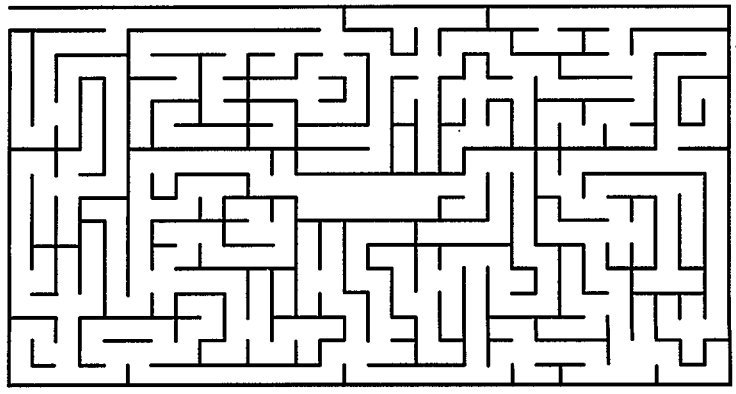
A MONITORING SYSTEM FOR DETECTING UNUSUAL PATTERNS IN DISEASE REPORTS

Glen David Williamson
Centers for Disease Control

(Not available for publication)

Session AA

Software Development for State and Local Level Application (Poster Session)



MATERNAL AND CHILD HEALTH INFORMATION SYSTEM (MATCHS)

Bonnie Brueshoff, Dakota County Community Services Division
Michael Hamberg

The Maternal and Child Health Program in Dakota County strives to improve birth outcomes and health outcomes for target populations through the provision of direct public health nursing and nutritionist services. For many years nurses observed interesting trends in regard to twenty-one (21) identified risk factors of pregnant women and ten (10) birth outcomes. However, to manually correlate all of these variables was prohibitive. Thus, options for automation were addressed.

The objectives of the automation project were to design and implement an automated maternal and child health information system that 1) meets the grant reporting requirements; 2) enables nurses to do better program management; and 3) will efficiently assist professional staff in managing their caseload responsibilities.

A system was designed to meet these objectives that uses a seamless personal computer/mainframe interface. This interface avoids duplicated entry of client data by utilizing data on the county's mainframe. The mainframe data is downloaded to a microcomputer via a menu option. Client specific information is then added on the microcomputer.

The result of the automation project is a computer program called MATCHS. MATCHS provides nurses with the capability to correlate client specific risk factors to birth outcomes. MATCHS information is used to evaluate and modify professional interventions. In addition, MATCHS produces required grant reports in minutes as compared to the previous months when done manually.

MATCHS has essentially moved Dakota County nurses into a new and exciting era. Essential programmatic information can be utilized not only to meet grant reporting requirements, but also to analyze critical health indicators for the development and optimization of maternal and child health services. MATCHS will now be modified for use in other health delivery systems which have differing computer environments, and will be enhanced to add an expert system component.

DEVELOPMENT OF A PUBLIC HEALTH ON-LINE DATABASE

B.B. Cohen; D.J. Friedman; R. Knorr; D. Rhoden; R. Venkatraman; and S. Condon. Massachusetts Department of Public Health

A personal computer based information system, the Health and Environment Assessment Database System-Massachusetts (HEADS-M) has been developed for use in Massachusetts. Currently, HEADS-M is composed of four data modules: cancer incidence, mortality, sociodemographic information, and birth data. The project is designed to provide detailed data for health assessments required by the Agency for Toxic Substance and Disease Registries for Federal hazardous waste sites in the State. (There are now 26 such sites.) The project has been expanded to encompass all cities and towns in Massachusetts. Basically, HEADS-M is a menu driven information system that allows users to identify specific geographic areas and then retrieve health related information for those areas. Summary reports and screens can then be printed out by the user. Information exists at the census tract, city-town and statewide level. Kinds of information include: standardized cancer incidence ratios by sex for twenty six different types of cancer; age-specific cancer rates; special rates of childhood cancer; standardized mortality ratios for twenty specific causes; age-sex cause-specific mortality rates; age and sex population counts for 1980-1990; area specific economic indicators based on Census data; birth rates; infant mortality; and other perinatal data.

The objective of HEADS-M is to allow easy access to a wealth of public health data used frequently in the Department of Public Health. This serves four basic purposes: 1) allows staff to be more efficient and effective in responding to public information requests; 2) simplifies health assessments performed for toxic waste sites; 3) increases access to information for researchers; and 4) assists in planning, program targeting and development.

HEADS uses a character based windowing environment to enhance the user interface, thereby, making the system more user friendly. The Windowing Library has been written in C and Assembler programming languages. The data modules are written in C to maximize system performance, enhance implementation of a relational model, operate independent of computer environment, and enable operation in a local area network. Technical specifications include: an IBM compatible microcomputer; DOS operating system; 2.5 MB of storage on the hard disk; a 5 1/4" 360K or 3 1/2" 720K DS/DD floppy disk drive; a MCGA, CGA, EGA, MVGA, or CVGA monitor, and a minimum of 181K of RAM.

For further information, please contact: *Bruce B. Cohen, Ph.D, Massachusetts Department of Public Health, 150 Tremont Street, Boston, MA. 617-727-2735*

Description

- Menu-driven, PC health statistics information system
- Choose health topic, select measure
- Identify area, generate report
- Requires NO special software
- IBM compatible
- Funded by Agency for Toxic Substances and Disease Registries (ATSDR)

Uses

- Public information requests
- Waste site health assessments
- Program planning
- Increased data available
  - within Department
  - to public & media
  - to Legislature
- Research ideas

Other Options

- Graphing population
- Printing screen
- Generating reports
- Storing data on disk

Future Directions

- More topics
- Enhanced graphics
- Greater user control
- Archived data retrieval
- Freeware

1 Select topic

- Cancer incidence
- Deaths
- Births
- Demographics

2 Select report

- Ratios (SIRs, SMRs)
- Rates (age, sex-specific)
- Counts
- Special reports

3 Select geographic unit

- City or town
- Census tract
- Hazardous waste site
- State

4 Select exact locale

- 351 communities
- 26 waste sites
- 113 census tracts
- Massachusetts

5 REPORT DISPLAYED

- Print screen
- Print report
- Save data

HARDWARE AND SOFTWARE NEEDS FOR COORDINATION OF EARLY INTERVENTION SERVICES (PUBLIC LAW 99-457)

Joyce M. Eatmon, Arkansas Center for Health Statistics

Introduction

In October of 1986, Congress enacted Public Law 99-457, which reauthorized the Education of the Handicapped Act (Public Law 94-142) and amended the Act to include an early intervention services program. Public Law 99-457 requires that states provide special services to developmentally disabled children under three years of age. Potential clients are evaluated by physicians or other health providers on an Eligibility Determination Form. These are sent to one of sixteen regional case management coordinators. The sixteen regions match the education cooperative regions established by the Department of Education. This was done so that when the child reaches age three, he/she could easily be transitioned into the 3 thru 5 program in the Department of Education. The sixteen regions are displayed in Figure 1.

In order to minimize paperwork each of the coordinators were equipped with Toshiba XE1100 laptop microcomputers. Data from the forms are entered into the laptops using EPIINFO Version 5. The coordinators were also supplied with word processing and spreadsheet programs to assist in office management. To minimize costs, shareware programs PCLite, for word processing, and ASEASY, a spreadsheet were provided.

Computer literacy was not a part of the job requirements for case management coordinators. Consequently, the staff of the Arkansas Center for Health Statistics (ACHS), the central office for the database, provided computer training for the coordinators. Also the staff packaged some of the procedures into batch files to simplify execution. These batch files comprise the main menu (Figure 2). This menu is the first thing the coordinators see when they turn on their computer.

Modems installed in microcomputers at ACHS and the laptops allow data to be retrieved, using the pcanywhere III remote access software. This software has two valuable functions: (1) as a communications package, it transfers files between the ACHS office and the laptops; (2) in the event that the laptop user has difficulties, ACHS staff can "take over" the laptop and operate directly.

Early Intervention System

Tracking of eligible children is also a component of Public Law 99-457. To achieve this, a new database system had to be created. In order to make the new system more user friendly, new software has been devised with the aid of dBASE IV Developer's Edition. The new system is composed of four databases, the Eligibility Determination Form, Child Identification, IFSP (Individualized Family Service Plan) Updates, and Early Intervention Services. All of these databases and screens were designed with the purpose of satisfying the reporting requirements for the Federal Government.

The Eligibility Determination Form (Figures 3a-3d) is composed of four screens. Included in this database are all children that have been referred for early intervention services, whether or not they are eligible. This database is a reproduction of the form that health providers receive for evaluating the child. The database includes three other factors not on the form, the region, whether the child is eligible for services, and whether the parents refused services.

The Child Identification database (Figure 4) is composed solely of eligible children. It has all the demographic information on the child along with other identifying information such as social security and medicaid number. An Eligibility Determination Form record must exist for a child before a Child Identification record can be entered into the database. All records are linked back to the Eligibility Determination Form with the ADH Id.

The IFSP Updates database (Figure 5) has basic information related to every IFSP written and evaluations made on a child. This is a multi-record database, so that new data can be entered without destroying the previous information. In this database a Child record must exist before an IFSP record can be entered. Each IFSP record is linked to its corresponding Child record with the ADH Id.

The Early Intervention Services database (Figure 6) has all relevant information on the services that a child receives, including where the services are provided and who is providing the service. This is also a multi-record database linked to the Child database with ADH Id.

Activity Report

The functions of the regional coordinators include activities other than case management of eligible children. They also give technical assistance and in-service training, receive training, and provide public awareness of the early intervention program in their regions. To keep track of all these activities, some sort of log or report needed to be made. The Activity Report (Figure 7) was created, using EPIINFO, with the purpose of simplifying this process. The data entry screen for this database allows the regional coordinators to record all of their activities into the laptop. Included in this database is the type of activity, the group or organization they were meeting with, the amount of time they spent doing the activity and how many miles they traveled.

Figure 1.

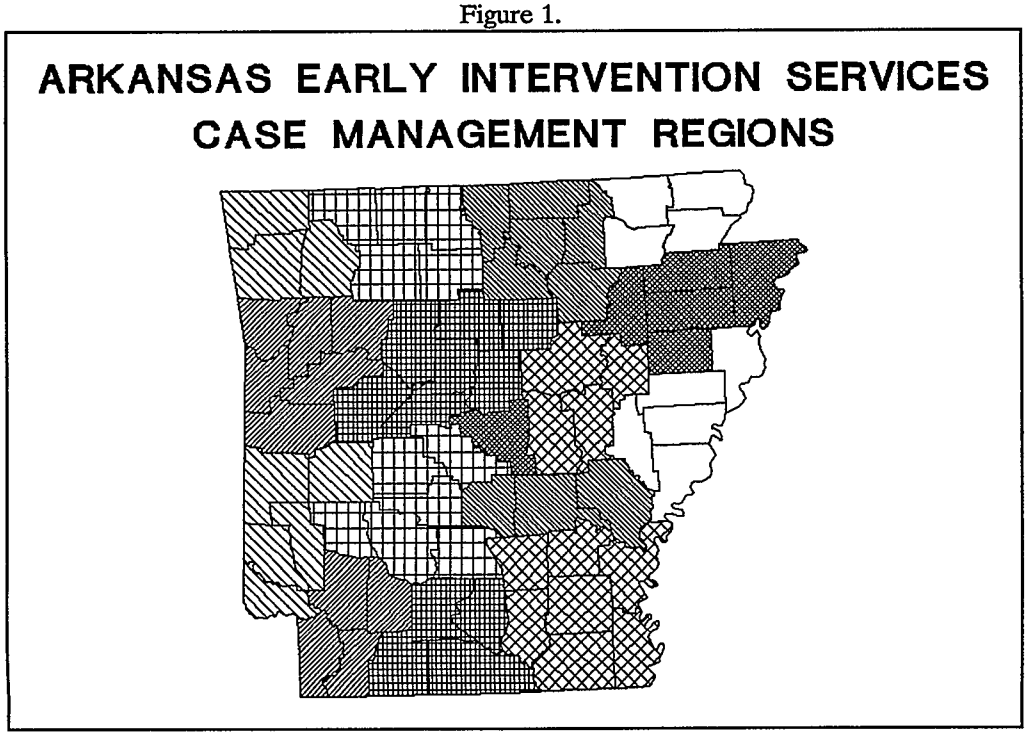


Figure 2.

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**********************************************************************

                        M E N U

        EIS    =  Early Intervention System
        ACT    =  Activity Report
        LITE   =  Word Processing
        AEA    =  Spreadsheet
        TV     =  Utilities
        MENU   =  This Menu

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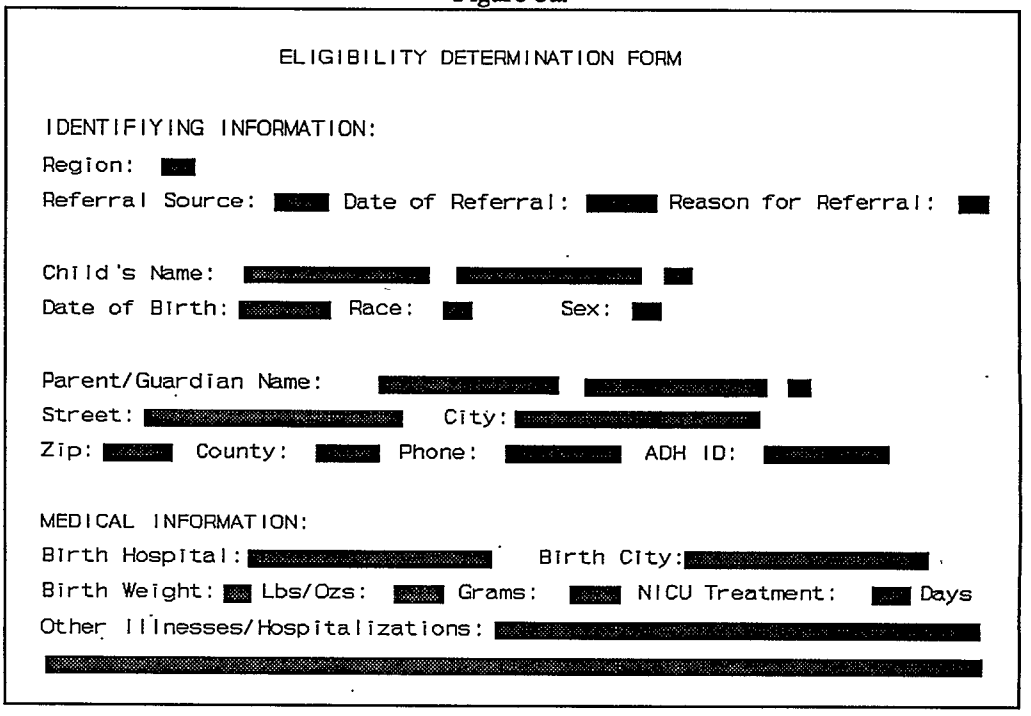
Figure 3a.



ELIGIBILITY DETERMINATION FORM

IDENTIFIYING INFORMATION:

Region:

Referral Source: Date of Referral: Reason for Referral:

Child's Name:

Date of Birth: Race: Sex:

Parent/Guardian Name:

Street: City:

Zip: County: Phone: ADH ID:

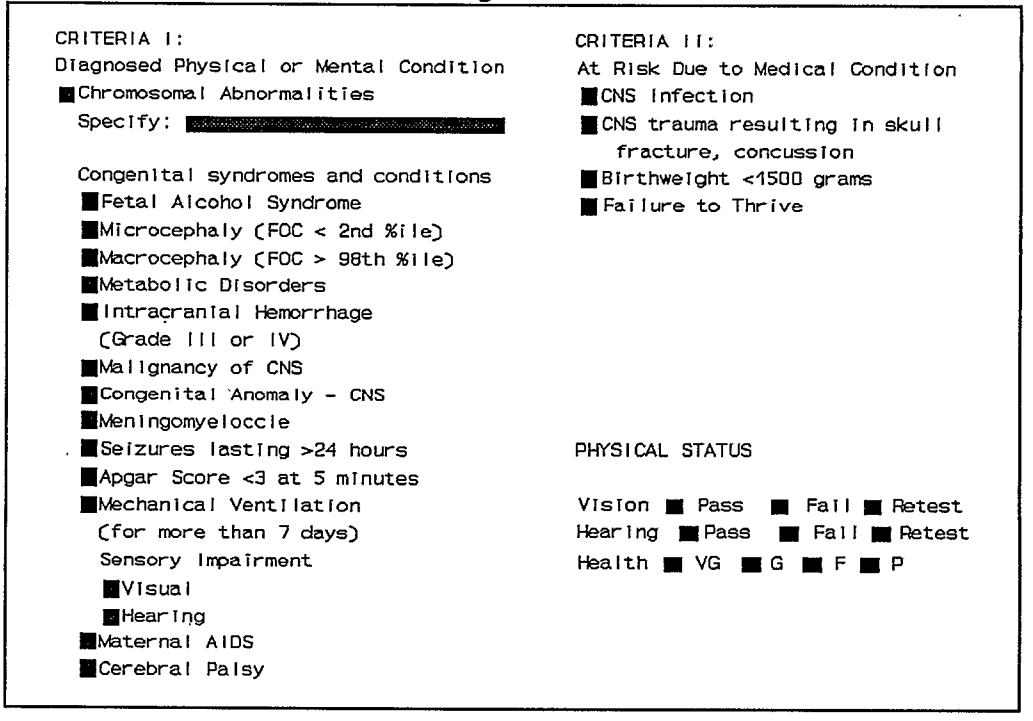
MEDICAL INFORMATION:

Birth Hospital: Birth City:

Birth Weight: Lbs/Ozs: Grams: NICU Treatment: Days

Other Illnesses/Hospitalizations:

Figure 3b.



CRITERIA I:

Diagnosed Physical or Mental Condition

- Chromosomal Abnormalities
  - Specify:
- Congenital syndromes and conditions
  - Fetal Alcohol Syndrome
  - Microcephaly (FOC < 2nd %ile)
  - Macrocephaly (FOC > 98th %ile)
  - Metabolic Disorders
  - Intracranial Hemorrhage (Grade III or IV)
  - Malignancy of CNS
  - Congenital Anomaly - CNS
  - Meningomyelocele
  - Seizures lasting >24 hours
  - Apgar Score <3 at 5 minutes
  - Mechanical Ventilation (for more than 7 days)
  - Sensory Impairment
    - Visual
    - Hearing
  - Maternal AIDS
  - Cerebral Palsy

CRITERIA II:

At Risk Due to Medical Condition

- CNS Infection
- CNS trauma resulting in skull fracture, concussion
- Birthweight <1500 grams
- Failure to Thrive

PHYSICAL STATUS

Vision Pass Fail Retest

Hearing Pass Fail Retest

Health VG G F P

Figure 3c.

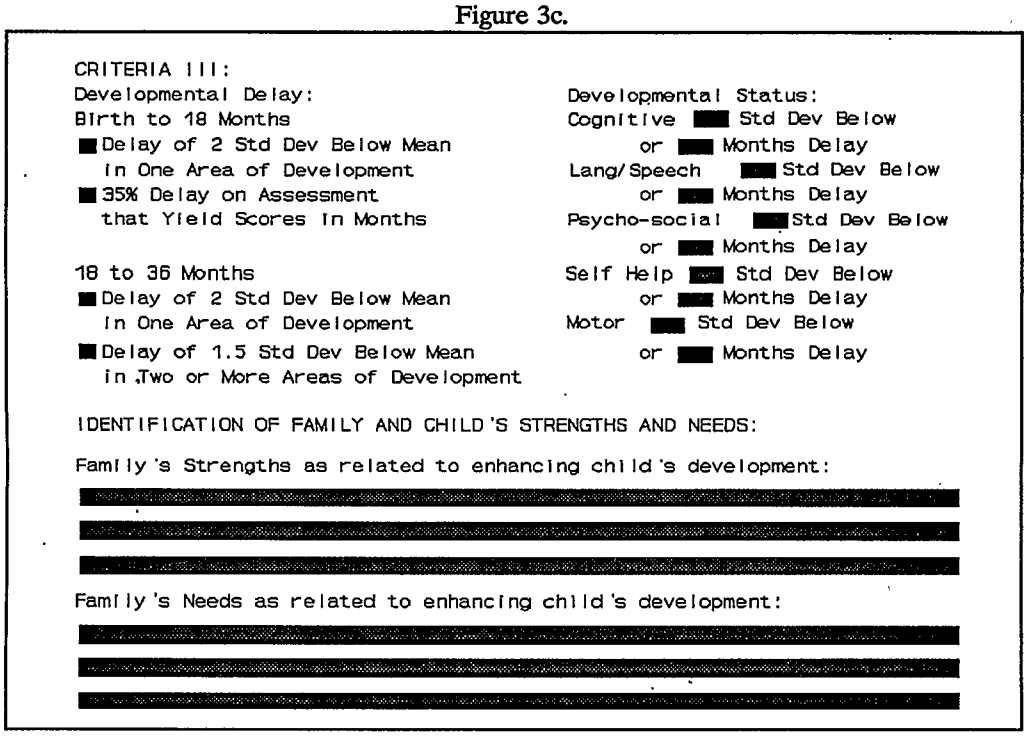


Figure 3d.

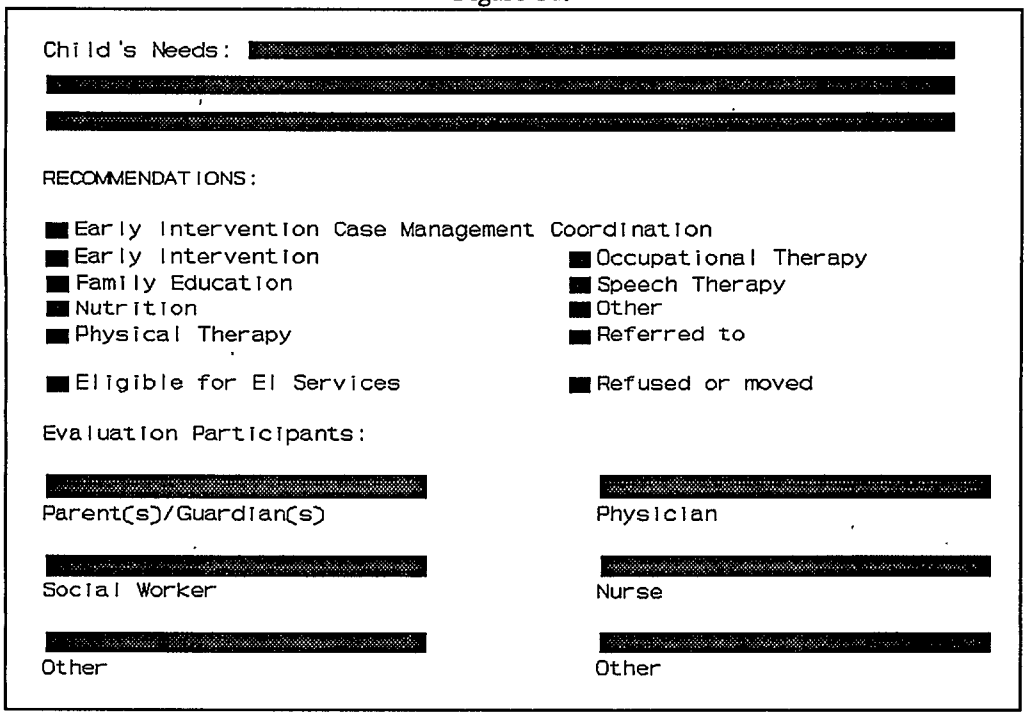


Figure 4.

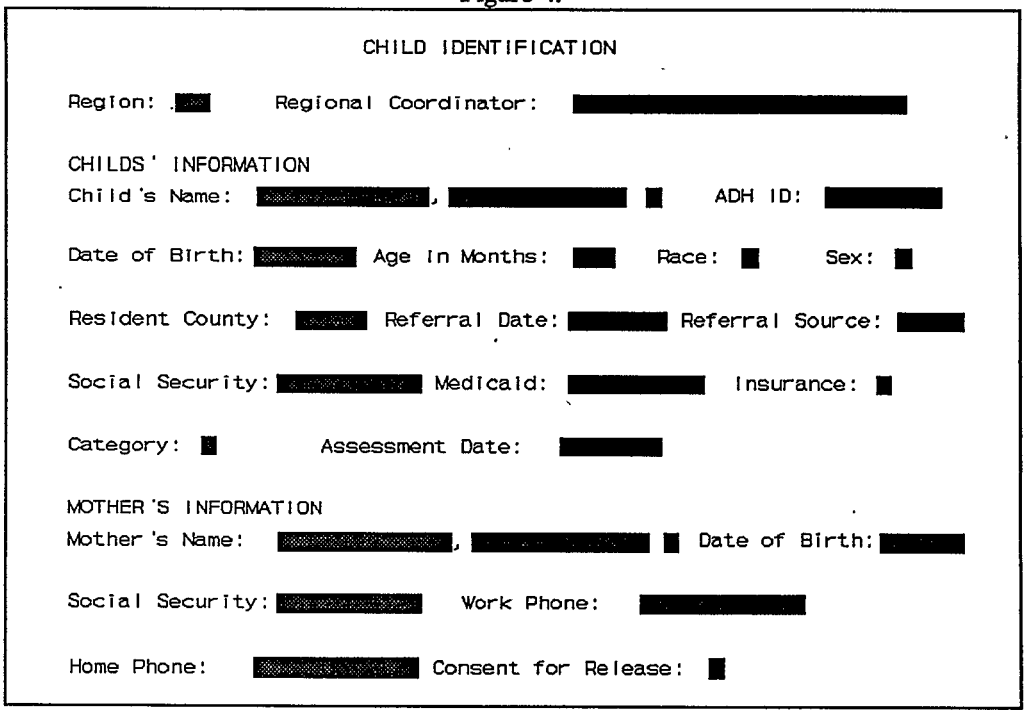


Figure 5.

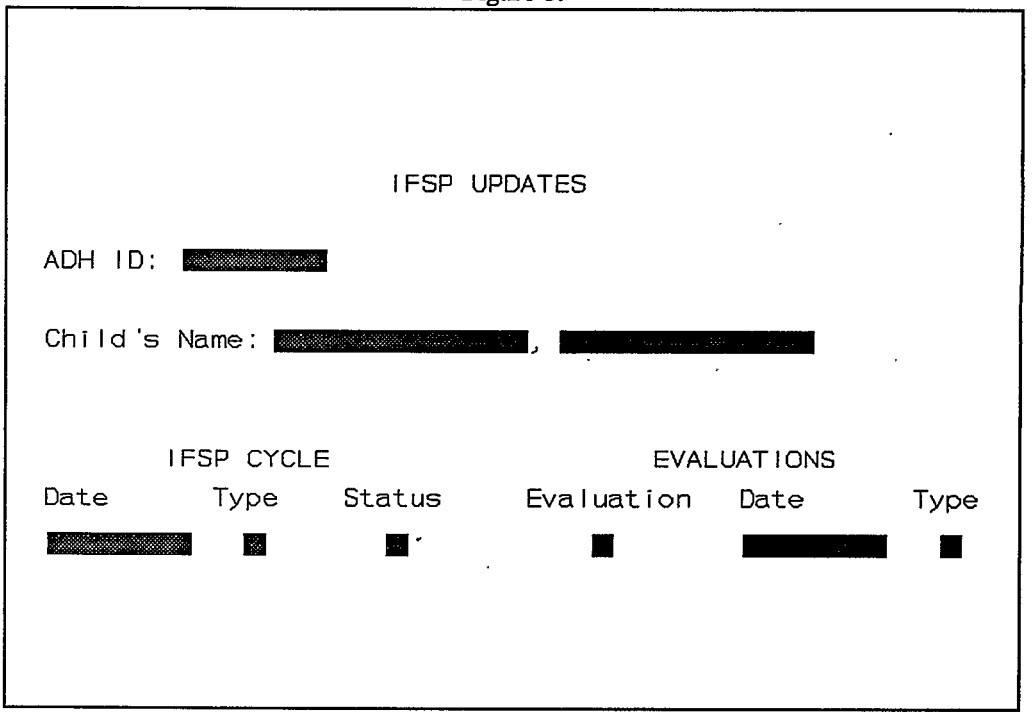


Figure 6.

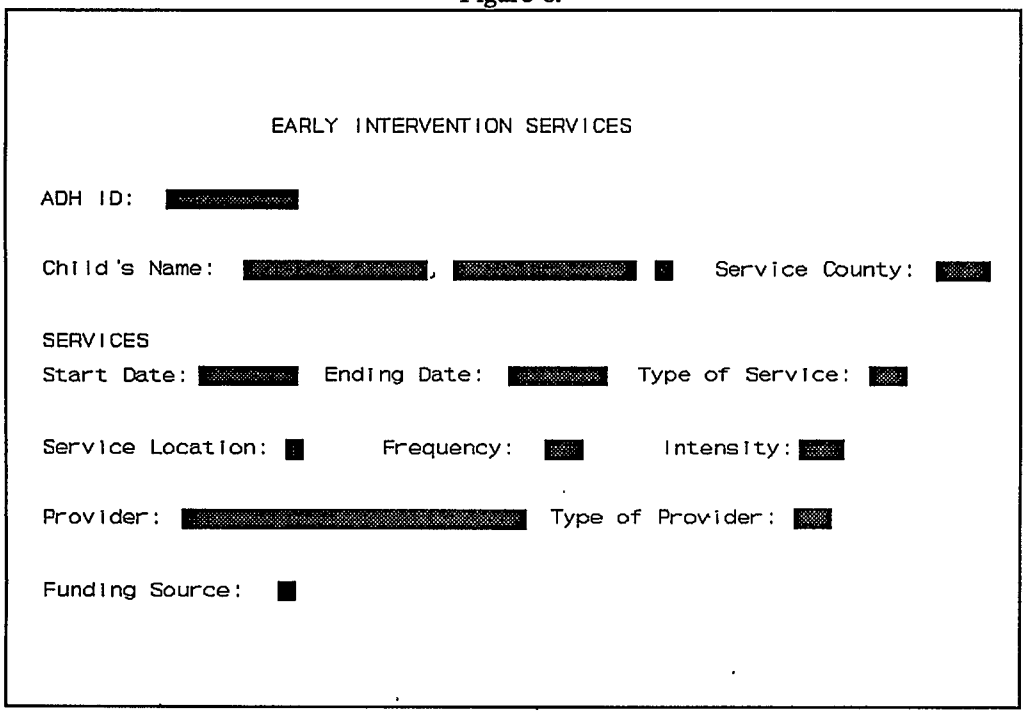
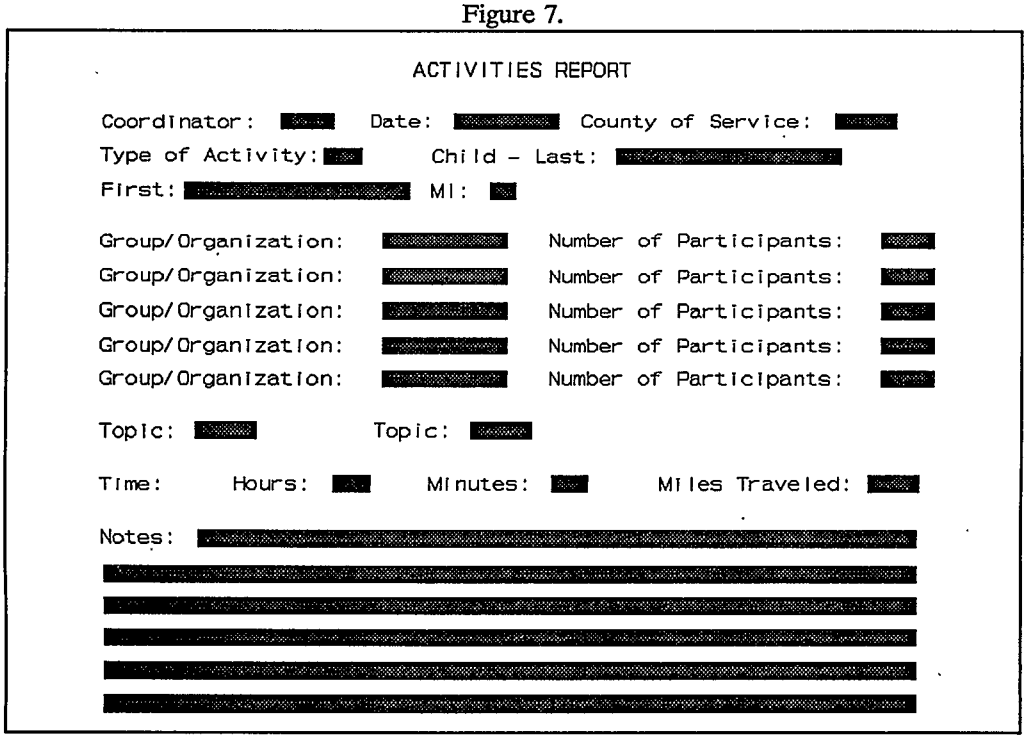


Figure 7.



AUTOMATED OCCUPATION/INDUSTRY CODING SYSTEM

Philip Freeman, Washington State Center for Health Statistics

The Problem:

Washington State's Center for Health Statistics needed to drastically reduce the time it took to manually code occupation and industry literals on the death certificates. It was taking about 2 weeks per month for a staff member to code the literals from the 3,000 to 4,000 death certificates received each month at the Center.

The Goal:

Integrate a program that would generate the Bureau of the Census codes for these literals into the mainframe program (resident on a UNISYS machine) that performed the monthly processing of death records. In order to prove effective in saving time, it was estimated that the program would have to code 60 to 70% of the literals from the certificates and do so with a low error rate (original goal set at 4%).

The Achievements:

The program segment was developed to perform the automated coding. It initially achieved a coding rate of about 70%. Today, with a few refinements added, it completely codes in excess of 75% of the death records it receives. Of the remaining records, more than two-thirds have one of the entries coded, requiring manual coding of only one entry. Based upon review of the coding produced by the program, the error rate for the program is less than 3%. The time required to process occupation and industry literal coding on a monthly basis has dropped from 2 weeks to a day-and-a-half.

The Features:

The program is written for a UNISYS mainframe computer and integrated into the monthly batch processing program. It is anticipated that this program will be rewritten and transferred to an IBM mainframe late next summer (1992).

The program logic incorporates the rules established in manuals put out by NCHS (specifically Instruction Manual Part 19). Additionally, the program includes a NIOSH program that checks for the validity of the codes and consistency of the codes between occupation and industry.

The program basically uses a straight-forward matching system, looking for industry first, then occupation. The file of industry names used was developed from three years of actual death certificate entries. The file of occupation data is directly extracted from the Census Bureau index. Several conversion files were added to help with the matching (for example, converting "accounting" to "accountant" for occupation). One main advantage of these files is the fact that they are maintained by the user, reducing programmer support time.

The editing and correction procedure is streamlined in two ways. First, the listings of uncoded entries is grouped by type (industry, occupation, or both) and by occupation literal in alphabetic order (e.g. all accountants are grouped together). Second, there is a system where the user can post corrections directly to this file and the mainframe will automatically update the main death file on its next run. This greatly speeds up the manual coding and checking processes.

The Future:

This is the first generation of the program. There are several known areas for improvement. The program presently cannot handle multiple occupation or industry entries in the literal (e.g. a listing of farmer/logger for occupation). The program cannot "go back" and refine an industry code; for example, an industry literal of "retail" and an occupation entry of "car salesman" will only give the generic retail code (691), and not the retail car sales code (612) which a manual coder would easily spot.

The program is not presently designed for personal-computer or on-line use. This would improve its applications for other departments and offices. Present plans only anticipate the "transplant" of this program to the birth processing system. PC-based and on-line uses are still further down the road.

AUTOMATED DEATH CERTIFICATE REGISTRATION:
FASTER, EASIER AND MORE ACCURATE THAN PAPER RECORDS AND ACHIEVABLE BEFORE THE YEAR 2000

Charles E Sirc, Karen Grady, R Fritz Hafer, NH Division of Public Health (DPHS)

Background

Building upon experience with electronic birth certificates, we now report continuing progress in creating an Automated Vitals Registration System (AVRS). Ultimately AVRS will entail the automated registration of all four vital events (birth, death, marriage and divorce). Because death registration is more complex and involves more individuals in the registration process as compared to the other three vital events, the automated death certificate (ADC) system is being implemented in a three-phase multiple-site data entry approach, based on certificate initiation locals, (Exhibit 1).

In the state of New Hampshire, local clerks are responsible for manually typing 8,000 death certificates annually. For each New Hampshire death, a certificate must be filed with the local clerk, within 36 hours of death and prior to final disposition or entombment. Once the local clerk has received the death certificate from the funeral director, (s)he issues the funeral director a burial-transit permit and types the state copy of the death certificate. The state copy is an exact replica of the original except for the provision for certification by the local clerk. Local clerks then forward the state copies to the New Hampshire Bureau of Vital Records and Health Statistics (NHBVRHS) between the sixth and twelfth days of the following month.

During the first phase of implementation, the ADC system will be used by the local clerks to produce a computer-generated state copy of the death certificate as well as an electronic data record. This phase will greatly reduce the amount of time the local clerks spend manually typing the state copy and will provide the state with virtually error-free electronic death data.

A modified ADC system will be used by funeral directors during the second phase. This version of ADC will allow the funeral director to generate both the original and state death certificates as well as an electronic data record and a burial transit permit. Formerly, New Hampshire required that all burial permits be issued from the clerk where the death occurred. New legislation permits the state registrar to designate funeral directors using the ADC system statewide subregistrars enabling them to issue their own burial transit permits. No longer will the funeral director have to travel from one end of the state to the other. Instead, within his office he will be able to generate the burial transit permit upon successful transmission of the ADC edited electronic data record to the state.

The third phase will entail placing the ADC system in institutions-hospitals or nursing homes-where approximately 80% of all NH deaths occur. This generation of the ADC system is planned to contain a simplified Mortality Medical Indexing, Classification and Retrieval (MICAR) module to be used by physicians and medical record staff for the keying of the cause-of-death data. The MICAR module will be able to instantly edit cause-of-death data for accuracy and completeness at the site of initiation. Once the medical certification data has been keyed the original death certificate could be printed and given to the funeral director in order to complete the remaining demographic data on or off site. If the certificate is completed on site using the ADC system,the funeral director may print the state and local copies as well as transmit the electronic data record to the state office. This would enable the funeral director to receive a burial transit permit directly at the health care institution.

In addition, we are planning to add the state medical examiner's office as a site of death certificate initiation. This will be an interim phase occurring between phases II and III. Through a combined effort with the Centers for Disease Control (CDC), hardware and software is presently being negotiated to enable the state medical examiner's office to utilize the ADC system. Based on the operators system password a condensed data entry procedure would be invoked prompting for those items necessary for medical certification. Upon arrival at the medical examiner's office, the funeral director will have two options for completing the death certificate. One option would be to receive a partially completed death certificate, containing medical certification only, from the medical examiner. The funeral director could then return to his office to complete the remaining death certificate items. The second option would be to use the medical examiner's ADC system to add the demographic information to the death record. The funeral director could then print both the original and state copies as well as transmit the electronic data record to the state office in order to receive his burial transit permit.

The ADC software, an interactive information system developed in-house, can be installed at each site's IBM-compatible personal computer. ADC evolved from concepts established in ABC, the State of New Hampshire's Automated Birth Certificate System. Like ABC, ADC uses modern interactive methods of data acquisition, storage, retrieval and reporting.

Methods

Beginning in October, 1990, three New Hampshire cities piloted the first of the three phase switch from paper to electronic death registration. Instead of mailing mid-month batches of paper documents, local clerks began transmitting weekly, edited electronic documents to the NHBVRHS. State-

wide implementation of phase I will begin in the fall of 1991 as resources permit. In phase II, fall 1991, three pilot funeral homes will begin to collect and enter legal, medical and demographic information. The third and final phase targeted for Jan 1993 will allow hospitals and long-term care institutions to key medical diagnoses and pass electronic records along to funeral directors for remaining data entry.

Enabling legislation (NHRSA 126:13,15,31,32; and RSA 290:7,9) took effect July 1, 1991. These statutes increase the Vital Record issuance fees for certified copies from $3 to $10, creating a Vital Records Improvement Fund and its advisory committee. This fund will be used to supply local clerks with the hardware necessary to run the ADC software and to provide for its support at the state level. The fund will also provide for the distribution of the ADC software to funeral directors and institutions as well as training and support.

In addition, NCHS is supporting the development of an electronic death certificate system through a subcontract with the State of New Hampshire. NCHS plans to integrate the NH ADC system with an industry and occupation coding module as well as with a refined version of MICAR. This version of MICAR would be able to interpret and code the literal cause-of-death entries similar to the TRACER program currently in operation in the United Kingdom. Some collaboration with British government has taken place and software exchanged. It is expected this will be ongoing.

When an electronic data file is received from a local clerk or funeral director it is downloaded to the personal computer containing the state statistical file. The Bureau will enter all non-automated certificates into an adapted state version of the system in order to complete the state statistical file. A report will be generated for all records indicating blank or unacceptable entries. These certificates will be flagged for query. Once a statistical record is complete and all queries have been answered, the records will be uploaded to the master file on the state's mini computer.

ADC is designed to be simple to use for the inexperienced user but to be fast and efficient for the more experienced user. It requires minimal computer skills among on-site personnel. Online edit checks are performed at data entry time, allowing quick and accurate data input. Exhibit 2 compares the manual and ADC systems task by task.

NHBVRHS personnel have met with clerks, funeral directors, legislators and appropriate committees of these groups on several occasions in order to explain this proposed system and to muster their support in expediting the transition from the old manual to the new automated system. These meetings have proved to be a crucial part of the whole development process.

Results

A 38% keystroke reduction and an approximately 20-fold decrease in required follow-up was achieved in ADC pilot phase I, with similar savings in labor costs. ADC has also had a significant impact on reducing data lag time. We have seen a 74% improvement, from approximately six months to seven weeks, in the timeliness of masterfile creation and a 96% drop in the time for statistical filing. Death certificate data which formerly had to be manually coded and keyed can now be accessed within one to two weeks instead of six months.

We estimate that during phase I and II, ADC will save the state four person-days per week. The savings are a result of less time spent processing queries and from the elimination the manual process of coding and keying death data. Additional labor savings will be realized during phase III when the cause of death is coded during data entry through the MICAR module.

Design Features

The ADC software was written in CLIPPER; an industry standard dbase compiler. The communications software KERMIT is used for the transmission of electronic data files. The software is provided by the state of New Hampshire along with on-site training at the time of installation. Additional telephone support and in-house training sessions are available.

The basic concept of an electronic data system is to reduce redundant effort and to eliminate data errors. The ADC system was designed to automate the processing of death certificates on an interactive basis during data entry operations. ADC allows hospital personnel, funeral directors and local registrars to type death certificate data directly into their personal computers and have it instantly edited for completeness and accuracy.

To assure completeness, ADC performs interactive and absolute edits to detect errors the moment they are entered. As information is keyed into this interactive system, ADC displays a query or edit and prompts the operator for a reply. The operator must then type an acceptable response which ADC immediately processes and prompts again or proceeds to the next data item. In all ADC performs up to 44 interactive range or validity checks, 58 absolute edits, edits that inhibit the operator from advancing to the next item until an acceptable entry is keyed, 5 program defaults and 13 computer filled responses. Of 68 death certificate variables, 66 (97%) use ADC query or edit support, (Exhibit 3).

Furthermore, ADC reduces the average number of keystrokes required to complete a death certificate by about 200 (38%). This was done by programming computer-filled entries based on initial responses to key items. For instance, once the facility of death is keyed by the funeral director, the city, county, state and zip code are computer-filled. In addition, the funeral director need only enter the physician license number and ADC searches the file for a match, prompts for verification and the fills the physician, name, title and address fields.

Discussion

Greater uniformity, speed, accuracy and completeness result from ADC use on-site at the record source with electronically-assisted data entry. As ADC incorporates both MICAR from NCHS to enable automatic cause of death coding and an analogous CDC package for industry/occupation coding, even greater time and cost savings and data quality improvements will emerge.

In addition, AVRS will reduce potentially fraudulent use of vitals certificates. Starting January, 1992, all certified copies will be issued on safety paper incorporating an invisible hologram that will print the word "VOID" if altered or copied. Such a step is possible only on original copies with direct issuance.

The principles established by AVRS can be applied to virtually any record system using a standard form. Thus this approach may be used to automate manual systems other than those employed in the registration of vital events. As other data systems become automated, record linkage will be enhanced enabling more extensive research and analysis of health data.

Conclusion

An Automated Vitals Registration System is faster, easier and more cost efficient than existing manual procedures. It also improves accuracy and completion of Vitals information. It computerizes public health records as closely as possible to the health event. In addition, Automated Vitals Registration Systems offer new possibilities for public health surveillance and prevention. They enable public health surveillance capabilities by providing information at a moment's notice.

Exhibit 1. Data Flow by Phase and Site of Death Certificate Iniation

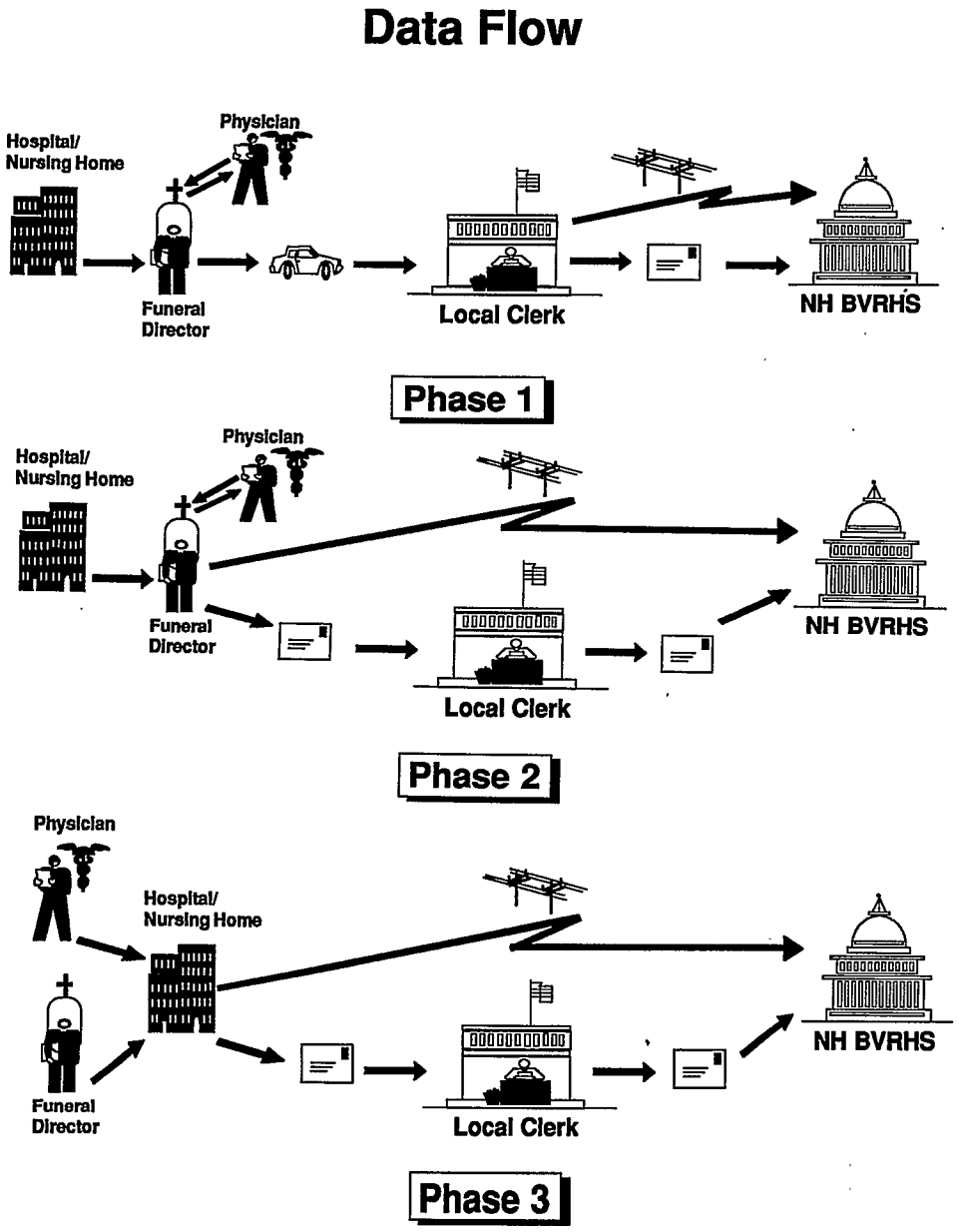


Exhibit 2: Comparison of ADC VS Manual Processing of Death Certificate

N.H. AUTOMATED DEATH CERTIFICATE (ADC) SYSTEM
FACT SHEET

ADC automates death certificate processing interactively at the data source. Local clerks, funeral directors, hospital personnel or physicians can type death certificate data into microcomputers with instant editing for completeness and correctness. Three products are created, a printed paper record, a computer data record and a burial-transit permit.

MAJOR DIFFERENCES BETWEEN PAPER SYSTEMS AND ADC

TASK	PAPER SYSTEM	ADC
Type certificate	Type certificate on typewriter	Enter death record data on computer terminal and print out when complete
Enter funeral director identifying information: name, address, etc.	Retype every time for each certificate	Permanently stored by computer; no need to enter each time
Correct typographical errors	Retype entire certificate multiple times until correct, or use liquid erasing fluid	Reenter only incorrect items at computer terminal as necessary
Correct information errors	Retype or correct as above	Reenter changed data only
Time to create certificate	10 minutes	5 minutes
Keystrokes needed	530	330
Create master data at State registry	Code paper record, reenter data into computer, edit data, printout missing or problematic data, phone questions to funeral directors for follow-up	Computer record files created at time of data entry on terminal at funeral director's office; minor data editing before loading to master file
Proportion of records requiring follow-up	1988 - 18.6 %	Expected less than 1%
Time period to create master file	Approximately six months	Approximately seven weeks
Time period to access statistical file	Approximately six months	Approximately one week

Exhibit 3: Death Certificate Items by Type of ADC Edit

AUTOMATED DEATH CERTIFICATE SYSTEM

DEATH CERTIFICATE ITEMS BY TYPE OF ADC ASSISTANCE

	WORKSHEET ITEM	TYPE OF ASSISTANCE					WORKSHEET ITEM	TYPE OF ASSISTANCE				
1												
2	Decedent's Name	*	#			&	20f Location of Final Disposition		#	@		
3	Sex		#				21a Funeral Director	*	#			
4	Date of Death	*	#			&	21b License Number	*	#			
5	Social Security Number		#				21c Name & Location of Funeral Home	*	#		+	
6	Age	*			+		21d Subregistrar/Health Official		#			
7	Date of Birth	*	#			&	21e City/Town		#			&
8	Birthplace	*	#			&	21f Date Signed	*	#			&
9	U.S. Armed Forces		#				22 Capacity of Individual Pronouncing Death	*	#			
9a	Place of Death	*	#				23a Pronouncer Name	*	#		+	&
9b	Facility Name	*	#		+	&	23b License Number	*	#			&
9c	City or Town of Death	*	#		+		23c Date Signed	*	#			&
10d	County of Death	*			+		24 Time of Death	*	#			&
11	Marital Status		#			&	25 Date Pronounced Dead	*	#			&
12	Spouse	*	#				26a Case Referred to Medical Examiner	*	#			&
12a	Decedent's Usual Occupation		#			&	26b Suspected to Have Had a Contagious Disease	*	#			
12b	Kind of Business/Indusry		#			&	27I Cause of Death/Duration	*	#			
12c	Manufacturing/Wholesale/Retail						27II Other Significant Conditions					
13d	Name of Employer		#				28a Was Autopsy Performed	*				
13a	Residence - State	*	#	@	+		28b Autopsy Findings Available	*	#			
13b	Residence - County		#		+		29 Manner of Death	*	#			
13c	City, Town or Location	*	#			&	30a Date of Injury	*	#			&
14d	Street and Number		#				30b Time of Injury	*	#			&
15	Zip Code		#		+		30c Injury at Work	*				
16	Race		#	@		&	30d Describe How Injury Occurred	*				
17	Decedent's Education	*	#			&	30e Place of Injury	*				
18	Father's Name	*	#				30f Location of Injury	*	#	@		&
19	Mother's Name	*	#				31a Certifier Capacity	*	#			&
19a	Informant's Name		#				31b Signature and Title of Certifier	*	#		+	&
20b	Mailing Address		#			&	31c License Number	*	#			&
20a	Method of Disposition		#				31d Date Signed	*	#			&
20b	Place of Disposition		#				32 Name and Address of Certifier	*	#		+	
20c	Location of Disposition		#	@		&	33a Signature of City or Town Clerk				+	
20d	Date of Disposition	*	#				33b Clerk of City/Town				+	
e	Place of Final Disposition	*	#				34 Date Filed		#			&

TOTAL NUMBER OF DEATH CERTIFICATE ITEMS 68

NUMBER OF ITEMS WITH ASSISTANCE			PERCENT WITH ADC ASSISTANCE
*	44	Interactive Edits (52 total)	65%
#	58	Absolute Edits (100 total)	85%
@	5	Program Defaults	1%
+	13	Computer Filled Responses	19%
TOTAL	66	Assisted Items	97%

& Contains more than one interactive or absolute edit.

Exhibit 4: Sample of Revised ADC Death Certificate

02436

The State of New Hampshire
DEPARTMENT OF HEALTH AND HUMAN SERVICES
CERTIFICATE OF DEATH

1. DECEDENT'S NAME - *(First, Middle, Last)*				2. SEX	3. DATE OF DEATH *(Month, Day, Year)*
4. SOCIAL SECURITY NUMBER	5a. AGE last birthday *(Years)*	5b. Under 1 Year: MOS. / DAYS	5c. Under 1 Day: HOURS / MINS.	6. DATE OF BIRTH *(Month, Day, Year)*	7. BIRTHPLACE *(City/Town, State or Foreign Country)*
8. Was decedent ever in U.S. Armed forces *(Specify Yes or No)*	9a. PLACE OF DEATH — HOSPITAL: / OTHER:				
9b. FACILITY NAME (If not institution, give street and number)			9c. CITY, TOWN, OR LOCATION OF DEATH		9d. COUNTY OF DEATH
10. MARITAL STATUS - (Married, Never Married, Widowed, Divorced — *Specify*)	11. SPOUSE (If wife, give maiden name)			12a. DECEDENT'S USUAL OCCUPATION *(Give kind of work done during most of working life. Do not use retired.)*	
12b. KIND OF BUSINESS/INDUSTRY	12c. check if applicable ☐ MFG ☐ WHLSE ☐ RETAIL			12d. NAME OF EMPLOYER (Referring to 12 a-b)	
13a. RESIDENCE - STATE	13b. COUNTY	13c. CITY, TOWN, OR LOCATION		13d. STREET AND NUMBER	
14. ZIP CODE	15. RACE - (American Indian, Black, White, etc. — *Specify*)	16. DECEDENT'S EDUCATION (Specify only highest grade completed) Elementary/Secondary (0-12)	College (1-4 or 5 +)		
17. FATHER'S NAME *(First, Middle, Last)*		18. MOTHER'S NAME *(First, Middle, Maiden Surname)*			
19a. INFORMANT'S NAME (Type/Print)	19b. MAILING ADDRESS (Street and Number or Rural Route Number, City or Town, State, Zip Code)				
20a. METHOD OF DISPOSITION: 1. Burial 2. Temp Entombment 3. Cremation 4. Donation 5. Mausoleum 6. Other — CODE	20b. PLACE OF DISPOSITION (Name of cemetery, crematory, or other place)	20c. LOCATION - (City/Town/State)		20d. DATE OF DISPOSITION (Refer to 20a.)	
	20e. IF ENTOMBED (OR CREMATED) PLACE OF FINAL DISPOSITION	20f. LOCATION - (City/Town/State)			
21a. Signature of Funeral Director	21b. N.H. LIC. NO. ONLY	21c. NAME AND LOCATION FACILITY *(City/Town/State)*			
21d. COUNTERSIGNED AGENT (CITY BD. OF HEALTH/SUB REGISTRAR *if applicable*)	21e. CITY/TOWN			21f. DATE SIGNED *(Month, Day, Year)*	
22. INDICATE OFFICIAL CAPACITY OF INDIVIDUAL PRONOUNCING DEATH: 1. Attending/Associate Physician 2. Non-Attending Physician 3. Pronouncing Reg. Nurse 4. ME/DEP. 5. Temp./Asst. ME. 6. Other — CODE	23a. To the best of my knowledge, death occurred at the time, date and place stated. *(Signature and Title)*	23b. N.H. LICENSE NO. ONLY		23c. DATE SIGNED *(Month, Day, Year)*	
	24. TIME OF DEATH	25. DATE PRONOUNCED DEAD *(Month, Day, Year)*	26a. Was case referred to Medical Examiner (Yes/No)	26b. Decedent had or is suspected to have had a contagious disease (Yes or No)	

PRONOUNCING ONLY

27. PART I. Enter the diseases, injuries, or complications that caused the death. Do not enter the mode of dying, such as cardiac or respiratory arrest, shock, or heart failure. List only one cause on each line. Must be **typed or printed in black ink** with no abbreviations. — Approx. Interval Between Onset and Death

IMMEDIATE CAUSE (Final disease or condition resulting in death) → a. _____

DUE TO (OR AS A CONSEQUENCE OF): b. _____

Sequentially list conditions, if any, leading to immediate cause. Enter UNDERLYING CAUSE (Disease or injury that initiated events resulting in death) LAST

DUE TO (OR AS A CONSEQUENCE OF): c. _____

DUE TO (OR AS A CONSEQUENCE OF): d. _____

PART II. Other significant conditions contributing to death but not resulting in the underlying cause given in Part I.		28a. WAS AN AUTOPSY PERFORMED *(Yes or No)*	28b. WERE AUTOPSY FINDINGS AVAILABLE PRIOR TO COMPLETION OF CAUSE OF DEATH? *(Yes or No)*
29. MANNER OF DEATH: 1. Natural 2. Accident 3. Suicide 4. Homicide 5. Pending Investigation 6. Could not be Determined — CODE	30a. DATE OF INJURY *(Month, Day, Year)*	30b. TIME OF INJURY	30c. INJURY AT WORK? *(Yes/No)*
	30d. DESCRIBE HOW INJURY OCCURRED		
	30e. PLACE OF INJURY (At home, farm, street, factory, office building, etc. — *Specify*)	30f. LOCATION (Street and Number or Rural Route Number, City or Town, State)	

31a. CERTIFIER — CODE

1. CERTIFYING PHYSICIAN (Physician certifying cause of death when another physician has pronounced death and completed Item 23) To the best of my knowledge, death occurred at the time, date, and place stated.
2. PRONOUNCING AND CERTIFYING PHYSICIAN (Physician both pronouncing death and certifying to cause of death) To the best of my knowledge, death occurred at the time, date, and place stated.
3. MEDICAL EXAMINER On the basis of examination and/or investigation, in my opinion, death occurred at the time, date, and place, and due to the cause(s) and manner as stated.

31b. SIGNATURE AND TITLE OF CERTIFIER	31c. NH LICENSE NO. ONLY	31d. DATE SIGNED *(Month, Day, Year)*

CERTIFIER ONLY

32. NAME AND ADDRESS OF PERSON WHO COMPLETED CAUSE OF DEATH (Item 27)

33a. SIGNATURE OF CITY OR TOWN CLERK	33b. CLERK OF (CITY OR TOWN)	34. DATE FILED *(Month, Day, Year)*

IT SHALL BE UNLAWFUL FOR ANYONE TO REPRODUCE THIS CERTIFICATE OTHER THAN THE LOCAL CITY/TOWN CLERK OF OCCURRENCE OR STATE REGISTRAR — ADC. VS 16-55 (5-80)

State Copy **A true copy, Attest:** _____ **Clerk of** _____ **Dated** _____ **19** ____

ECONOMIC STATUS, RACE, AND MORTALITY IN BALTIMORE CITY, 1982-88

Leigh A. Henderson and Monroe Lerner
The Johns Hopkins University School of Hygiene and Public Health

INTRODUCTION

Mortality rates for blacks are in general higher than those for whites [1-2]. Low income is also associated with higher mortality rates [3-5]. In the US, low income is disproportionately concentrated in the black population, with 33.1% of blacks below the poverty level in 1987 compared to only 10.5% of whites [6]. (For Baltimore City the comparable figures in 1979 were 31.0% and 12.7%, respectively [7]).

A question of interest is how much of the higher black mortality can be attributed to lower economic status and its attendant problems. The Baltimore City Health Department sponsored a study of this issue based on mortality data for the period 1982-88. The purposes of the study were: 1) to compute and compare statistically age-, sex-, and race-specific mortality rates for 33 causes of death; 2) to analyze statistically the separate and joint effects of economic status and race on mortality, using census tracts as the units of observation; 3) to identify areas of unusually high ("excess") mortality within the city; and 4) to prepare presentation-quality maps of mortality patterns by census tract for use by the Department.

Minimal resources were required. The data used were from readily available sources; no additional data collection was performed. All statistical analyses and mapping were performed on an IBM PC using commercially-available software (SYSTAT and Atlas Graphics).

METHODS

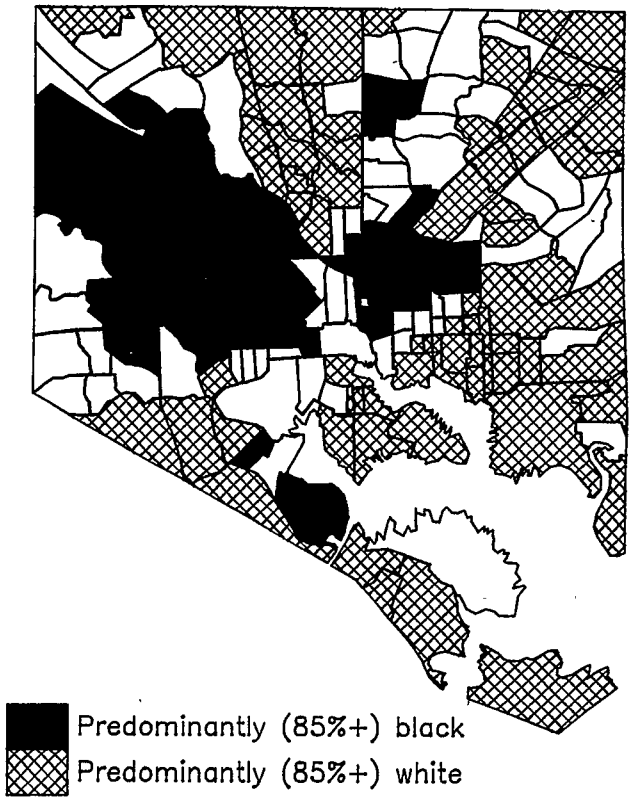
Census tracts were selected as the units of analysis because their populations are small enough (in Baltimore City, about 4000 persons) to be racially and economically homogeneous, but large enough to provide stable mortality rates. In addition, both the US Census Bureau and local agencies report data based on these units. Census tract of residence is recorded on the City's death certificates, while other economic information is not.

Mortality data were provided by the Baltimore City Health Department. Seven years of records (1982-88) were averaged around 1985 for stability of rates, and adjusted by the direct method to the US population of 1940 as the standard. Population estimates for 1985 by tract, age, and sex were developed from multiple sources: the US Bureau of the Census (population by tract, age, sex, and race for 1980); the State Planning Department (by age, sex, and race for 1985); the Regional Planning Council (by tract and age for 1985); and the Baltimore City Health Department (birth and death data by tract for 1980-85).

Neither population nor economic status could be calculated by race for individual tracts. However, almost 75% of Baltimore City residents live in census tracts where the racial composition is extremely homogeneous (Fig. 1). Therefore rates were calculated for each tract as a whole, rather than for white and black populations within each tract. The effect of this in the regression analyses would be to underestimate tract differences. (Note: The terms "white" and "black" are used here throughout. "Other" ethnic groups constituted only 1.3% of the 1980 population of Baltimore City.)

Fig.1 Racial Composition

Baltimore City Census Tracts

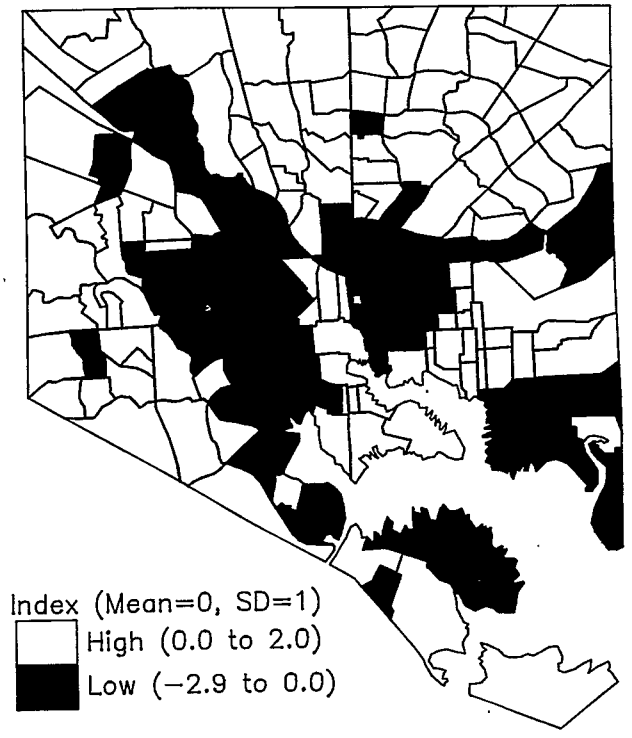


A standardized index of economic status (Fig. 2) was developed using principal components analysis. Four of some 15 measures of economic status were retained in the final model. These were, from the US 1980 Census, 1) percent of households with public assistance income; 2) percent of families with incomes below poverty level; 3) percent of persons 16+ who were unemployed; and from the Regional Planning Council, 4) 1985 median household income.

Racial composition (measured as percent black) and score on the economic index were used as continuous variables in simple and multiple regressions. "Excess mortality" in a tract can be defined in a number of ways, for example, tracts with rates in the highest quintile, or tracts with rates more than 2 standard deviations above the

Fig. 2 Economic Status

Baltimore City Census Tracts



mean rate for all tracts. Therefore, tract rates were tabulated in quintiles, and means and standard deviations reported. In addition, however, because high rates are strongly associated with both economic status and race, a multiple regression model including these variables was used to generate "expected" rates for each tract. These were compared statistically with the actual rates to identify tracts with mortality rates higher than would be expected given the tract's economic status and racial composition.

RESULTS

Mortality rates were calculated for 33 causes of death, 15 of which are presented here (Table 1). These included the leading natural causes of death, cancer and heart disease, and a number of more specific sites (at the 3-digit ICD level), as well as the leading external causes of death. Table 1 also compares black and white rates. Black rates were significantly higher than white for most of the causes examined. A notable exception was ischemic heart disease, where black rates were significantly lower than white. For several cancer sites of current interest (respiratory, female breast, and cervical), black rates were higher than white, but not significantly so.

Table 2 presents the beta coefficients for simple regressions. Both low economic status and a high percentage of blacks were independently very strong predictors of high tract mortality for most causes. Significant exceptions were ischemic heart disease, where high rates were associated

TABLE 1

City-wide mortality rates[1] by race
Baltimore City 1982-88

Cause of death (ICD-9 number)	Total	Black	White	Relative risk (B:W)
All causes of death (001-E999)	845.2	917.5	745.8	1.23 ***
All external causes of death (E800-E999)	82.3	92.1	65.8	1.40 ***
All natural causes of death (001-799)	762.9	825.4	680.0	1.21 ***
Diseases of the heart (390-398, 402, 404-429)	268.5	266.4	262.9	1.01
Hypertensive heart disease (402)	20.2	28.6	11.8	2.43 ***
Ischemic heart disease (410-414)	105.0	82.7	120.8	0.69 ***
Cerebrovascular disease (430-438)	45.4	52.0	37.7	1.38 ***
All malignant neoplasms (140-208)	192.1	213.0	172.5	1.24 ***
Respiratory system & larynx (160-163)	57.3	62.2	53.0	1.17
Female breast[2] (174)	28.1	28.9	26.6	1.09
Cervix uteri[2] (180)	5.5	7.2	3.9	1.83
Prostate[3] (185)	24.2	35.8	15.9	2.25 ***
Alcohol dependence syndrome (303)	8.2	10.8	4.9	2.20 **
Chronic liver disease & cirrhosis (571)	17.2	19.8	13.5	1.47 *
Nephritis, nephrotic syndrome & nephrosis (580-589)	13.9	21.0	8.0	2.63 ***

1. Per 100,000 population, age-adjusted to the 1940 US population.
2. Per 100,000 female population.
3. Per 100,0000 male population.

*** $p \leq .001$
** $p \leq .01$
* $p \leq .05$

TABLE 2

Simple regression coefficients (Bs) of mortality rates[1] on economic status[2] and race[3]
Baltimore City 1982-88

Cause of death (ICD-9 number)	Economic status	Race
All causes of death (001-E999)	-171.041 ***	+30.239 ***
All external causes of death (E800-E999)	-25.182 ***	+3.938 ***
All natural causes of death (001-799)	-145.859 ***	+26.301 ***
Diseases of the heart (390-398, 402, 404-429)	-38.111 ***	+4.318 ***
Hypertensive heart disease (402)	-9.594 ***	+2.250 ***
Ischemic heart disease (410-414)	+7.983 ***	-2.785 ***
Cerebrovascular disease (430-438)	-9.221 ***	+2.460 ***
All malignant neoplasms (140-208)	-28.042 ***	+6.080 ***
Respiratory system & larynx (160-163)	-11.095 ***	+1.270 **
Female breast (174)	-0.637	+0.456
Cervix uteri (180)	-2.534 ***	+0.379 **
Prostate (185)	-4.566 ***	+2.331 ***
Alcohol dependence syndrome (303)	-6.687 ***	+1.035 ***
Chronic liver disease & cirrhosis (571)	-9.977 ***	+1.379 ***
Nephritis, nephrotic syndrome & nephrosis (580-589)	-5.086 ***	+1.511 ***

1. Per 100,000 population, age-adjusted to the 1940 US population.
2. Index score (see text); B = change in mortality rate per unit change in economic status.
3. Percent black; B = change in mortality rate per 10% change in percent black.

*** $p \leq .001$
** $p \leq .01$
* $p \leq .05$

TABLE 3

Multiple regression coefficients (Bs) of mortality rates[1] on economic status[2] and race[3]
Baltimore City 1982-88

Cause of death (ICD-9 number)	Economic status	Race
All causes of death (001-E999)	-153.271 ***	+7.036 *
All external causes of death (E800-E999)	-24.665 ***	+0.204
All natural causes of death (001-799)	-128.606 ***	+6.832 *
Diseases of the heart (390-398, 402, 404-429)	-44.047 ***	-2.350 *
Hypertensive heart disease (402)	-6.332 ***	+1.292 ***
Ischemic heart disease (410-414)	+1.536	-2.553 ***
Cerebrovascular disease (430-438)	-4.872 ***	+1.722 ***
All malignant neoplasms (140-208)	-20.540 ***	+2.971 **
Respiratory system & larynx (160-163)	-12.770 ***	-0.663
Female breast (174)	+0.832	+0.582
Cervix uteri (180)	-2.555 ***	-0.008
Prostate (185)	+2.140	+2.655 ***
Alcohol dependence syndrome (303)	-6.594 ***	+0.037
Chronic liver disease & cirrhosis (571)	-10.513 ***	-0.212
Nephritis, nephrotic syndrome & nephrosis (580-589)	-2.054 **	+1.200 ***

1. Per 100,000 population, age-adjusted to the 1940 US population.
2. Index score (see text); B = change in mortality rate per unit change in economic status.
3. Percent black; B = change in mortality rate per 10% change in percent black.

*** $p \leq .001$
** $p \leq .01$
* $p \leq .05$

with higher economic status and with a higher percentage of whites; and female breast cancer, which was not associated with either economic status or a particular race.

Table 3 presents the beta coefficients for multiple regressions. The associations of mortality with race were significantly weakened or eliminated for many causes of death. Low economic status tended to remain a strong predictor of high tract mortality rates. For respiratory and cervical cancer, and for external causes of death, the significant associations with race seen in the simple regression were entirely explained by low economic status. This was true also for both alcohol dependence and cirrhosis. For prostate cancer and ischemic heart disease, the significant associations with economic status in the simple regressions were in fact due to race.

Another measure of the importance of a risk factor is the amount of variance in the dependent variable for which it is responsible (the squared multiple correlation coefficient, R^2). Table 4 shows that economic status alone accounted for up to 60% of the differences in mortality rates among tracts. In no case did race alone account for more than 33%, and in many cases most of its apparent effect was explained by low economic status.

CONCLUSION

Economic status appears to be responsible for a large proportion of the difference seen between black and white rates in Baltimore City in the 1980s. This may reflect problems of access, inadequate insurance, or income-related behaviors. Alcoholism, in the data here, is clearly such a behavior.

It is more difficult to explain apparent "racial" differences. Diseases related to high blood pressure (hypertensive heart disease, cerebrovascular disease, nephritis) continued to show significant black excess mortality even when economic status was taken into account. The excess mortality due to prostate cancer in black males may indicate that they have not been targeted for screening to the extent that white males have been. In this respect, the lack of a significant racial difference between white and black females for breast and cervical cancer may be encouraging--it could indicate that screening was reaching both groups equally.

MAPPING

For each cause of death, the 80 tracts (top 2 quintiles) with the highest mortality rates were mapped, and tracts with excess mortality indicated. Because economic status and/or race explained much of the variance in mortality rates for many causes of death, there are generally few tracts with excess mortality.

TABLE 4

Percent of variance (R^2) in mortality rates[1] explained by economic status[2] and race[3]
Simple and multiple regression models
Baltimore City 1982-88

Cause of death (ICD-9 number)	Simple regressions		Multiple regression
	Economic status	Race	
All causes of death (001-E999)	59.0	30.5	59.8
All external causes of death (E800-E999)	46.0	18.5	45.7
All natural causes of death (001-799)	56.1	30.2	57.2
Diseases of the heart (390-398, 402, 404-429)	36.6	7.4	37.7
Hypertensive heart disease (402)	36.1	33.1	42.7
Ischemic heart disease (410-414)	6.9	14.4	14.2
Cerebrovascular disease (430-438)	24.3	29.0	32.9
All malignant neoplasms (140-208)	29.6	23.1	32.7
Respiratory system & larynx (160-163)	21.4	4.3	21.8
Female breast (174)	0.0	0.6	0.2
Cervix uteri (180)	11.5	4.0	11.0
Prostate (185)	5.3	24.6	25.0
Alcohol dependence syndrome (303)	30.5	11.9	30.2
Chronic liver disease & cirrhosis (571)	35.7	11.0	35.6
Nephritis, nephrotic syndrome & nephrosis (580-589)	22.5	33.4	35.4

1. Per 100,000 population, age-adjusted to the 1940 US population.
2. Index score (see text).
3. Percent black.

In general, the geographic distribution of tracts with high mortality rates (Figs. 3-5) reflects the statistical associations with economic status and race demonstrated in the multiple regression models. For example, heart disease mortality was strongly associated with economic status, and only slightly with race. The distribution of tracts with high heart disease mortality rates (Fig. 3) resembles that of tracts with low economic status (Fig. 2).

Hypertensive heart disease (Fig. 4) was strongly associated with **both** economic status and race. Its distribution includes tracts with low economic status as well as tracts with a high percentage of blacks. (Note also the cluster of tracts with excess mortality in East Baltimore.) Ischemic heart disease (Fig. 5) was associated only with race in the multiple regression model, and high rates are found largely in predominantly white or mixed-race tracts.

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Fig. 3 All Heart Disease

Baltimore City 1985

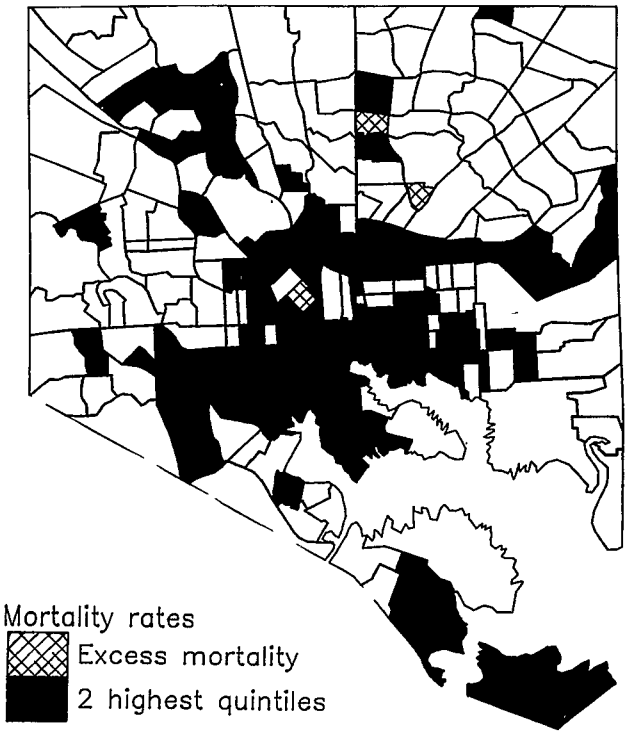


Fig. 4 Hypertensive Heart Disease

Baltimore City 1985

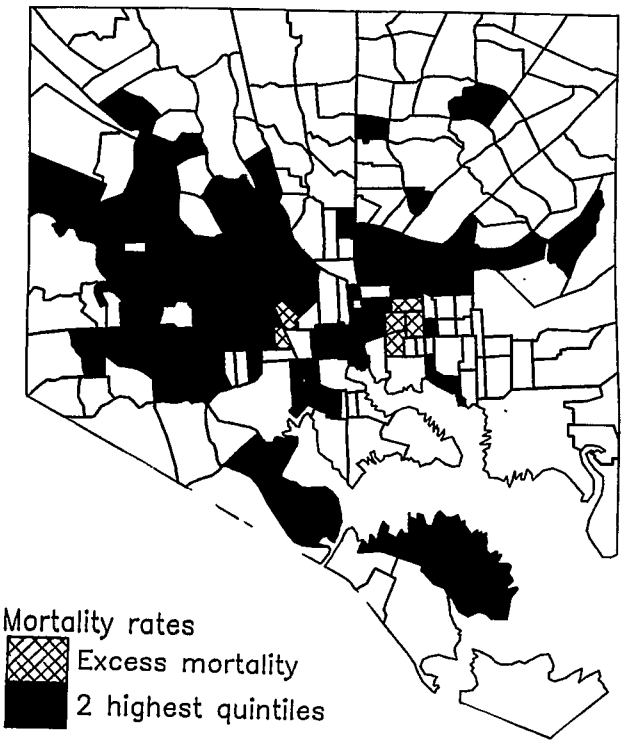
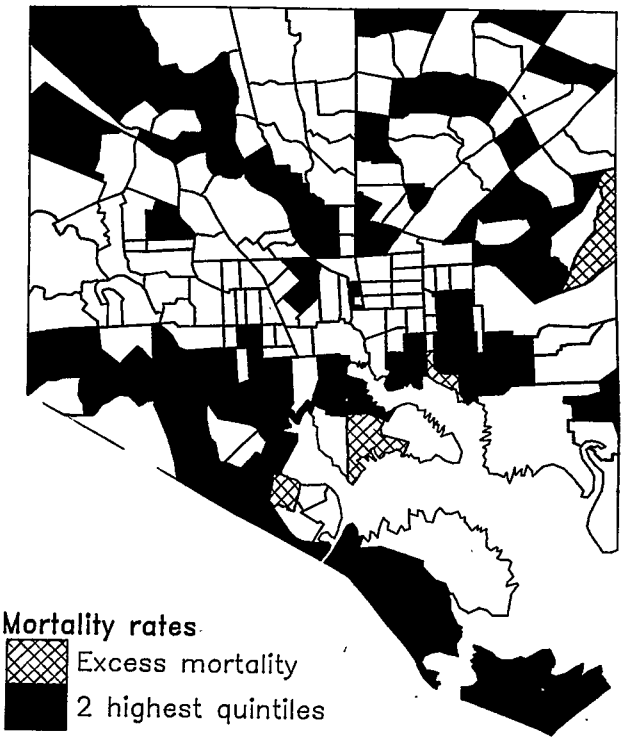


Fig. 5 Ischemic Heart Disease

Baltimore City 1985



ENHANCEMENT OF VITAL STATISTICS THROUGH GEOGRAPHIC INFORMATION SYSTEMS

Linda H. Jacobs
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Health and Environmental Control

(Not available for publication)

SCHOOL-BASED CLINIC MANAGEMENT INFORMATION SYSTEM

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(Not available for publication)

DEVELOPING A SYSTEM TO TRACK HEALTH OBJECTIVES AND INDICATORS

Stephen Kelso, Washington State Department of Health

Do any of the several hundred national year 2000 health objectives deal directly with the subject of osteoporosis?

Which of the objectives are exclusively for females?

Which of the objectives are aimed at children aged two and younger?

How does your state, county, or organization compare with nation in progress toward specific year 2000 objectives? If you are better or worse off than the nation as a whole, are you going to set numeric targets which are more or less ambitious than the national targets?

In Washington State we started thinking about such questions in the spring of 1990, anticipating the September release of the Conference Edition of Healthy People 2000 and subsequent interest in the health status of Washington State's population. Top managers of the Washington State Department of Health asked my office, the Office of Health Policy Support, to produce a report showing how Washington compares with the nation for a representative sample of about 20 key health objectives.

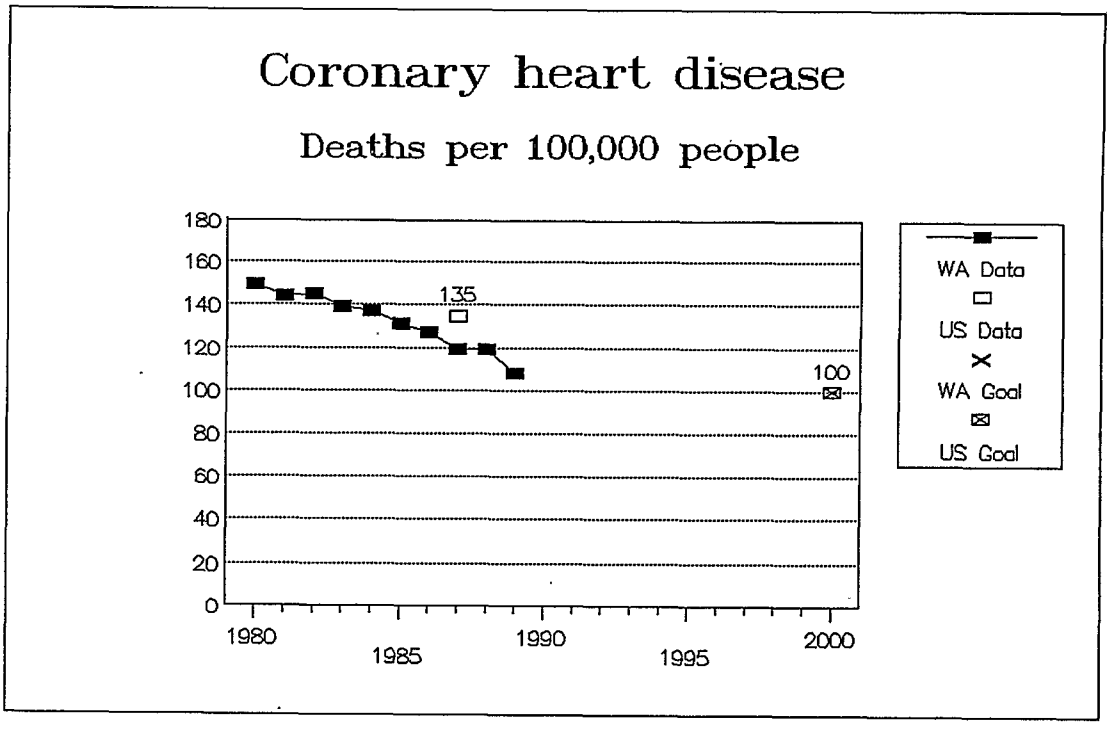
We produced that report "manually." That is, we selected the objectives, designed a format for presenting them, located and analyzed the data, wrote narrative, produced graphs, and put the whole works together in a 43 page publication. We wrote the text in WordPerfect, did the graphs in Harvard Graphics, and maintained manual paper file folders for each of the objectives.

The state data came from a wide variety of sources. Documenting the data sources and complexities was no great problem at first, but we hit a threshold, somewhere between 10 and 20 objectives, where the manual process got extremely cumbersome and inefficient and the benefits of an automated database system became clear.

We have now developed a prototype computerized system to track health objectives in Washington State, with particular emphasis on the year 2000 national health promotion and disease prevention objectives published by the U.S. Public Health Service in Healthy People 2000. We refer to the system as HOITS (Health Objectives and Indicators Tracking System).

HOITS is a database application developed in Paradox 3.5. It is now capable of producing charts like that in Figure 1 for each of the national objectives, showing how Washington State compares with the nation. (The limitation, of course, is that the comparison cannot be made unless the state data are available.) We have state data in the system for about 50 objectives. Developing the complete data for all the remaining objectives would be a major task; it may be that development of some of the data never becomes a priority in

FIGURE 1: Graph of one objective



the state.

We designed HOITS to be flexible, so it can track additional objectives not in Healthy People 2000. With some modification it also could be used by other states, counties, or even by employers to track health promotion and disease prevention efforts related to large populations or employee groups. It allows year-to-year and geographic comparison and analysis. It permits quick access to information for grant-writing, planning, and presentation development. It provides a tool for highlighting problems, successes, and opportunities for health promotion and disease prevention.

As it turned out, the major work of creating this system was not highly technical in a computer programming or data processing sense. The major effort lay in such areas as becoming familiar with the entire body of national objectives, understanding their structure and classification, and doing the conceptual work for fitting that body of objectives into a database framework.

After describing the database briefly, I will elaborate on some of the issues involved in creating and using it.

Figure 2 shows the data entry form for a HOITS database table called "Text," which is primarily textual in nature. Numeric data on national and state baselines and goals are stored in another table called "Data." A common ID field links records in the two tables. The fields in the "Text" table are as follows:

Subject is the briefest possible statement of the subject matter of the objective, usually taken directly from the contents page at the beginning of each priority area in Healthy People 2000 and amplified when necessary to further identify sub-objectives and multiple objectives (more later on this). The subject becomes the title of the graph shown in Figure 1.

ID is the identification number, again usually taken directly from Healthy People 2000 but amplified when necessary (more later on this also).

Measure is the unit of measure which gives meaning to the numbers displayed in the graph. In Healthy People 2000 the national numeric baselines and goals (and of necessity the measures) are included in the wording of the objective. We stripped the numbers and measures out of the wording of the objectives in order to produce a generic database system which may be used by any geographic or organizational entity. The measure becomes the subtitle of the graph in Figure 1.

Goalarea is one of twenty-two major categories of objectives, called "Priority Areas" in Healthy People 2000. Probably we should have called this field "Priorarea." Maybe we'll change it.

Objective is the statement of the objective, taken directly from Healthy People 2000 but without the numeric goals, baselines, or measures. It is always a single imperative sentence such as, "Reduce the postneonatal mortality rate among American Indians/Alaska Natives."

Narrative is a brief paragraph about the subject matter of the objective. It is limited to 255 characters--the maximum field size in Paradox. Other similar fields could be added if further narrative is necessary. We concentrated on trying to give a national or state context in addition to what could be inferred from the graph of the data. That is, we did not want to simply say, "As you can see from the graph, the trend in Washington State is downward and we are below the national average." We tried, instead, to let the graphs speak for themselves and use the narrative field for additional information.

FIGURE 2: Text entry screen with completed entries for one objective

```
TEXT ENTRY FORM      Subject: Coronary heart disease
Id: 01.01***       Measure:  Deaths per 100,000 people
Goalarea:  01: Physical Activity and Fitness
Objective: Reduce coronary heart disease deaths.



Narrative: Though the coronary heart disease death rate in the U.S. has
           declined 40% in the last 15 years, it still is the leading
           cause of death. Modifiable risk factors include smoking, high
           cholesterol, high blood pressure, overweight, and physical
           inactivity.
Goaltype: hs   Indtype: de  Dups: 1/4  Subs: y  Mults: n  Owner: a  Sex: b
Race: a   Age Range:  0     to 99     Condition: pd Datasource:  WCHS
Datacontact: Pat Starzyk, 6-6028
Datanotes: State and national death rates are age-adjusted to the 1940
           U.S. population.  1987 national crude rate: 249.  ICD codes:
           410-414, 402, 429.2.
```

Goaltype is one of three established in Healthy People 2000: Health Status (hs), Risk Reduction (rr), or Services and Protection (sp).

Indtype is a code for the type of indicator being tracked in the objective. We developed these after considerable analysis of the entire body of objectives. The most common ones are Personal Behavior (pb), Disease (di), Death (de), Presence of Services, Programs, Policies, Facilities (sp), Use of Services (us), and Personal Conditions (pc).

Dups tells whether this objective is duplicated in one or more other priority areas. In the example in Figure 2, the entry "1/4" indicates that this is the first of four instances of the same objective. A database table called "Dupes" lists the ID numbers for all duplicated objectives.

Subs contains a "y" entry if this objective either has or is a sub-objective (usually for special population targets). In the entire body of 621 unduplicated national objectives, we identified 89 which have sub-objectives and 238 which are sub-objectives.

Mults contains a "y" entry if this is a multiple objective. Multiples are an important and complicated aspect of the taxonomy of the national objectives. An example is objective 9.3 regarding motor vehicle crash deaths. It actually contains two objectives--one to reduce deaths per capita and one to reduce deaths per vehicle miles traveled--and each requires its own database record. In the entire body of 621 unduplicated objectives, we identified 187 multiple objectives. (There are places where the combinations of subs and mults get very complicated, and the way we wound up classifying them is by no means the only solution.)

Owner indicates what entity "owns" the objective. We included this field so our state or other geo-political or organizational entities would have the option of adding objectives not included in the body of national objectives.

Sex indicates whether the target population of the objective is male, female, or both sexes.

Race indicates the race or ethnicity of the target population.

Age Range is actually two fields--one for the minimum age of the target population and one for the maximum age. In some cases these are stated explicitly in the wording of the national objective. In other cases we made our best guess at the age range. These are subject to discussion and change.

Condition is a field which will accept coding such as "pg" for pregnant or "li" for low income. So far we have made little use of this field.

Datasource indicates the source of the state data. (We should probably add a field for the source of national data as well.) This is a short field with room for just an acronym. More detailed explanation of sources can go in "Datanotes," below.

Datacontact contains a name and phone number for the person contacted regarding the state data.

Datanotes records information about age-adjustment, ICD codes, definition of terms, sources, and other qualifications of the data. There are a surprising number and variety of such qualifications.

The remaining data in the system reside in a table called "Data." Currently, this table is structured so there is just one record for each objective. The first field is the ID number, which links information in the "Data" table with information in the "Text" table. The remaining fields are for state and national numeric data for each year from 1980 through 2000, plus the goals for the year 2000. Thus, there are fields labeled "WA1980" through "WA2000" and "US1980" through "US2000," plus two additional fields for the state and national goals--a total of 45 fields for each record in the "Data" table.

Database aficionados may recognize immediately that this is a particularly inelegant way to design a relational database. The current HOITS "Data" table is a prime example of what is called a "non-normalized" data table. A "normalized" table would contain many fewer fields and have multiple records for each objective. For example, it would probably have one field for ID numbers, one for geographic areas, one for time periods, one for values, and one for goals. A complete picture of one objective would then require multiple records--one each for any time period and geographic area being tracked.

This article will not attempt a detailed discussion of the pros and cons of normalized and non-normalized databases. Any further development of this system should probably move in the direction of a normalized data table. This would make the system more "generic" and permit its use by a wide variety of geographic and organizational entities with a minimum of modification.

For the time being, however, the system has a distinctly non-normalized data table for two reasons:

1) When I developed the system I didn't know a normalized data table from a flat rock.

2) It works.

It works particularly well for designing and generating on-screen and paper reports quickly and easily. Because all the data for any particular objective reside in only two database records--one in the "Text" table and one in the "Data" table--there is no need to pull data from multiple records to create reports. This has been a great advantage for me, a relative newcomer to database programs and

a virtual non-programmer. For example, I created the standard form shown in Figure 3 in just a few hours. With this form, users can toggle through the objectives as quickly or slowly as they wish, viewing combined information from the "Text" and "Data" tables with virtually no delay.

Enough on the technicalities of database design. I would like to spend the rest of this article discussing some issues which we have found to be particularly important and which were by no means self-evident when we started. It was rather like climbing a mountain and finding that the cliffs that appeared so difficult from the bottom were really a piece of cake but that the real problems lay in the brushy undergrowth of the approach and the swarms of insects that no one anticipated.

Probably the biggest challenge was coming up with a numbering and classification system that would fit in a database structure, be faithful to the numbering already established in Healthy People 2000, and incorporate a confusing array of duplicate, sub, and multiple objectives.

Figure 4 shows a list of objectives by ID number and subject. Note that we have added leading zeros to permit database sorting, so that objective 1.3 in Healthy People 2000 becomes 01.03 in our taxonomy.

The first pair of digits is for the priority area (in this case Physical Activity and Fitness).

The second pair of digits specifies the general subject within the priority area. For example, all the 01.02 objectives deal with the general subject of overweight.

The third pair of digits appears only when there is what we call a "multiple" objective. This is a refinement which does not appear in Healthy People 2000 but which we found necessary to establish an individual database record for each objective which has its own distinct numeric baseline and goal. For example, objective 1.2, presented as a single objective in Healthy People 2000, really contains two distinct objectives--one for adults aged 20 and older and one for adolescents aged 12 through 19. We designated the objective for the older group as 01.02.01 and that for the adolescents as 01.02.02.

The alpha characters are for sub-objectives, usually for sub-populations. In the overweight example, they all appear to be sub-groups of the adult population (though this gets ambiguous in places, as when we get to "people with disabilities" which could be adolescents as well as adults and are not specified).

The relationship between multiple objectives and sub-objectives is not always easy to follow, but there is a definite logic to it.

Finally in the numeric classification system, we added from one to three asterisks to show when an objective is duplicated in one, two, or three other priority areas. For any objective with an asterisk in its ID number, there will be an entry in the "dups" field such as "1/4," which tells you that this is the first of four instances of this objective appearing in the entire sorted list of objectives. Another table shows the ID numbers of the duplicates, and it would be relatively easy to automate the display of those ID numbers, though we have not yet done so. We also hope to establish one of each set of duplicates as primary, so that secondary duplicate records are updated automatically when changes are made to the primary one.

Beyond the classification system, the biggest piece of work we encountered was

FIGURE 3: Standard form combining data from two tables

Coronary heart disease
Id: 01.01*** Measure: Deaths per 100,000 people
Objective: Reduce coronary heart disease deaths.

	WASHINGTON	UNITED STATES
1980	149.2	
1981	144.1	
1982	144.9	
1983	139.2	
1984	137.2	
1985	131.5	
1986	127.3	
1987	119.9	135
1988	119.9	
1989	108.2	
YEAR 2000 GOAL		100

Data Source: WCHS

Data Notes:
State and national death rates are age-adjusted to the 1940 U.S. population. 1987 national crude rate: 249. ICD codes: 410-414, 402, 429.2.

that of entering the textual and coding information into the system. As with any data entry process, this was partly just a matter of slogging through tedious and repetitive keyboard work. But a great deal of it required skill, concentration, and judgement. Defining the measures and expressing the objectives in a generic, non-quantitative way was primarily an editorial task. Producing the narrative required looking at both state and national information and writing a concise summary. The entries for indicator type and age range at times required a lot of discussion and thought. The data notes consumed a great deal of time.

There were many judgement calls all the way through this process, so I would not expect others to blindly follow what we have done without evaluating and perhaps modifying it. On the other hand, a good deal of what we have done could be used exactly as is by other agencies and organizations.

I can't emphasize enough that this is primarily a verbal information system. The numeric data is perhaps the keystone, but the bulk of the information in the system consists of words and codes in various combinations. What we have done is the difficult work of editing, organizing, and systematizing those words and codes so they can be used by others to produce information and answer questions.

HOITS does not at this time have a sophisticated or friendly user interface. It can be run only by someone who knows how to use Paradox. Development of a full-blown user interface is a possibility if a significant number of people need to see and manipulate the data on-screen.

The future directions and uses of HOITS are not at all clear. It may remain a standalone database application running on one personal computer. It may serve as a data repository and a source of information for electronic or paper reports produced elsewhere. It may be a primary tool for producing electronic and paper reports itself. It may get turned into a mini or (horrors) mainframe-based application. It may get installed on some sort of network. It may disappear altogether.

The future for systems like this depends largely on whether people see them as useful, accessible, and efficient. We have distributed our work, on disk with some written instructions for use, to a large number of agencies in the last few months. We are interested in cooperating with national, state, and local organizations to reduce duplication. We are interested in sharing ideas, products, and developments. And last, but certainly not least, we are interested in sharing the costs of moving HOITS from a prototype to a fully functioning system.

FIGURE 4: List of objectives by ID number and subject

Id	Subject
01.01***	Coronary heart disease
01.01a***	Coronary heart disease, blacks
01.02.01***	Overweight, adults
01.02.01a***	Overweight, low-income women
01.02.01b***	Overweight, black women
01.02.01c***	Overweight, Hispanic women
01.02.01d***	Overweight, American Indians/Alaska Natives
01.02.01e***	Overweight, people with disabilities
01.02.01f***	Overweight, women with high blood pressure
01.02.01g***	Overweight, men with high blood pressure
01.02.02***	Overweight, adolescents
01.03**	Moderate physical activity
01.04.01	Vigorous physical activity, adults
01.04.01a	Vigorous activity, low income adults
01.04.02	Vigorous physical activity, aged 6-17
01.05	Sedentary lifestyle
01.05a	Sedentary lifestyle, aged 65 +
01.05b	Sedentary lifestyle, people w/disabilities
01.05c	Sedentary lifestyle, low-income
01.06	Strength, endurance, and flexibility
01.07*	Weight loss practices
01.08	Daily school physical education

USE OF MAPPING SOFTWARE TO GEOGRAPHICALLY DISPLAY HEALTH STATUS INDICATORS IN BOSTON'S NEIGHBORHOODS

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(Not available for publication)

REDUCTIONS IN MORTALITY AND COST DUE TO DECREASES IN CIGARETTE SMOKING: ENHANCEMENTS TO THE SAMMEC II SOFTWARE.

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ABSTRACT

The SAMMEC II software program from CDC estimates the total number of smoking attributable deaths, years of potential life lost (YPLL), and direct and indirect financial costs associated with morbidity and mortality. SAMMEC II presently does not allow users to estimate the savings due to reducing the proportion of current smokers and/or increasing the proportion of people who never smoked. The number of deaths in the 27 smoking related categories and the total medical costs cannot easily be reduced to reflect declines in smoking prevalence.

The Arkansas Center for Health Statistics has added several enhancements to the SAMMEC II program to address these limitations. The resulting estimates allow policy makers to weigh the costs of smoking reduction programs against potential savings and to accurately assess the impact of achieving specific goals, such as those outlined in Healthy People 2000.

With the enhanced SAMMEC II, the user enters the desired reductions in percent never smoked and percent quit smoking and the cost of programs to promote smoking cessation and prevention. Based on the "reduced" smoking prevalence, the program generates expected overall mortality in the 27 categories, direct medical costs, and the new percentages of current and former smokers. Tables show expected smoking attributable mortality, YPLL, direct and indirect costs, differences between current versus expected mortality and costs, and benefit/cost ratios of smoking reduction programs.

For example, smoking prevalence for Arkansas was "reduced" to the Healthy People 2000 targets. This resulted in 655 fewer smoking related deaths, 10,829 YPLL, and a reduction in overall costs of $79,298,251. If programs costs needed to produce this reduction were $3,000,000 the benefit/cost ratio would be $22 saved for every dollar spent.

Many other enhancements for SAMMEC II and related programs are possible. CDC should establish a clearinghouse to encourage and review modifications submitted by users.

INTRODUCTION

Reducing the number of people who smoke in the United States is one of the major items on today's healthcare agenda. According to the U.S. Department of Health and Human Services, cigarette smoking is the chief, preventable cause of premature mortality in the United States. In the United States in 1985, it was estimated that there were 390,000 deaths which were attributable to smoking (USDHHS, 1989). These deaths resulted in the loss of 5,850,000 years of potential life (Warner, 1987). The total economic costs attributable to smoking was over $52 billion.

The SAMMEC II software program from CDC was developed to estimate the type of statistics presented above. It calculates the total number of smoking attributable deaths, years of potential life lost (YPLL), and direct and indirect financial costs associated with morbidity and mortality. These statistics indicate the savings which might be expected, in lives and dollars, if smoking were totally eliminated, but the attainment of a total smoke free society is a distant dream. In the meantime, statistics on the potential savings due to a reduction in the percentage of smokers could provide valuable information. SAMMEC II presently does not allow users to estimate the savings due to reducing the proportion of current smokers and/or increasing the proportion of people who never smoked. The process of manually calculating these savings can be rather time consuming and cumbersome. The Arkansas Center for Health Statistics has added several enhancements to the SAMMEC II program to address this problem. The resulting software is titled SAMMEC/ADH. The user enters a desired decrease in the percent of current smokers and the projected proportion of this decrease which would be due to smoking cessation The user also enters the cost of smoking reduction and prevention programs. The software then calculates: the new or target smoking-attributable mortality, morbidity and economic costs; the difference between the current and target statistics; and the cost benefit ratio of the prevention and/or reduction programs. The resulting estimates allow policy makers to weigh the costs of smoking reduction programs against potential savings and to accurately assess the impact of achieving specific goals, such as those outlined in Healthy People 2000.

DISCUSSION

The user inputs four basic sets of data into SAMMEC II. They are the current smoking prevalence, mortality in 27 smoking related diagnostic categories, total direct healthcare costs and the estimated population for the group under study. These data are then used to calculate the smoking-attributable measures. When the number of smokers is reduced, three of these four input variables will change. The population estimate must remain constant in order to compare the decreases in smoking-attributable diseases, but the mortality and healthcare costs will change. For example, when the number of smokers is reduced, the number of smoking attributable deaths will decrease. This decrease in smoking attributable deaths will result in a decrease in the number of total deaths. Therefore, the total deaths in the

27 categories needs to be reduced in order for calculations of the smoking-attributable to be accurate. The same argument holds true for direct healthcare costs.

SAMMEC/ADH has the user supply data on the desired reduction in cigarette smoking and the projected proportion of this decrease due to smoking cessation. Using this data, SAMMEC/ADH calculates the target percentage of smokers, former smokers and people who have never smoked. In addition, SAMMEC/ADH computes the total number of deaths in the 27 diagnostic categories and the total healthcare costs. The smoking prevalence, mortality and healthcare costs are then input into the SAMMEC II program for calculation of smoking-attributable mortality, morbidity and economic costs at the reduced smoking levels. The difference between the current and target smoking-attributable measures is also calculated. The difference in the economic costs is then used to compute the cost benefit ratio of smoking prevention and cessation programs.

In order for the estimates, on the savings due to smoking reduction, to be valid there are several assumptions which must hold true. The first is that the relative risks for both mortality and healthcare costs will not change over time. To reduce the smoking percentages to the target levels may take a rather long time, and the relative risks in SAMMEC II are estimates of the current impact cigarette smoking has on mortality and morbidity. The assumption is that the impact cigarette smoking has on mortality and morbidity in 5 or even 50 years will be the same. This assumption is much more stable for the relative risks associated with mortality. The relative risks for mortality are based on a body of research conducted over a long period of time, and are therefore likely to be remain stable. The relative risks for the direct healthcare costs are not as well understood. The relative risks for hospitalization and physicians' visits in SAMMEC II come from a 1987 NHIS study. The relative risks for former smokers was higher than that for current smokers, in some age groups. This may reflect the fact that these smokers quit smoking because of their poor health. In the future, if more people quit before they become very ill, then the relative risks for former smokers would decrease. This would change the estimates of smoking-attributable healthcare costs.

A second assumption is that distribution of smokers within each age group will be similar in the current and target populations. In other words, the reduction of smokers did not all occur among a subset of the age group, for example the group aged 35-45, but instead was consistent across the whole 35-64 year old age group. A change in the distribution of smokers within an age group will have an impact on the estimate for direct healthcare costs and disability. In general, younger smokers will have fewer medical expenditures and are less disabled, so if the reduction occurs only in the youngest subset, the estimated savings in direct healthcare and disability costs will be overstated.

A third assumption is that the relative costs of treating neoplasms, circulatory and respiratory diseases compared to all other diseases will remain constant. If an expensive treatment is developed for any of these diseases, it could increase the percentage of healthcare dollars spent for neoplasms, circulatory and respiratory diseases. SAMMEC II bases its estimate of smoking-attributable healthcare costs on the current percentage of total healthcare costs spent treating these three smoking-related diseases, so if this percentage changes the estimated savings in healthcare expenditures will be inaccurate. A related assumption with SAMMEC/ADH is that the number of disability days will remain constant over time. If the amount of disability associated with these diseases changes, then the estimated savings will be inaccurate.

The assumptions used in estimating the savings in mortality and mortality costs should be rather stable. The same can not be said for healthcare costs. Two rather large assumptions are made concerning healthcare costs. They are that the relative risks will stay the same, and that the distribution of healthcare costs will remain constant. Given the many shifts in healthcare delivery and costs over the past several decades, it is questionable to assume that anything in the healthcare field will remain constant. Therefore, the data on smoking-attributable healthcare costs should be reviewed very carefully and used judiciously.

There are some limitations with SAMMEC/ADH. The first is, that at the present time, only the original 27 SAMMEC II diagnoses can be used. The software has not been structured to accept any additional diagnoses. This means that if diagnoses have been added to SAMMEC II, they must be deleted and the calculations rerun before SAMMEC/ADH can be used. This will ensure more accurate comparisons. Another limitation is with burn deaths. SAMMEC II gives no relative risks for burn deaths. The user either determines the actual number of smoking-attributable burn deaths or uses one-half the number of total burn deaths as an estimate of smoking-attributable burn deaths. Because there is no relative risk, the reduction in the number of burn deaths, as a result of lowered smoking prevalence, can not be calculated. This means that the difference in the "other" diagnosis category will be zero. A third limitation is with maternal smoking. There are relative risks associated with perinatal mortality, but no estimates for the morbidity or healthcare costs associated with these conditions. As a result, the difference in mortality and mortality costs for perinatal conditions can be calculated, but the total cost associated with maternal smoking will not contain morbidity or healthcare costs and therefore will be greatly underestimated.

A final limitation or "challenge" is determining a time frame for when the savings in smoking-attributable lives and costs will be realized. An important component for determining this is the percentage reduction in smoking prevalence due to cessation. If all of the reduction in smoking prevalence was projected to be due to smoking cessation, the time frame for accomplishing the target smoking prevalence could be short (5-10 years).

But if the reduction is projected to be due in part to smoking prevention, then it will take much longer to realize the savings. The reason for is that most smoking prevention programs are aimed at the teenage population, but the population groups SAMMEC looks at are aged 35 and over. To increase the number of people who have never smoked, the cohort of non-smokers aged 0-20 will have to replace the current cohort of 35-64 year old smokers. It will take 15 years for the oldest of these youths to even reach 35 and another 30 years for the whole 35-64 year old cohort to be replaced. Much can happen in 45 years, and the assumptions discussed earlier may well not hold true. If estimates are being calculated for certain target events, such as Healthy People 2000, the conservative approach would be to project that most of the reduction in smoking will be due to smoking cessation. SAMMEC/ADH will then give a fairly accurate estimate of the savings when the target smoking prevalence is reached. This does not mean that the software can not be used to determine the impact of increasing the number of people who have never smoked. But, given the time lag in accomplishing this goal, it may be best to think of the results as a "what if" scenario, instead of as actual savings which could be expected when these smoking levels are actually accomplished.

METHODOLOGY

The enhancement, like SAMMEC II, is written with macros in Lotus 1-2-3. The user is guided through the software with a series of menus. Three sets of data are entered by the user. Two are used to calculate the new or target smoking percentages, and the other is used to calculate the cost benefit ratio of smoking reduction and prevention programs. The user enters the percentage reduction in the number of current smokers. This is entered for five groups, men age 35-64, men age 65 and over, women age 35-64, women age 65 and over, and women of child-bearing age. Next the user projects the proportion of smoking reduction which is to be due to smoking cessation and enters this for all groups except women of child-bearing age. The relative risks for former smokers and people who have never smoked are different. Therefore, the user must decide the proportion of reduction due to cessation and the proportion due to prevention. The proportion of the reduction due to cessation is not entered for women of child-bearing age, because at present there is no known difference in outcome between pregnant women who are former smokers and those who have never smoked, therefore, no distinction needs to be made between former and never smokers for this group. Using the data on smoking reduction, the target percentage of current smokers, former smokers and those who have never smoked (never smokers) is calculated by SAMMEC/ADH.

The third set of data entered into SAMMEC/ADH is the cost of smoking prevention and cessation programs. This is entered for men 35-64, men 65 and over, women 35-64 and women 65 and over. It is not entered for women of child-bearing age because the total savings due to smoking reduction does not include morbidity and healthcare costs and therefore an accurate cost benefit ratio can not be determined.

The target distribution of current, former and never smokers is used to calculate the new total mortality and total direct healthcare costs. To do this, the age and sex specific relative risk for both the current and target smoking levels is calculated, for each of the 27 diagnostic categories. The percentage difference in relative risks between current and target smoking levels is then computed and the current total mortality is reduced by this percentage. This is the new or target mortality which is input into the SAMMEC II program to calculate the smoking-attributable measures. An example of this methodology is:

MALES 45-50

Current Smoking Prevalence

Current	Former	Never
35.9%	34.6%	29.5%

% Reduction Smoking Prevalence 42.1%
% Reduction Smoking Cessation 95.0%

Target Smoking Prevalence

Current	Former	Never
20.8%	49.0%	30.3%

Relative Risk of Mortality due to Lung Cancer

Current	Former	Never
22.36	9.36	1.00

Current Population Relative Risk

(22.36*.359)+(9.36*.346)+(1*.295)=11.56

Target Population Relative Risk

(22.36*.208)+(9.36*.490)+(1*.303)=9.19

Percentage Difference in Relative Risk = -20.5%

Current Number of Lung Cancer Deaths = 35.0

Target Number of Lung Cancer Deaths = 27.8

The number of smoking-attributable deaths would be based on a total of 27.8 lung cancer deaths for males age 45-50 for that year.

Unlike mortality, in which only smoking related diagnoses are used, total healthcare expenditures for all diagnoses are input into SAMMEC II. But, the calculations of smoking-attributable measures are based only on expenditures for diagnoses related to smoking. SAMMEC II contains the age and sex specific percentages of total healthcare dollars spent on

neoplasms, circulatory and respiratory diseases. Total healthcare expenditures are multiplied by these percentages to determine total costs for smoking related diagnoses. Healthcare expenditures for these diseases are multiplied by the smoking-attributable fractions of hospitalization and physicians' visits to determine the smoking-attributable healthcare costs.

To estimate total healthcare expenditures for the target smoking prevalence, SAMMEC/ADH uses a similar methodology to the one used to calculate target mortality. Some additional steps are needed because total healthcare expenditures is the input variable. The first step is to calculate the expenditures for neoplasms, circulatory and respiratory diseases. Next, the population relative risks for hospitalizations and physicians' visits are calculated. Then the percentage difference between the current and target relative risks are computed. The expenditures for the smoking-related diagnoses are then reduced by this percentage. To calculate the total target healthcare expenditures, the differences between current and target expenditures for the smoking related diseases are subtracted from the total current healthcare expenditures. The final step is to calculate the new percentage of total healthcare expenditures accounted for by neoplasms, circulatory and respiratory diseases. This is done by dividing the target amount spent on smoking-related diseases by total target healthcare costs. The following is an example for males aged 35-64.

Current Smoking Prevalence

CURRENT	FORMER	NEVER
35.9%	34.6%	29.5%

Percentage Smoking Reduction 42.1%
Percentage Reduction Due To Cessation 95.0%

Target Smoking Prevalence

CURRENT	FORMER	NEVER
20.8%	49.0%	30.3%

Current Healthcare Costs

	TOTAL ALL CAUSES	PERCENT TOTAL
Total	4,057,651,844	---
Hospitalization	1,664,154,967	9.43%
Physician Fees	911,719,842	8.74
Nursing Home Costs	450,995,138	1.92
Medications	407,433,575	9.48
Other Professional	121,795,654	0.20

Relative Risks

	CURRENT	FORMER	NEVER
Hospitalization#	1.98	1.92	1.00
Physician Visits##	1.17	1.14	1.00

Population Relative Risks

HOSPITALIZATION

Current

(1.98*.359)+(1.92*.346)+(1.00*.295)=1.67

Target

(1.98*.208)+(1.92*.490)+(1.00*.303)=1.66

PHYSICIAN VISITS

Current

(1.17*.359)+(1.14*.346)+(1.00*.295)=1.11

Target

(1.17*.208)+(1.14*.490)+(1.00*.303)=1.06

Percentage Difference in Relative Risks

Hospitalization	-0.9%
Physicians Visits	-4.5%

Expenditures on Smoking-Related Diagnoses

	CURRENT	TARGET	DIFF###
Total	324,218,734	321,989,909	2,228,825
Hospitalization	156,938,555	155,516,103	1,422,452
Physician Fees	79,656,138	79,353,064	303,074
Nursing Home Costs	8,672,562	8,593,956	78,606
Medications	38,632,303	38,485,315	146,988
Other Professional	243,591	241,383	2,208

Target Healthcare Costs

	TOTAL (ALL CAUSES)	PERCENT TOTAL
Total	4,061,237,843	---
Hospitalization	1,664,288,237	9.34%
Physician Fees	913,593,322	8.69
Nursing Home Costs	451,262,414	1.90
Medications	408,295,844	9.43
Other Professional	121,802,104	0.20

#Hospitalization relative risk is also used for Nursing Home Costs and Other Professional Costs.

##Physician Fees relative risk is also used for Medications.

###These differences are added to the differences for males 65+, females 35-64 and females 65+ to come up with the total difference between current and target expenditures. This total difference is then subtracted from total current expenditures to estimate total target expenditures.

RESULTS

The Healthy People 2000 target for smoking reduction in Arkansas was used to generate the expected savings in lives, years of potential life and economic costs. The goal is to reduce smoking from the 1988 level of 24.5% to 15%, which is a 42.1% decrease. Another goal is to reduce smoking among women of child-bearing age 52%. Since the time-frame for reaching this goal is relatively short, 95% of the reduction was projected to be due to smoking cessation. The estimated cost of programs aimed at reducing smoking to this level is $3 million a year over an eight year period.

If the Healthy People 2000 goal is met there would be an estimated 655 fewer smoking-attributable deaths and 10,829 years of potential life would be saved. The total economic savings would equal $79,298,251. The majority of the economic savings is due to reduced mortality costs. Savings in mortality and morbidity are $77,076,136 and $7,113,782 respectively. But, the healthcare costs actually increased by $4,891,667. Most of the reduction in smoking was due to cessation, therefore, the number of former smokers greatly increased. This, coupled with the higher relative risk for former versus current smokers for some groups, resulted in the increase in smoking-attributable healthcare costs. If the reduction in smoking had been due to smoking prevention, medical costs would have decreased. The total economic savings of $79,298,251, equals $158 for every resident of Arkansas. The benefit cost ratio of the smoking cessation and prevention programs would be $22. The savings are impressive, but it is important to note that smoking-attributable mortality, morbidity, and economic costs remain high. There would still be 4,073 deaths, 54,838 years of potential life lost and $483,142,202 in economic costs attributable to cigarette smoking.

With the entry of just a few pieces of information, SAMMEC/ADH calculates a number of useful statistics on the savings due to the reduction in smoking prevalence. It should be noted that the results should be carefully interpreted. There are several assumptions which must hold true for the estimates to be valid. Predicting the future is always difficult. But, the estimates can be used as general benchmarks in measuring the impact of our efforts to achieve a smoke-free nation.

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PCSAMPLE: SOFTWARE FOR SELECTING SCHOOLS, CLASSES, AND STUDENTS

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WHAT IS PCSAMPLE?

PCSample is a computer program developed to select a systematic random sample of schools with probability proportional to enrollment size for state and local Youth Risk Behavior Surveys. The program also generates individualized Sampling Instructions for the random selection of classes or students from each sampled school. When the program is properly used, the final sample of students is self-weighting.

The program, which is written primarily in the C programming language, was designed to run on IBM or PC-compatible computers. Additionally, the computer must have:

1. 640K RAM operating under PC DOS Version 3.0 or higher;
2. One hard disk drive and a floppy disk drive; and
3. Hercules, CGA, EGA, VGA, OR MGA video board and a working clock.

To use PCSample, the user must have a computerized text file of schools to use as a sampling frame. Sampling frames may be supplied by Westat or created by the site, but each must have the following characteristics:

1. The file must be in an ASCII format;
2. The record length must be no longer than 255 columns;
3. There must be one record per school;
4. The file must be created with a fixed record length and column format;
5. The number of students per school, without commas, must be the last item in each record;
6. A blank space must precede the number of students per school; and
7. The school file may contain no more than 2,500 records.

WHO USES PCSAMPLE?

PCSample was developed for cooperative agreement program directors in State and local departments of education (SEAs/LEAs), and others who plan and conduct a Youth Risk Behavior Survey, as part of cooperative agreement activities with the Division of Adolescent and School Health (DASH), National Center for Chronic Disease Prevention and Health Promotion, and the Centers for Disease Control (CDC). Currently, 71 sites throughout the United States and its territories are under cooperative agreement with DASH.

Westat is under contract to DASH to provide technical assistance to these program directors in planning and conducting surveys. During Westat's first contract year, it became evident that the SEA/LEA program directors were very concerned with selecting scientifically valid samples for their Youth Risk Behavior Surveys. In the course of providing technical assistance, Westat project staff conceived the idea of developing software to assist the sites in selecting their samples.

The main goal for PCSample was to enable a program director, without a specialized knowledge of sampling and statistics, to select a "good" sample. If used properly, PCSample provides just such a sample. A "good" sample consists of:

- An efficient sample design, which will produce more precise results than other possible samples of the same cost;
- A scientifically selected probability sample, which gives each eligible school in the population a known probability of being in the sample; and
- A well documented sampling process. Even when a sample is selected on a probability basis, the results can be interpreted appropriately only when information concerning the sampling process is documented thoroughly.

In addition to the software, the SEA/LEA program directors received the PCSample User's Guide. Included in the Guide is the Preliminary Information Worksheet. If care is taken by the program directors in completing this form, they will have gathered all the information required by PCSample and will have it available in a useful form while operating the software. The typical project director will spend several hours assembling and updating a computerized text file of the site's sampling frame, another hour or two completing the Information Worksheet, and generally less than an hour using the PCSample software to select the sample. Westat verifies the samples within 48 hours of receiving the sample verification files from a site.

HOW DOES PCSAMPLE WORK?

PCSample is menu-driven and consists of five modules -- EDIT, SELECT, COPY, VIEW, and PRINT. The typical user will use all of PCSample's modules in the course of selecting a sample of schools.

The EDIT Module

All users are encouraged to update their sampling frames before selecting a sample, as any improvement in the accuracy of the school frame results in a better sample. Regardless of the source of the sampling frame, enrollments have

changed, schools have opened, and other schools have closed since the sampling frame was assembled. The EDIT module enables users to add or delete schools and to update other information as needed, such as an enrollment size or a school's street address.

One of the more helpful features of the EDIT module is the Choose Fields option. This option allows the user to choose specific data fields with which to work, rather than trying to work with all the fields associated with one school's data. For example, if the only fields in the sampling frame that require updating are the school name, gradespan, and enrollment size, the user simply "tags" these fields for display. In contrast, if the complete school record is displayed, the user must scroll back and forth across several screens to view all the data associated with that one school.

The user may select this option again at any point during the editing session and "tag" different fields or display the entire school record. This process may continue as long as the user wishes to continue modifying the sampling frame.

The Edit/Create Frame option allows the user to create a computerized text file of the sampling frame, or to edit an existing file, if the file's layout matches the layout of the frames provided by Westat. Once the sampling frame is loaded into the software, the user may use the arrow keys to move to any individual school record or field within a school record. If a new school has opened since the file was created, the user may add the school to the sampling frame by pressing the F2 key and responding to the prompts. If a school has closed since the frame has been created, the user may delete it by moving the arrow key to the record and pressing the F3 key.

The EDIT module also contains a Print Frame option. Before or after modifying the frame, the user may print the entire sampling frame, or only the fields tagged for display during the Choose Fields option. The time and date of the report are printed at the top of the first page of the list. The names of the fields that are included in the report also are provided. In the PCSample User's Guide, the user is urged to print and review a copy of the modified sampling frame file before exiting the EDIT module.

The Sort Frame option may be used to reorder the school records in the sampling frame file. For example, the user might want to reorder the file by descending size of school enrollment to ensure that all the largest schools in a district have been included in the frame. In addition, the user might want to stratify the school records before selecting a sample.

For most users of PCSample, the order of the schools in the sampling frame will not affect the school sample. PCSample automatically sorts the schools during the sample selection process. However, in the event the user wishes to stratify, and it is appropriate to do so within the constraints of PCSample's sample design, the reordered frame may be saved and the order maintained during the sample selection process.

The user has the option of exiting the EDIT module at any time by selecting the Return to Main Menu option. Upon exiting, the user may decide to do so without saving changes. Otherwise the changes will be saved and included in the sampling frame file. Upon exiting, the user is returned to the Main Menu.

The SELECT Module

Upon entering the SELECT module, the user is encouraged to complete the Preliminary Information Worksheet provided in the PCSample User's Guide. The users' responses to many of these prompts will determine the characteristics of the sample that PCSample will draw. The information needed for PCSample includes:

- The name of the State or local department of education;
- The name of the sampling frame file;
- The location of the school names in the sampling frame file;
- Whether or not to maintain the order of the sampling frame;
- How to sample students - by classes in all schools, by students in all schools, or by classes in some schools and by students in other schools;
- The name and phone number of a contact person for the student sampling instructions;
- Whether or not active or passive parental permission will be required;
- If parental permission is required, the proportion of students likely to receive permission;
- Proportion of students in secondary schools who attend school on a typical day; and
- How many students per school are desired in the sample, or how many schools are desired in the sample.

Once all of this information is entered, a screen appears consisting of two parts. The top part is a description of the sample that will be selected. If the narrative displayed on the screen is acceptable to the user and F1 is pressed, the sample is selected. However, if the narrative is not acceptable to the user, the user may change the information displayed on the lower half of the screen. As the user makes a change below, the narrative on the top part of the screen reflects the changes just entered. The user continues this interactive process until the displayed figures are acceptable and the user presses F1 to continue.

In addition to the sample being selected, several files are created by the software. They include:

- The Sample File [sitename.SMP], which contains a list of the sampled schools. The file includes the following information for each sampled school: the position in frame number, the school

name, the number of eligible students, the expected number of students sampled, the school selection weight, and the within school interval.

- The Sample Verification file [sitename.SVF], which includes all the information about the sample selection process required to verify the sample. Items included in the file are the number of completed questionnaires desired and the anticipated response rates for the school level and the student level, a copy of the "description of the sample which will be selected" screen, the number of schools selected with certainty and a list of them, the sampling interval and random start for the non-certainty schools, the number of schools that were selected with a probability less than 1, the number of eligibles below which the measure of size was revised to preserve the self-weighting feature of the student sample, and a list of the remainder of the school data file with the non-certainty schools flagged with an "n."

- The Student Sampling Instructions File [sitename.SSI], which contains instructions for selecting classes, or students, or both. Depending on what the user selects, the file contains one form per school to select classes, one per school to select students, or one of each for sites selecting both classes and students. For the forms to be useful, each school must compile a numbered list of classes or a numbered list of students. By matching numbers on the two lists, the Student Sampling Instructions will indicate which classes or students are sampled.

- The Survey Tracking Form File [sitename.STF], which contains a form per school. The page may be duplicated by the school and used to list all the sampled classes or schools. If the forms are used properly, the forms contain all the information a statistician requires to determine if a site's data may be weighted.

The COPY Module

PCSample users are instructed to have their samples verified. In order to accomplish this, the user must copy all of the files generated by PCSample to diskette and mail the diskette to Westat for a statistician to verify. The COPY module makes this an easier process for the user. The output files are compressed and then copied to a floppy diskette. The COPY module determines how large the compressed file is and whether or not it will fit on a single diskette. If it is too large to fit, the user is prompted for another disk, ensuring that the Westat statistician receives all the information needed to verify the sample. If the data are not copied successfully, the user is informed and urged to call Westat immediately. After copying the files, the user is returned to the Main Menu.

The VIEW Module

The user may view the PCSample output files by choosing the VIEW module from the Main Menu. A second menu appears with a list of the files which may be viewed: the school data file, the sample, the student sampling instructions, or the survey tracking form. After viewing a file, the user may select another file to view or return to the Main Menu.

The PRINT Module

The user may print the PCSample output files by selecting the PRINT module from the Main Menu. A second menu lists the files the user may print: the school data file, the sample, the student sampling instructions, or the survey tracking form. Once a file is selected, the user is asked to indicate the proper print queue, to ensure that the printer is on, and to make certain that the printer has plenty of paper. A message is displayed on the screen as the file is printing. If the file is not printing, the user is notified and provided with suggestions concerning what might be wrong. If unable to print, the user is urged to call the Westat hotline.

QUIT

Whenever the user is returned to the Main Menu, QUIT may be selected. If a decision to quit is made, the user is returned to the DOS prompt.

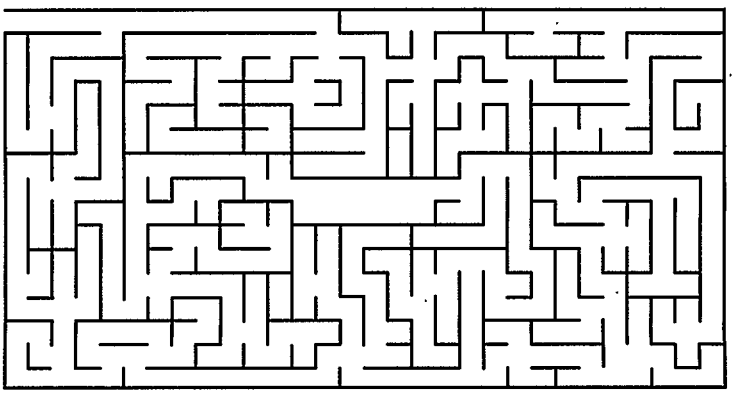
IS PCSAMPLE USED?

By October 1, 1990, 50 SEAs/LEAs had requested PCSample (Version 1). Version 2 was released in November 1991, and as of June 24, 1991, 55 requests for PCSample have been received.

For further information about the PCSample software, contact Dr. Laura Kann at DASH, Centers for Disease Control, (404) 488-5330.

Session BB

New Developments in Survey Methods



DEVELOPMENT OF METHODS TO MAXIMIZE ACCURACY OF REPORTING HEALTH RISK BEHAVIORS IN A YOUTH SURVEY

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Introduction

In theory, the process a respondent goes through in formulating a response to a survey question can be categorized under four broad headings: understanding and comprehension of the question; retrieval, processing and coding of information; affective evaluation of retrieved information; and respondent motivation. These issues are particularly important for studies that collect information from young respondents, but they apply across the entire spectrum of the survey respondents.[1]

This conceptual framework is being used to guide the research we are currently conducting for the National Center for Health Statistics (NCHS) and the Centers for Disease Control (CDC). This research has focused on developing and testing techniques for administering the Youth Risk Behavior Survey (YRBS), which will be administered as a supplement to the 1992 National Health Interview Survey (NHIS).[2] For this supplement, respondents 12 to 21 years old will be asked questions about the major health risk behaviors that affect youth, including behaviors that frequently result in injuries, drug and alcohol use, tobacco use, sexual behaviors that may result in HIV infection, other sexually transmitted diseases, unintended pregnancies, physical activity, and dietary behaviors and disorders.

Both the sensitivity of the topics and the age of the respondents pose special challenges for investigators. Some younger respondents (12 to 14 years old, for example) do not read sufficiently well to adequately comprehend the survey questions. Also, young people are less proficient in handling abstract concepts and are less skilled in using efficient techniques to conduct memory searches and in organizing the retrieved information. Other factors that influence the development of survey questions for youth are related to the variability in terminologies, language, and concepts among various ethnic and socio-economic groups.

The efforts described in this paper have focused primarily on developing methods of administering the YRBS in respondents' homes. The investigation also was designed to determine how well youths aged 12 to 21 understand the concepts and language of the YRBS questionnaire. The methods used include group interviews conducted with both youth and parents, individual interviews that dealt mostly with issues of comprehension and understanding, other individual interviews that probed the feasibility of alternative modes of questionnaire administration, and a series of field trials in which the YRBS interview and a debriefing questionnaire were administered in respondents' homes. Participants in these various interviews ranged from 12 to 21 in age, with males and females being represented in approximately equal numbers, and included Black, Hispanic, and Asian youth.

These investigations evaluated the YRBS questionnaire in terms of the four steps that respondents in every survey must complete satisfactorily if responses are to be complete and accurate, and in particular, how these steps apply to issues related to youth. The four steps are outlined in the figure below and each of these steps is then discussed in greater detail, with the YRBS questionnaire used to illustrate the issues.

Steps in Respondent Answer Formulation Process
I. Understanding and Comprehension of Question
II. Retrieval, Processing, and Coding of Information from Memory
III. Affective Evaluation of Information
IV. Effects of Respondent Motivation
Outcome: Responses Reflect All of the Previous Steps

Step I: Understanding and Comprehension of the Question

- Linguistic and Semantic Understanding (Vocabulary Used and Complexity of Sentence Structure)
- Comprehension of Concepts
- Shared Understanding of Technical Terms

The first task of this research was to ascertain whether the respondents and researcher shared the same meaning and interpretation of the questions. The process respondents go through in formulating answers to survey questions begins with their understanding and comprehension of the question. This issue can be broken down into the three general components outlined above.

While there are major substantive problems that must guide the design of questions, Step I concerns the broader issue of question interpretation and what is required of the respondent. When more than one plausible interpretation of a question exists, respondents need to consider and evaluate the various possible interpretations. This often means that they must create and answer their own "internal" question in order to decide how to interpret and answer the question as written by the researcher. Unfortunately, there is no guarantee that the internal question created by respondents matches the question as written and intended by the researcher.

Two examples from the YRBS questionnaire illustrate such problems of understanding. One question that caused some respondents particular difficulty was "*During the past 30 days, on how many days did you have at least one drink of alcohol?*". Respondents reported that they had to reformulate this question, by resolving for themselves the following definitional issues:

(1) What does the phrase "*at least one drink*" include?;
(2) Should I count the beers I started but only drank half?;
(3) What do they mean by "*alcohol*"? Does that include beer and wine?;
(4) What about wine coolers? Are they alcohol?

In several other YRBS questions the respondent's and the researcher's concepts did not match. For example, in the question "*During the past 12 months, how many times were you in a physical fight?*", respondents differed in what constituted a physical fight. For many, a physical fight meant kicking, hitting, or punching, while for others, the use of a weapon was necessary for it to be considered a fight. Others used the criterion of whether or not injuries occurred. Many respondents reported that they did not include fights with family members in responding to this question and indicated that their answer would have changed had they included fights with family members.

Definitional problems also arose on questions that asked about driving after drinking alcohol. When asked during debriefing interviews if, when answering these questions, they were thinking only about people driving **when they were drunk**, or people driving after having had **any alcohol** (no matter how much), nearly one out of four respondents said that they were responding only in terms of someone driving while drunk. Clearly then, a substantial minority of youth were answering this question with a concept which differed from that intended by the researchers. Such ambiguity, if left uncorrected, could generate significant errors in the estimated risks of driving after the consumption of alcohol.

These findings demonstrate the need for systematic developmental work and testing during the process of writing survey questions. Such research is necessary in order to create questions that have the same meanings for all respondents, and to insure that the researcher is indeed measuring the intended behavior or attitude.

Step II: Retrieval, Processing, and Coding of Information

- Decisions on Retrieval Process (What and How to Search)
- Retrieval from Memory (Attitudes, Beliefs, Experiences, Facts)
- Organization of Retrieved Information
- Coding Retrieved Information

The next step for the respondent is retrieving, processing, and coding the information into the response categories provided to answer the question. This is the stage of information processing that includes an assessment by respondents of what information is needed in order to respond accurately, and a determination of what cues or frames of reference are relevant to guide the search process. The retrieval process concludes when the respondent codes the information into the categories provided in the questionnaire.

The process of information retrieval frequently becomes complex, requiring considerable effort to produce accurate and complete responses. Respondents may accept the task only provisionally and may provide accurate responses only as long as little effort is required to understand the question and to provide adequate responses. As this suggests, some information may be inaccessible to the respondent either because it was never in memory storage, or because it was accessible at one time but now cannot be retrieved at all or not with the level of accuracy required.

The time lapse between the event, or storage of the information and the request for recall, are a major factor in the abilities of respondents to recall the event. Closely allied and interacting with the temporal dimension is the salience or importance of the event and its psychological impact at the time retrieval is attempted.

The ability of respondents to report the frequency of events within a specific time period is a problem that is ubiquitous in survey research and is one that potentially has serious effects on response accuracy. Especially problematic is asking for relatively important or repetitive events and reporting the frequency within a lengthy reference period. For example, consider the following YRBS question:

"*During your life, on about how many days have you had at least one drink of alcohol?*".

Our work with this question (in the context of the YRBS survey) showed that 12 to 14 year old respondents had no real problems in calculating an answer to this question, since their lifetime frequency of alcohol consumption was nearly zero. However, older youth reported considerable difficulty in answering this question, since many of these older youth had been drinking regularly for several years. Because of the frequency of the behavior and the length of the recall period, it was simply impossible for them to answer the question with an acceptable degree of accuracy.

When respondents feel that retrieving information is difficult or impossible, they usually shift to **other** retrieval modes: that is, respondents may make estimates, or they may simply guess. The problem becomes even more serious when the respondent recognizes that, while true recall was expected, an estimate or guess appears to be satisfactory to the interviewer. This encourages the respondent to continue this easier task performance mode in answering subsequent questions, and is a threat to the response validity of the survey questions. The solution for the researcher is to correct survey questions during the developmental stages when it becomes clear that a question requires respondents to retrieve episodic information at too complex a level.

The problems respondents encounter in retrieving, processing, and coding information are illustrated by the preliminary results of our attempts to obtain some measure of how accurate and truthful respondents were in answering the YRBS questionnaire. At the end of each field interview, respondents were given a self administered, anonymous form that asked them to provide a rating of the accuracy of their responses to specific survey questions, as well as an overall assessment of the accuracy of their responses. Respondents reported that they had difficulty in reporting behaviors accurately, especially when on frequent behaviors. Many respondents reported that their answers were simply guesses.

Step III: Affective Evaluation of the Information Retrieved

- Evaluation of Information in Terms of Self-Image, Self-Esteem, Social Desirability, and Embarrassment
- Censoring of Information to Conform to These Precepts
- Decision on Whether or Not to Report the Information

After respondents have retrieved the information required to answer a survey question through the processes outlined in Steps I and II, they must next evaluate this information in terms of its affective meaning. Reporting this information in responding to a survey question may threaten their self-image, their self- esteem, or may violate social norms. On the basis of this perception, responses may be **censored.** If the information is seen as non-threatening it can be reported, but if seen as threatening or as having no particularly positive value to the respondent, the response may be **distorted** or the information **not reported at all.**

The perception of respondents that the information required to answer a survey question is in some way threatening or socially undesirable is a barrier to the accuracy of reporting in all surveys. This problem is **particularly** likely to affect the accuracy of responses by youth about highly personal or even illegal activities such as illegal drug usage, alcohol consumption, or sexual activity. This threat is especially great when youth are asked to report such behaviors in their own homes.

Closely intertwined with the perceived emotional cost of answering a question is that of **privacy.** Asking questions on sensitive or threatening topics during any interview is difficult, but the problem is especially critical in face-to-face household interviews with youth. To avoid revealing sensitive information about themselves to other household members or to the interviewer, young respondents may modify their responses or refuse to answer questions.

A common solution to this problem has been the use of written self-administered questionnaires. However, this technique is not without shortcomings, especially for 12 to 13 year old respondents, who demonstrated considerable variability in comprehension, reading skills, and conceptual understanding of the questions.

In an attempt to solve these problems, three modes of self-administered questionnaires were evaluated: (1) a traditional, written questionnaire; (2) a version during which respondents listened to a pre-recorded audio tape of the questions played over headphones connected to a small, portable cassette player; and (3) a combination of these two methods during which the respondent followed a written questionnaire while listening to the questions using the headphones. In all three modes respondents marked their responses on an answer sheet that revealed neither the question nor the answer. That is, the answer sheet included response categories that did not reveal the content of the question. For example, if a question asked about how many times a respondent had engaged in a particular behavior, the answer sheet displayed only response categories labelled "1 to 2 times", "3 to 9 times", and so forth, with no other identification.

Results showed that the written questionnaire by itself was the preferred mode for older youth, mainly because they were more facile in reading and

wanted to complete the survey task as quickly as possible. Younger respondents preferred the tape because it addressed reading and comprehension problems. Respondents of all ages felt that the tape, either with or without a written questionnaire, provided adequate **privacy**. Our experience is that the that use of the audio tape by itself is readily accepted by youth of all ages, and it has distinct advantages from the standpoint of reading and comprehension.

At the beginning of our research, we were concerned about potential technical problems generated by the use of the cassette tape player, such as rewinding and pausing, and with interviewers' reactions to this mode of administering a questionnaire. These concerns were unsupported as the cassette tape players worked well, and respondents were able to stop the tape player if they required additional time to respond to a question.

On the basis of these investigations, the final pretest of the YRBS questionnaire was conducted using only the cassette tape player without a written questionnaire. The results of this effort showed that young respondents were able to use the tape players, and interviewers reported that they actually enjoyed the change of pace from their normal interviewing tasks that the taped interview represented.

Step IV: Respondent Motivation

- Level of Effort Expended to Maximize Question Comprehension
- Level of Effort Given to Memory Searches and Cognitive Organization
- Level of Willingness to Report Potentially Threatening Information

Steps I, II, and III cover the various activities or behaviors needed to obtain a valid response. Step IV is more closely related to an attitude, an affect, or an orientation respondents have towards the response task. It is motivation that activates efforts to comprehend the question, to conduct an effective memory search, and to report potentially embarrassing information. Most respondents will accurately report information that is readily accessible and non-threatening. As tasks become more demanding, however, respondents may not make the effort to comprehend the reporting task adequately, they may not work hard enough to retrieve information from memory and organize it efficiently, and they may not accept even a minimal risk of embarrassment.

One possible way to increase respondent motivation to provide accurate answers to sensitive or threatening questions is to link a monetary reward with the efforts respondents make in completing the survey. Initially we paid respondents $20 for their study participation as a way to increase the overall response rate. However, as group discussions and interviews proceeded it became clear that further efforts were needed to increase the honesty of respondent reports as well, since in these group discussions participants thought that their peers would not report accurate information on such behaviors as sexual activity and drug use. In an attempt to maximize the truthfulness of reports, the $20 respondents were being given was tied to a commitment to be diligent and accurate in reporting their answers. In laboratory and field experiments, psychologists have found that getting a person to commit him/herself to a particular action significantly raises the probability that the activity will be performed. Each respondent signed a form that was an agreement not only to be a respondent in the survey but to report as accurately and completely as possible. The Commitment Statement was:

> *It is very important that you answer each question accurately so that the research will be useful. To show our thanks we will give you $20 for the time and effort you make to provide accurate information for our research. Will you agree to answer each question as accurately as you can?*
>
> *Please sign here to show that you agree to participate and that you agree to give accurate answers.*

How powerful the commitment respondents felt to answering the questions as accurately and honestly possible cannot be assessed. In post interview debriefings it was instructive to note that comments were made that if $20 was given it must be important information to the researcher. Other statements were made by respondents to the effect that if the person accepted the money he/she felt a responsibility to carry out the commitment to report accurately. In response to debriefing questions, a majority of youth equated the payment with the seriousness with which they took the survey, and indicated that they believed respondents who took the survey more seriously would be more likely to respond accurately and truthfully.

Step V: The Response

In the schema of response outlined in this paper, the quality of the response to the survey question is the net result of the effects of the preceding steps. It is probable that the single major risk to the qualities of survey data depends on the positive and negative focus effecting the respondents' activities in carrying out these steps. Two statements summarize our ideas about the tasks

respondents face in answering questions in survey interviews:

(1) *The task demand level is the sum of the cognitive demands imposed by the requirements for information retrieval and processing and the affective demands imposed by the threat of the information requested;*

(2) *The quality of respondent performance is a function of the difficulty of the task and the level of effort achieved by the respondent.*

Our developmental work has convinced us anew that careful and thoughtful work is required to develop and test survey questions and procedures that achieve their intended objective. This statement applies equally to adult, as well as youth surveys.

NOTES

1. Charles F. Cannell, Peter V. Miller, Lois Oksenberg. "Research on Interviewing Techniques." in *Sociological Methodology, 1981*, Leinhart (ed.). San Francisco: Jossey-Bass, 1981.

2. This project was supported under a cooperative agreement from the Centers for Disease Control through the Association of Schools of Public Health.

SURVEY METHODOLOGY AND MENTAL HEALTH: RECENT DEVELOPMENTS

James S. Larson Ph.D.

Introduction

Two years before the reunification of Germany, a study was reported comparing the mental health of West Germans and Americans. The study reported that West Germans had "significantly more tendency toward depression" [1] than Americans, but that they were about the same in levels of anxiety. The study concluded that respondents with the highest levels of anxiety and depression in both countries rated their overall health lowest among all respondents.[2]

Cross-national studies of this type, studying mental health, are rare. Systematic annual morbidity statistics on mental illness "are not being produced by any country."[3] And yet, mental health is vitally important to our perceptions of physical health and the enjoyment of health.

Mechanic and Hansell report, in a study of 1,057 adolescents in 19 public schools, that self assessment of health is influenced primarily by psychological well-being and activity in school, and not by physical symptoms. They conclude that health in this age group is largely a mental and social concept, related to one's attitude about oneself.[4] Lubin and Zucherman report similar results among adults, as frequencies of volunteer activities and social activity correlate negatively with depression and positively with positive affect.[5]

Wolinsky et al. report similar findings from a study of 401 elderly respondents in the St. Louis area. They use factor analysis to associate health-related variables, and find that perceived physical health and mental health have "pristine" loadings on the same factor.[6]

In a study of heart patients, Maeland and Havik find that perceived global health status is related to levels of psychological distress. And, that the severity of myocardial infarction is "of relatively limited importance for self-evaluated health."[7] In a study of elderly patients in an HMO, Hall et al. report that patients' ratings of overall physical and mental health are more related to their own emotional health ratings than physician ratings.[8]

In addition, poor mental health may cause physical symptoms and illness. Verbrugge notes that bad moods "consistently trigger physical problems and health actions" in both men and women of all ages.[9] Health actions may include seeking medical care, medical drug use, lay consultation and restricted activity.[10] Peterson et al. observe that, "Pessimism in early adulthood appears to be a risk factor for poor health in middle and late adulthood."[11]

Thus, mental health is a variable which must be considered when assessing the overall health of populations. There are no systematic data on the existence of mental health and well-being in the population, but two studies indicate its prevalence. Ware et al., in an article based on the prestigious RAND health insurance study, estimate that 10-20% of the U.S. population have substantial psychiatric impairment.[12] In a smaller study, Sanders observes that the most prevalent chronic diseases in a sample population include obesity, heart disease, arthritis and mental disorders.[13]

Definitions of Mental Health and Well-Being

Mental health is related conceptually to physical and social health. The World Health Organization defines health, in the Preamble to its Constitution, as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."[14] The word "well-being" often is interpreted to indicate positive aspects of health, as opposed to defining health in a negative way as the absence of disease or disability. Well-being implies not only lack of illness, but also higher levels of health.

Mental health should also be distinguished from mental well-being in the same way. Mental health is the absence of mental illness or mental disorder, whereas mental well-being is a higher state of mental health. Mental health and illness are largely the focus of psychiatry, which attempts to heal patients with serious mental disorders, such as schizophrenia. Mental well-being is more the focus of psychology, which often studies mental processes and behavior in persons who are not incapacitated, but have problems with psychological distress. Table 1 illustrates the relationship between mental health and well-being.

(SEE TABLE 1)

Mental health is divided into two categories: the absence of mental disorders, and mental well-being. Mental well-being is further subdivided into the absence of psychological distress and positive well-being. The distinction between mental disorders and psychological distress is spelled out in the American Psychiatric Association's definition of mental disorder. While "no definition adequately specifies precise boundaries for the concept 'mental disorder'[15] it is

generally defined as: a clinically significant behavioral or psychological syndrome or pattern that occurs in a person and that is associated with present distress (a painful symptom) or disability (impairment in one or more important areas of functioning) or a significantly increased risk of suffering death, pain, disability, or an important loss of freedom.[16]

This syndrome or pattern "must not be merely an expectable response to a particular event" but "must currently be considered a manifestation of a behavioral, psychological or biological dysfunction in the person." This does not include deviance or conflicts between individual and society unless they are "symptoms of dysfunction."[17]

In contrast psychological distress, as defined in this paper, involves "painful symptoms" that are not "clinically significant." Distress does not cause dysfunction in the individual, requiring the aid of a psychiatrist or clinical psychologist. A person experiencing distress is able to continue normal activities without professional counseling.

Surveys of the general population are best targeted toward measuring mental well-being, rather than mental disorder. Measures of mental disorder usually take the form of clinical instruments used by psychiatrists or clinical psychologists in evaluating patients. Aday notes that, in general population surveys, researchers need to decide whether they want to study physical, mental or social aspects of health. If combined, they need to relate to the target population.[18]

Yergan et al. observe that most general population surveys of mental well-being measure 4 constructs: "anxiety, depression, positive well-being, (and) self control."[19] Wolinsky and Zusman note that there is little agreement on how to measure mental well-being. They observe further that "the validation of psychological health status measures has barely progressed beyond content validity."[20] With more emphasis on health promotion and higher levels of health,[21] researchers need to improve measures of mental well-being in population studies.

Global Measures of Mental Health and Well-Being

Measures of Mental Health

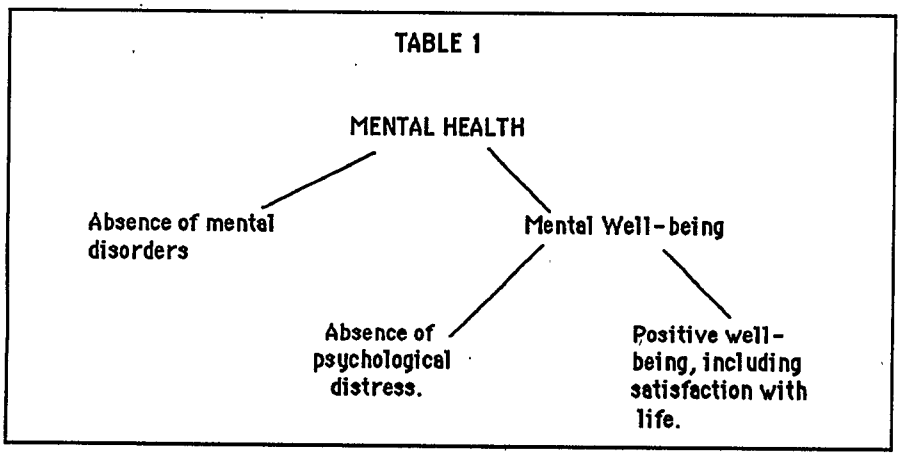
Global or generalized measures of mental health often focus on mental illness or mental disorders. They are used as tools for a preliminary diagnosis of mental disorder among patients in a clinical or institutional setting. They are used rarely in general population surveys.

A rare instance of a general population survey, using measures of mental disorders, is the Epidemiologic Catchment Area (ECA) Survey of Mental Disorders. The purpose of the study was to collect data on "the prevalence and incidence of mental disorders and on use of and need for services by the mentally ill."[22] It was "the largest and most comprehensive survey of mental disorders ever conducted in the United States."[23] Data were collected by 5 universities in collaboration with the National Institutes of Mental Health (NIMH), with a total sample of 18,571. A household survey and an institutional survey were used at each site, with 2 personal interviews one year apart and a brief telephone interview in between.[24]

Three measures of mental health were used in the ECA study: (1) the 20-item version of Goldberg's General Health Questionnaire (GHQ), (2) a self-assessment of "whether a disability day occurred due to an emotional problem," and (3) the Diagnostic Interview Schedule (DIS), version III, which includes a screening instrument called the Mini-Mental State Examination. The Mini-Mental State Examination is based on "criteria specified in the Diagnostic and Statistical Manual, Third Edition (DSM-III) of the American Psychiatric Association."[25]

Diagnoses derived from the DIS include the following disorders: "manic episode, major depressive episode, dysthymia, bipolar disorder, alcohol abuse or dependence, drug abuse or dependence, schizophrenia, schizophreniform, obsessive compulsive disorder, phobia, somatization,

TABLE 1



panic, antisocial personality, and anorexia nervosa."[26]

Two findings are reported from the Baltimore ECA study in the recent literature. First, low income individuals are more likely to experience mental disorders than higher income individuals. It was found that "12% of individuals with incomes below 130% of the poverty line a have serious mental health problem."[27] Second, health and mental health status affect the decision to seek care but not the provider of care. There was no significant preference for general medical versus mental health versus informational providers.[28]

In addition to the DIS and GHQ, the World Health Organization has developed and tested an instrument to measure social adjustment and mental disorders called the WHO/DAS (World Health Organization/Disability Assessment Schedule). It is "designed to assess the social functioning of patients with a mental disorder" and it is "applicable in a variety of cultural settings."[29] The present version of WHO/DAS "was finalized only after extensive field trials, and studies in over twenty countries have shown it since to be a valid and reliable tool for cross cultural comparison of psychiatric disability."[30]

WHO/DAS questions are grouped into five areas: overall behavior, social role performance, patient in the hospital, modifying factors, and a global evaluation.[31] The questionnaire should be filled out by "a psychiatrist, a psychologist, a sociologist, or a social worker."[32] Results from the questionnaire indicate that "schizophrenic and other psychotic patients" exhibit similar "clinical, behavioral, and social characteristics" across different cultures.[33]

Corcoran and Fischer review other instruments for measuring mental well-being in a clinical setting. They concentrate on rapid assessment instruments, with less than 45 items, which measure the "most common problems seen in clinical practice."[34] They review instruments in the following areas: anger, anxiety, depression, eating problems, guilt, hostility, loneliness, mood, obsessive-compulsivity, schizotypical symptoms, self-concept and esteem, social support, stress, and other areas.[35]

Psychiatrists and clinical psychologists use a variety of instruments to assess mental disorders, instruments which are not widely used in general population surveys. Reilly observes that the most prominent tests include the Minnesota Multiphasic Personality Inventory (MMPI), the Thematic Apperception Test (TAT), and the Rorschach Test.[36] Mental status questionnaires are "the most widely used method of assessment" in clinical psychology.[37]

Measures of Mental Well-Being

Mental well-being is concerned with the positive aspects of mental health, including feelings about satisfaction with life, as well as the relative absence of psychological distress. It is not concerned with debilitating illnesses or disorders, such as schizophrenia.

McDowell and Newell review several instruments for measuring mental well-being. Under the topic "psychological well-being" they review: the Health Opinion Survey, the Twenty-Two Item Screening Score of Psychiatric Symptoms, the Affect Balance Scale, the General Well-Being Schedule, the Mental Health Inventory, and the General Health Questionnaire.

They give highest praise to Goldberg's GHQ, which provides :

> a good method for screening for general psychological and psychiatric disorders. It has been used internationally, and many validation studies have demonstrated its psychometric properties."[38]

The GHQ identifies two types of problems: "inability to carry out one's normal 'healthy' functions, and the appearance of new phenomena of a distressing nature." Thus, it measures both mental disorders and psychological distress. It measures four elements of distress: depression, anxiety, social impairment and hypochondriasis.[39] There are several versions of the GHQ, with 12, 20, 28 30, or 60 questions.

Despite its clear conceptual basis and high degree of validation, the GHQ has certain shortcomings. Response categories are not sensitive to symptoms that are lengthy and which the respondent has become accustomed to feeling. And, certain items in GHQ-60 are not suitable because they reflect physical symptoms and create false positive responses. And finally, some critics object to the use of somatic questions to screen for psychiatric disorders.[40]

The only instrument which McDowell and Newell review, which also is reviewed by Corcoran and Fischer, is the Life Satisfaction Index, which measures quality of life. Corcoran and Fischer list 16 instruments to measure anxiety and 10 instruments to measure depression.[41] Anxiety and depression are the two most commonly mentioned elements in psychological distress.

The literature on globalized measures of mental well-being mentions the Sickness Impact Profile (SIP) in a number of studies. The SIP is reviewed by McDowell and Newell under the rubric of "general health measurements." The SIP contains measures of psychosocial functioning in the areas of social interaction, alertness behavior, emotional behavior and communication.[42]

In a study of 332 patients hospitalized for mental and psychiatric

problems, the SIP was compared with the MMPI and the Carroll Depression Rating Scale. The psychosocial subscale of the SIP correlated .72 with the Carroll Scale and .18 to .50 with 6 MMPI scales, including anxiety and depression. The authors of the study concluded that the SIP "discriminates psychosocial and physical dysfunction" and is "strongly related to depression" measures.[43]

In another study, the SIP was used to measure psychosocial functioning in patients with head injuries. The SIP was found to be highly correlated with measures of helplessness and withdrawal.[44]
And in another study, it proved to be a useful predictor of disability among patients with low back pain.[45]

The RAND Corporation also has developed instruments to measure mental health and well-being which are widely used. In the RAND Health Insurance Study (HIS), measures of physical, mental and social health were used, in conformity with the WHO definition. Measures of mental health focused on "symptoms of affective (mood) disorders and of anxiety disorders, positive well-being, and self-control, and emphasized psychological states (rather than somatic or physiological manifestations of these states)."[46]

Epstein et al. use RAND HIS items to measure depression, anxiety and overall well-being among patients and persons caring for them.[47] Connelly et al. report the results of another RAND instrument, called the General Health Perceptions Questionnaire, in a study of health perceptions and their influence on utilization of primary services. They find that primary care patients with low health perceptions have greater levels of anxiety, depression and health-related worry. Even controlling for physical health, these patients make more office calls, more telephone calls and have more office charges.[48]

Another significant instrument used to measure mental well-being is the Quality of Well-Being Scale. Like the SIP, it is a general health measure, and it measures 3 dimensions: mobility, physical activity, and social activity.[49] It combines measures of functioning and symptoms to give a rating from 0 (death) to 1 (optimal health).[50] Steinwachs observes that the SIP places more emphasis on mental health and well-being than the QWB,[51] therefore it is the preferred instrument.

There is a variety of other instruments reported in the literature which measure mental well-being. The OARS Questionnaire (Older Americans Resources and Services) contains 21 mental health and well-being items which fall into 4 general categories: life satisfaction, psychosomatic symptomatology, alienation and cognitive deficit.[52]

The Arthritis Impact Measurement Scales also are used to measure health in elderly populations. They include 64 items in 9 categories, which may be summarized as measures of physical disability, psychological states (anxiety and depression), and pain.[53]

Nelson and Berwick review several instruments for measuring mental health and well-being among adults who are not psychiatric patients. They include: the Mental Health Inventory/Short Form (Stewart), the Self-Rating Anxiety Scale (Zung), the Self-Rating Depression Scale (Zung), the General Health Questionnaire (Goldberg), and the Mental Health Inventory (Ware). They list the strengths and weaknesses of each measure, but draw no conclusions about which instrument is best.[54]

Particularized Measures of Mental Well-Being

Particularized measures of mental well-being include more focused measures of the absence of psychological distress and of positive well-being. The literature on measures of psychological distress is vast, and the most commonly measured symptoms of distress are anxiety and depression. In a recent study of psychological distress and well-being, it was found that items measuring psychological well-being are normally distributed in the population, whereas those measuring distress, including anxiety and depression, are not normally distributed.[55]

Hersen and Bellach present a long list of instruments used to measure anxiety and depression in their Dictionary of Behavioral Assessment Techniques. The list includes the Zung Self-Rating Anxiety Scale, the Zung Self-Rating Depression Scale, and the Beck Depression Inventory.[56] Another list is provided by Goldman and Busch, which also includes the scales of Zung and Beck.[57]

In another reference guide to instruments, Reilly notes there is a debate over whether anxiety and depression are "different aspects of the same state, on the same continuum, or mutually exclusive states." He contends that they are "distinct affective states," which can occur "conjointly, sequentially, or separately," and "each state can be manifested somatically, cognitively, and in psychomotor activity."[58]

The literature on psychological tests and psychometrics mentions the Beck Depression Inventory (BDI) frequently, and it appears to be the most widely used instrument for measuring depression. In a review of the same literature, no single measure emerged as the most widely used measure of anxiety. Therefore, this paper will focus its limited discussion of psychological distress on the Beck Depression Inventory.

The BDI is a simple test for the "presence and depth of depression." It is

widely used in the clinical setting and "has become the inventory of choice for researchers in selecting depressed subjects from a larger population."[59] It has been used among psychiatric in and out-patients, general university populations, and adolescents. It correlates well with psychiatric ratings of depression (concurrent validity of .77 with psychiatric ratings) and correlates .75 with the MMPI. Its face validity is apparent, and it has a test-retest reliability above .90.[60]

A Chinese version of the BDI was administered to 2150 Chinese students in secondary school, and the instrument was found to have "high internal consistency as a scale and high item-total correlations for most of the items." Factor analysis of the scale abstracted two factors: general depression and somatic disturbances. The results support "Beck's multi-dimensional view of depression as a construct."[61]

However, the BDI is not without its critics. One study of 37 adolescents found that high scores on the BDI "were not found to be specific to symptoms of patients with a diagnosis of depressive syndrome but rather measured the degree of subjective dysphoria." Dysphoria is psychological distress. The authors conclude that the BDI is useful as a screening devise, but inadequate for clinical diagnosis of depression using DSM-III criteria for depression.[62]

In a study of 36 psychiatric patients, scores on the BDI and Zung depression scales were compared. Both were significantly correlated with depression criteria in the DSM-III. But only the Zung depression scale was successful in differentiating patients with depression versus mixed depression versus other types of disorders.[63] Thus, according to these studies, the BDI has limited uses among psychiatry populations.

Another approach to measuring mental well-being is the use of quality of life instruments. Kaplan et al. identify two conceptual approaches to quality-of-life measurement: the tradition of health status measurement, which includes the SIP, RAND measures, the QWB, and the WHO definition; and quality of life as independent of health status, using traditional psychological measures.[64]

However, Bergner notes that quality of life "is not well conceptualized in the medical and health literature." The search for the best measure of quality of life is impeded by lack of information about its clinical usefulness and uncertainties about the best strategies for administration.[65] In a similar vein, Mor and Guadagnoli note that the proliferation of quality of life studies "has occurred without a uniform approach nor a 'clear conceptual framework." Establishing the psychometric properties of quality of life measures "is dependent upon a well-articulated theory" and resolution of the question of objective versus subjective quality of life conceptions. They call the current quality of life measures a "psychometric Tower of Babel."[66]

Nevertheless, measures of quality of life and life satisfaction appear to be related conceptually to mental well-being. They represent the positive side of well-being. McDowell and Newell review the following instruments under the topic "quality of life and life satisfaction": the Quality of Life Index, the Four Single Item Indicators of Well-Being, the Life Satisfaction Index, and the Philadelphia Geriatric Center Morale Scale.[67] They give highest marks to the Philadelphia Geriatric Center Morale Scale.[68] However, they conclude that quality of life is not a "rigorously defined concept in the health sciences" and there is little agreement over how "empirical measurements of quality of life relate to conceptual definitions of related themes such as morale and psychological well-being."[69]

Conclusions

This paper has four conclusions concerning the measurement of mental health and well-being through survey methodology. First, there is a need to acknowledge the importance of mental health and well-being to the overall health of the population. Without such an acknowledgement, there will not be a serious commitment of the resources needed to measure and monitor mental health and well-being on a regular basis. If, on the other hand, it is not considered important to an overall profile of health, we should be content with measuring only physical health.

Second, there is a need to define more clearly the distinction between mental health and mental well-being. A review of the literature indicates that these distinctions are not as precise as they might be. A good method for making this distinction might be a survey of psychologists and psychiatrists to determine their definitions of the terms. Such a survey might be accomplished by using the membership lists of the American Psychological Association and the American Psychiatric Association.

Third, there is a need to find the best measures of mental health and mental well-being. Once again, this might be accomplished by a survey of professional psychiatrists and psychologists. Such a survey would concentrate on those professionals with expertise in the area of psychometrics, rather than those with general training.

Finally, there is a need to measure mental health and well-being in the population on an annual basis. Without annual data, measures of mental health and well-being tend to become a mere footnote to the regularly-collected measures of

physical health. Data on mental disorders of a serious nature may be obtained from the annual publications of the National Institutes of Mental Health. But, systematic surveys need to be developed to measure the mental health and well-being of those who are not institutionalized as in-patients or out-patients. Development of such a survey, with the backing of the mental health community, might take a number of years, but the end product would be a more complete measure of national health.

* Footnotes available upon request.

ACCURACY OF SELF REPORTS BY OLDER RESPONDENTS

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The theme of this conference four years ago was "Data for an Aging Population." That theme and the many papers presented at that time reflected a basic demographic trend: the elderly, and in particular those over age 85, constitute one of the fastest growing groups in American society, and it is projected that their number will continue to grow well into the next century. The implications of this growth in terms of the health status of the population and the needs for health care and ancillary services are being debated vigorously. There is, however, consensus on the need for comprehensive and valid information on the old and the oldest old.

This paper addresses the use of survey research methods for the collection of epidemiologic, behavioral, and social data on older populations. Although many older adults remain as alert and healthy as younger adults, those in this age group are more likely to be experiencing health and cognitive problems that may keep them from participating at all in surveys or that may introduce errors into their responses. These problems are particularly common among the very old and those who are institutionalized. Thus, questions are often raised about the suitability of using traditional survey techniques that rely primarily or exclusively on self-reports for collecting data about older and oldest Americans and about ways to modify these techniques to better accommodate these age groups.

Perhaps the most obvious characteristic associated with old age is deteriorating health. Most health problems reported by the oldest old are chronic rather than acute, and these often limit daily activities. Moreover, vision and hearing impairments become increasingly frequent and severe with age, as do severe cognitive impairments. Memory performance and certain dimensions of intelligence decline. Indeed, the problems associated with interviewing the old and oldest old are often conceived as those arising from the minority who can be classified as "the frail elderly" who are "not institutionalized, but . . . cannot function independently" and who "tend to be neglected . . . because they are more difficult to locate and to interview" (Streib, 1983, p. 40). They or their caretakers may judge that their cognitive impairments would make it too difficult for them to follow interview questions and to provide accurate information and so decline to participate. Once participation has been secured, sensory, cognitive, and physical health problems may affect performance in a standard interview. The respondent has to understand the question properly, and retrieve the relevant information from memory. Many distortions may occur during retrieval. If the information cannot be retrieved, rules of inference may be applied to reconstruct the information (Bradburn et al., 1987; Loftus, Fienberg, and Tanur, 1985; Turner and Martin, 1984). Older adults are more likely than younger adults to disregard the standardized scale format and respond in terms that do not easily translate into the given format (Jobe and Mingay, 1990). They also tend to sidestep questions and converse "on the side" (Moles, 1987). As a consequence, older adults generate more missing data problems (Colsher and Wallace, 1989; Gergen and Back, 1966; Glenn, 1969) and need more frequent assistance from the interviewer in the form of repeating questions and response categories (Herzog and Rodgers, 1988; Moles, 1987).

In this paper we review the available evidence in order to establish whether more frequent difficulties are encountered in collecting data from older persons by standard survey procedures, whether these difficulties produce greater error, and if so which particular features of the standard survey seem to contribute to the difficulties. We also consider some possible modifications of standard survey procedures that may help in surveying the elderly. We must point out, however, that the literature bearing directly on potential errors in surveys with older adults is rather sparse, particularly with respect to needed modifications of standard procedures. Therefore, our remarks draw also on a much more broadly defined literature, sometimes forging rather speculative links to surveys with the elderly, and on informal observations by gerontological researchers, many of which still await systematic investigation.

Errors in surveys of the elderly

Investigations of the validity of answers to survey questions are mixed but have sometimes demonstrated rather large biases. For example, between 20 and 35 percent of adults inaccurately reported whether they voted in various elections; and most of them erred in the direction of overreports, thereby creating bias in the estimates of voter participation (Rodgers and Herzog, 1987). The reasons for such errors in surveys are sometimes motivational, as when a respondent does not want to report the correct but unpleasant fact that he uses drugs or engages in other illegal behaviors. In other cases the reasons for errors are cognitive, as when a respondent misunderstands the survey question, cannot recall the requested information, or is otherwise misled by the survey process.

Response validity is usually assessed by one of the following methods: by comparing individual survey responses with independent information from records; by comparing average statistics based on survey responses with the same average statistics based on other data sources; and by comparing data obtained using different measures of the same concept. A fairly substantial body of research has addressed response validity of survey questions using one or the other form of design. Specific survey characteristics such as the formulation of the survey questions and the response categories, the nature of the requested information, the context of the questions, and the mode of data collection have also been investigated.

The survey process is often assumed to be particularly challenging for older adults because of some of the well-documented age differences in cognitive functioning. However, this assumption has not always been upheld. For example, we found no increased error with age when examining factual survey questions that can be checked against external records (Herzog and Dielman, 1985; Rodgers and Herzog, 1987). There is a bit more evidence that the responses of older adults to attitudinal and other

subjective items have more measurement error than those of younger adults, at least in part because the answers of older people are somewhat more influenced by question format and less by the substantive content of the question. However, the age differences are small and not entirely consistent (Andrews and Herzog, 1986; Kogan, 1961; Rodgers, Andrews, and Herzog, in preparation; Rodgers, Herzog, and Andrews, 1988; Wallace, 1987). Colsher and Wallace (1989) observed less consistency in the responses of the oldest old than in the young-old adults, and they further documented that the inconsistencies were accounted for in part by relatively poor memory performance.

Three comments must be made about existing research on validity of responses among elderly adults. First, survey errors due to cognitive impairment are most likely to be found among the oldest old because cognitive impairments are relatively frequent in that age range. However, most of the investigations examining response error among the elderly do not include sufficient numbers of respondents over 80 or even over 70 for reliable estimates on these age groups. Therefore, the oldest old are usually combined with those over age 60 or 65, and because of their relatively small proportion they do not noticeably affect the findings for the broader age range. Second, those older adults who are most likely to have difficulties in answering survey questions are also those least likely to participate in the survey. Physical and mental health problems are a major reason for nonresponse among the elderly. In other words, if all sampled older adults were to participate in the survey, most likely many more difficulties with answering the survey questions would be observed. Third, age differences are not likely to be general across all types and formats of questions. Rather we would expect interactions, with older adults displaying particular problems with specific question formats. For example, it has often been argued that questions about information that has to be retrieved from long-term memory is more difficult for the elderly.

In the following paragraphs we review the evidence for response errors among the elderly with regard to specific aspects of the interview process and discuss suggestions for improvements to facilitate higher quality of data.

Characteristics of the survey questions

Differences in the meaning of questions for different age groups have been pointed out by gerontological researchers. For example, today's elderly seem to be less willing than younger age groups to draw comparisons between themselves and others, as is often requested by survey questions ("Compared to others your age ..."), because admitting that one is better than others would seem presumptuous. Or, older adults seem less comfortable with the kinds of psychological self-descriptions that are the mainstay of personality and mental health scales. In particular, it has been suggested that questions assessing satisfactions with various domains of life and similar evaluative questions may yield biased answers among older adults because of the desire among the elderly to maintain a positive view about themselves and associated defensive mechanisms (Carp and Carp, 1981; Herzog and Rodgers, 1986). More generally, older adults dislike the highly standardized format of the typical survey questions and response categories and they often attempt to avoid direct responses by digressing from the question and by rewording answers without using the provided categories (Jobe and Mingay, 1990; Kane and Kane, 1981).

Anecdotal evidence reported by several gerontological researchers suggests that survey questions developed on younger adults can be too complex for older adults. Gerontological researchers must be very careful about the wording even of established and well-validated scales, if the validation was conducted on younger respondents.

One aspect of the question wording that has received a good deal of confirmation through actual research is the number of response categories. Seven to nine categories result in responses of higher validity than do two to four (Bollen and Barb, 1981; Cochran, 1968; Cox, 1980). Although concerns have been raised that fewer response categories may be easier for older respondents and therefore produce more valid responses (Lawton, 1977), recent work (Rodgers, Andrews, and Herzog, in preparation; Rodgers, Herzog, and Andrews, 1988) demonstrates that seven to nine categories are probably optimal for those over as well as those under 60 years of age.

Seven to nine response categories might indeed seem like a large number to present to an older respondent. A particular format that appears to aid in the presentation of a relatively large number of categories is that of unfolding. According to this format the response categories are presented in a step-wise fashion, with major distinctions (e.g., "Do you agree or disagree?") asked first and minor distinctions probed thereafter (e.g., if the respondent agrees, "Do you agree very much or just somewhat?"). Preliminary data support such a format (Rodgers, Andrews, and Herzog, in preparation).

Length of interview

The opinion is often expressed that interviews may be tiring for elderly respondents, resulting in relatively high nonresponse rates and in poor data quality. Quantitative substantiation of this assertion is less easy to come by, but there is some supporting evidence (Moles, 1987; Herzog, Rodgers, and Kulka 1983; Gibson and Aitkenhead, 1983). By keeping the interviews as short as possible, tiredness and its effects may be minimized. Another way of dealing with a lengthy and tiring interview is proposed by Gibson and Aitkenhead (1983), who used an abbreviated interview that could be administered to an impaired respondent or to a proxy. In the Iowa Established Population for Epidemiologic Studies of the Elderly (EPESE), visits were sometimes split into two sessions. Carp (1989) also suggests dividing the interview into two halves and conducting the parts on different days.

A slightly different interpretation holds that it is the complexity of many of the standard survey questions, the tedious sequencing of many surveys, and the respondents' lack of interest in the topic of the survey, rather than the sheer length, that accounts for its tiring effect. Procedures that have been suggested to deal with these problems include structuring the sequence in which the questions are asked so as to put exhausting and less important questions toward the end, and breaking up long sequences of questions by changes in topic areas or interspersing physical activities.

Interviewer training

Interviewers in studies of older adults are generally given at least some special training to acquaint them with the problems often encountered with such respondents.

Such procedures include, for example, the use of video tapes and role-playing exercises. In some studies -- most notably the evaluation of the National Long Term Care Channelling Demonstration Project conducted by Mathematica Policy Research -- considerable effort went into sensitizing interviewers who are not elderly to physical problems often faced by old and frail people. For example, impaired vision was simulated by having the interviewers wear glasses smeared with Vaseline, and popcorn in the interviewers' shoes simulated the discomfort of walking for someone with problems such as arthritis.

Respondent training

Training and intervention procedures have been used in survey research and in gerontological research on cognitive functioning. In survey research, one set of procedures (Cannell, Miller, and Oksenberg, 1981) is based on the recognition that those who are selected for an interview are often unclear about what is expected of them in the role of respondent, and that instructing them in this role improves their reporting. The procedures, which include three dimensions -- commitment, instructions, and feedback -- have been shown to improve reporting in face-to-face and telephone interview surveys on health and mass media use (Cannell, Oksenberg, and Converse, 1977; Cannell et al., 1981). Because today's older adults have had less experience with standardized testing and interviewing than younger cohorts, it is possible that they could benefit from some guidance in how to view and relate to a survey interview. Procedures such as those developed by Cannell and his colleagues should be investigated.

Proxy reporters

Proxy reporters appear to be a much more important source of information about the oldest old than about younger adults, because of higher nonresponse rates among this age group and because of substantial proportions who, because of cognitive impairment or frail health, may be incapable of providing accurate responses to survey questions or even participating in the interview. For example, in the 1984 SOA of people 55 years of age and over, 8.5 percent of all the interviews were with proxies, but for those age 85 and older the rate was 26.6 percent (Fitti and Kovar, 1987). There appears a fair amount of consensus among gerontological investigators that proxy respondents must be used in research on the old and oldest old in order to avoid biasing the data in favor of healthy older persons.

Although a body of research evaluates the relative quality of responses provided by proxy reporters, most of this research is flawed by a critical design feature: sampled persons for whom a proxy is sought are different in their physical and mental health from sampled persons who can respond for themselves. Consequently, in most studies it is impossible to separate the effects of proxy-reporting on response quality from the effect of self-selection: Either proxy information is collected on a subset of respondents who are not healthy enough to answer for themselves and the quality of this information is contrasted with the quality of self-reports by those healthy enough to do so, or proxy and self-reports are collected on the same persons, but only those who are healthy enough to report for themselves are eligible. Either design is flawed because of confounding and likely bias. Furthermore, external validation criteria are rarely available to establish which of two discrepant reports is more accurate. These and other methodological problems affecting most existing investigations of the quality of proxy responses are discussed in a literature review by Moore (1988).

With these caveats in mind, the existing literature on proxy information in epidemiological studies suggests that its validity varies considerably depending on the relationship of the proxy to the respondent, on the type of information sought, and on the time period over which information is being sought. Regarding the relationship of the proxy, household surveys typically ask a close relative such as the spouse or an adult son or daughter to serve as proxy, while in institutional settings the immediate caretaker is often sought. It would seem logical that the choice of proxy be determined by the nature of the information sought. For example, caretakers may be more knowledgeable than family members about the physical health and functional symptoms of institutionalized respondents, while family members might be more knowledgeable about personal and family history, economic situation, and the like.

Regarding the type of information, the assumption is widely shared that proxies can be asked to report about factual information but not about feelings such as satisfactions or depression nor about cognitive performance. Recent findings (Bassett and Magaziner, 1988; Epstein et al., 1989; Rodgers and Herzog, 1989) suggest that reports by properly chosen proxies can provide about as valid information as self-reports can. However biases may be present; for example, proxies tend to judge the respondent as less satisfied than does the respondent him or herself. It is also suggested that subjectively experienced symptoms may indeed be less accurately reported by proxies than specific conditions or observable functions (Magaziner et al., 1987; Magaziner et al., 1988).

Assistors

By standard practice, survey interviews are sought in private and participation by other family members is actively discouraged on the assumption that the presence, and especially the participation, of another person may influence the respondent and thereby decrease response accuracy. This may be true for younger respondents, but one can speculate that family members or caregivers could actually play a beneficial role for older adults, because some older adults may find it difficult to deal with a rather formal interview conducted by an interviewer they do not know. The presence of a familiar adult might make the older respondent more comfortable with the interview situation. More importantly, the familiar adult might assist the older respondent in recalling some information, or could even conduct the interview under the interviewer's guidance, thereby alleviating fears about the interview situation and facilitating communication during the interview. At the most extreme, the familiar adult would answer the questions instead of the older respondent, effectively acting as a proxy as discussed above.

Obtaining information from administrative sources

A promising means of upgrading the quality of data on older adults is to supplement self-reports with administrative records. The National Death Index (NDI) is rapidly gaining popularity as a means of following up respondents who are lost from a panel and may have died and as a

means of confirming reports by others that the panel member has died. The NDI was created for nationwide tracking of deaths that have occurred in research populations (Rogot et al., 1983; Wentworth, Neaton, and Rasmussen, 1983). Upon approval by the NDI, the NDI will match submitted names and identify the states in which the deaths occurred, the dates of the deaths, and the corresponding death certificate numbers. Copies of the actual death certificates including the cause of death can then be obtained from the appropriate state offices.

The Medicare file compiled from data collected by the Health Care Financing Administration (HCFA) represents a source of information on dates of hospitalizations and diagnoses. It can also be matched with research data to supplement self-report information. The MEDSTAT files that are currently being developed will contain information on Medicaid enrollees that can be linked to research data files. The information is compiled and managed by HCFA and includes information on eligibility history, health service utilization, expenditures, and personal information.

Interviewer observations and systematic tests

Self-report information can also be supplemented by conducting standardized tests and systematic interview observations. Although tests have often been considered off-limits to the personal survey, several recent examples document the feasibility of including tests of verbal intelligence and memory into a personal interview (e.g., O'Hara et al., 1986; Scherr et al., 1988; Herzog and Rodgers, 1989). Tests of cognitive impairment in the form of the Mental Status Questionnaire (Pfeiffer, 1975) and the Mini-Mental Status Questionnaire (Folstein et al., 1975) have been included in many surveys of the aged.

Tests of physical performance have also been developed and used in surveys of older adults. For example, a test of a range of motion was used by Branch and Jette in the Massachusetts Health Care Panel Study. More recently the MacArthur Program on Successful Aging has developed a number of balance and gait measures that are currently being used in several sites.

Systematic observations by interviewers are usually collected upon the completion of an interview, but are mostly aimed at some very global assessment of the respondent's willingness and ability to participate and of the physical environment. These observations could be expanded to include critical incidents of cognitive and physical impairment. In most instances such observations could also be improved by more specific and particularly behavioral description of the characteristics to be rated and by more careful development of the rating scales.

Mode and form of survey administration

Mode of survey administration -- by telephone, by mail, or face-to-face -- is related to response error and thus must be considered when attempting to reduce such errors. Compared to surveys conducted face-to-face, telephone surveys result in higher proportions of item missing responses but yield similar response distributions (Groves and Kahn, 1979). These findings do not differ if only older respondents are examined, but the interview is experienced as more burdensome by the elderly when it takes place on the phone than face-to-face (Herzog and Rodgers, 1988; Herzog, Rodgers, and Kulka, 1983). The findings suggest that telephone surveys can be conducted with older adults, but that special attention and interviewer training may have to be devoted to reduce item missing responses, and that the length of the interview has to be controlled rigorously.

Telephone surveys may also be considered as a means of conducting follow-up surveys or for completing an interview that had to be cut short because of frailty and tiredness of the respondent.

Much less is known about mail surveys with elderly adults. Although there are examples of mail surveys conducted with older adults, the mail mode has not been systematically evaluated for use with this age group. Pertinent information is summarized by Herzog and Kulka (1989) and led to the conclusion that mail surveys should not necessarily be discounted as a means of data collection by gerontological researchers but that more systematic research is needed.

Conclusions

We have reviewed currently available survey research methods with respect to surveying the elderly and have evaluated the use of these methods with older populations in light of the existing evidence. Although much systematic research remains to be carried out, we are willing to venture some suggestions. In our own work and that of others we have not been able to identify disproportionate response errors among surveys of older Americans. To be sure, data collected with survey techniques potentially contain many forms of errors, but this is true for the entire adult population and does not appear to be more serious among those over 60 years of age. Also, we do not deny that the structure and meaning of specific measures may differ for different age groups and that careful evaluation of measurement equivalence is always necessary for age comparisons. But in this review we have focused more narrowly on the quality of survey data collected from older adults, addressing a concern that is often voiced in the context of discussions on data needs on older Americans.

However, we do believe that such a concern may be justified with respect to the oldest old, and particularly the impaired and unhealthy among them. It has been suggested that the highly structured and standardized interview format typical for most surveys might have to be relaxed for interviews with some of these elderly. Standardized interview questions and procedures are the rule in established survey research organizations because variations in survey and interview procedures can introduce variable error and bias into resulting data. But the inflexibility of these methods may introduce errors of their own into surveys of older and particularly the oldest old: information is lost when respondents refuse to participate in what they judge to be an onerous interview or decline to answer an unintelligible question; and information is erroneous when respondents guess answers or misunderstand questions. Critics have pointed out that standardized interviews violate norms of ordinary discourse, thereby introducing error; and they point out that interviews should more closely follow the conventions of normal discourse, which has several characteristics that distinguish it from the course of the typical survey interview (Briggs, 1986; Jordan and Suchman, 1987; Mishler, 1986). This criticism might be particularly relevant to interviews with specific subgroups such as older respondents (as

noted in the collaborations between cognitive psychologists and survey methodologists; cf. Jabine et al., 1984), among whom resistance to the standardized interview format has been noted by many researchers. Efforts to design more flexible interview procedures that can be adjusted to the specific respondent are therefore needed.

A good understanding of the limitations and potentials of the various types of survey methods is critical for an informed interpretation of the resulting data and certainly for the mounting of actual data collection efforts. Given the trend toward increasing numbers and proportions of the elderly in the U.S. population, and their disproportionate contribution to soaring health care costs, the need for accurate data about the elderly should be obvious to all. Research is urgently needed to evaluate the efficacy of the various procedures that have been suggested for improving the quality of such data, and to stimulate the development of improved procedures.

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DISCUSSION

Thomas B. Jabine

I would like to compliment the session organizer and the speakers for a well-informed and thought-provoking review of some important features of health survey design and methodology. I will discuss all three papers. The first and third papers, presented by Messrs. Cannell and Rodgers, cover data collection procedures for surveys that target particular age groups: youth and older persons. These two papers can conveniently be discussed together. The second paper, by Larson, is content-oriented. It looks at underlying concepts in the measurement of mental health and provides a review of instruments or scales that have been developed to measure different states of mental health, including mental disorders, psychological distress and mental well-being.

The title of this session is New Developments in Survey Methods. Actually, most of the material in these papers will be known already to dedicated survey researchers. An exception is the use of tape-recorded interviews, in conjunction with printed questionnaires and separate recording sheets, to collect sensitive data from youths. One hopes to hear much more in the near future from Cannell and his colleagues about the costs and benefits of this method of data collection, which was developed primarily to keep individual youth's survey responses confidential from other members of their households, especially their parents. A recent pretest in Houston, with about 100 interviews, will provide additional information.

One should not expect surprise breakthroughs in survey methodology, comparable to those that sometimes occur in the physical sciences. However, major changes have occurred in recent years. One is the use of automation in a variety of ways in the data-collection stage of surveys. Cannell's "Walkman" interview is still another example of this trend. Another significant change is the much greater attention that is being given to the cognitive aspects of survey data collection: how survey researchers and respondents communicate with one another to attain the desired results. Both Cannell and Rodgers discuss the cognitive processes of respondents in their target age groups at some length, as befits representatives of a survey organization that led the way in exploring the cognitive aspects of survey interviews.

Improvements in the quality of surveys also come from paying careful attention to a myriad of details and learning from the experience of others. Much more could be learned if organizations that conduct major surveys would routinely compile and publish fairly detailed performance statistics, following the example provided by the Quality Profile for the Survey of Income and Program Participation.[1] It would have been useful if the papers by Cannell and Rodgers could have cited completion rates, noninterview rates by reason and item non-response rates by age of sample persons from several surveys, but I suspect that it would have been quite difficult for them to obtain such data.

Surveying youth and older persons

Cannell has looked at some special aspects of collecting information from youths from ages 12 to 20 on several sensitive topics. This work has been done for the National Center for Health Statistics (NCHS) in preparation for a planned 1992 supplement to the National Health Interview Survey (NHIS) covering health risk behaviors of persons in this age group.

A major question for the supplement is how to collect information on topics like substance abuse, sexual behavior and dietary behavior from teenagers in their own homes without revealing any of their responses to other household members, especially their parents. The process is complicated by the need to obtain permission from parents to interview those aged 12 to 17. Cannell was surprised by some of the topics, such as consumption of certain foods, that were considered sensitive by prospective respondents. I suspect further exploration of the reasons for sensitivity would show that the desire to withhold certain kinds of information from their parents was a common thread.

In focus group interviews, some youths said they would underreport certain kinds of behavior in the survey so that they could tell their parents how they had answered some particularly sensitive questions without incurring their parents' disfavor. Did it occur to them that this would in fact be a double lie, to the survey researcher and to their parents! Maybe this supplement requires a double commitment: one from the sample youths to report accurately and one from the parents or other relatives to refrain from asking the respondents about their answers. This particular example illustrates a more general issue that hasn't always received adequate attention in household surveys: how to collect personal information without revealing to other household members data that respondents may not wish them to have. The same question would have to be considered in surveys of older persons in the light of Rodgers' suggestion that it might be useful to have other family members present during interviews.

Both papers find that there are differences for subsets, defined by age, of their target populations, especially with respect to the cognitive abilities of respondents. This should be fairly obvious for older persons: it is generally accepted that the ability to recall events and some other cognitive abilities decline with age. For youth, there are two opposing factors operating: those at the lower end, say 12 to 14, may have more difficulty reading or understanding questions and developing appropriate recall strategies but their task is made easier for some types of behavior because they have fewer events to recall.

I was intrigued by Rodgers' observation that older persons are more resistant to "playing the game" according to the rules established by survey researchers: that they have a tendency to digress and to give answers that are not included in the set of response categories made available to them. Could it be that this kind of behavior results, at least in part, from the experience and broader view of the world's complexities that come with age? When such reactions occur in the questionnaire development stage, I would suggest that survey researchers take them seriously and perhaps try to revise the rules of the game in ways that make more sense to respondents, or at least make clear to respondents why they need to ask questions in a particular format. As one who has been a respondent to many surveys, what I have found most burdensome is being asked to give superficial, oversimplified responses to questions relating to complex and often hypothetical matters.

The general conclusions that I would draw from these two papers are: first, that survey designers should be conscious of the special problems associated with each type of target population, whether it be defined by age, ethnicity, gender, occupation, or any other characteristics; second, that it is possible to collect good quality data from most such groups, provided one is aware of their special needs and willing to invest the necessary resources to meet those needs; third, that more research on survey methods for special populations is desirable, as suggested by Rodgers, but that much progress could be made at little cost if more survey organizations were willing to document their experiences and share them with others.

Measures of mental health

A few years ago I was one of a group of four consultants (Charles Cannell was also one of the group) who developed recommendations for the NCHS for revising the content of the NHIS. One recommendation was that NCHS should, for the first time, collect some information on mental health as part of the annual core, that is, the short set of items for which data are collected every year. The items we recommended were a measure of self-perceived mental health status, based on not more than five items with scaled responses, and an item to determine whether any mental health services had been used during the 12 months preceding the interview. We also recommended that more detailed information on these subjects be collected every third year.

Given this background, in reading Larson's paper I looked for answers to specific questions. Are there short modules to measure self-perceived mental health status that could be used in a national survey by interviewers with no special training in the mental health professions? If so, what specific concepts or states would they be able to measure successfully?

Larson's presentation of mental health concepts was quite helpful. In the table (last page) I diagrammed them differently, using a decision table format. I assumed, perhaps incorrectly, that persons with mental disorders would also be subject to psychological distress and absence of positive well-being. With respect to the NHIS my question to Dr. Larson is: Which of the four states shown at the bottom of the table could be reasonably well distinguished either by a short module in the annual core or by a longer module included as a supplement to the survey at three-year intervals? From his review, I suspect that it would not be possible to identify persons in State 1 (with mental disorders) reliably, even were it considered good policy to attempt to do so in a general-purpose national health survey.

In my search for answers to the above questions, I found Larson's review of existing measures of mental health less helpful than his discussion of concepts. To make choices for use in the NHIS, one would need to know something about the operational requirements for administration of each candidate instrument or scale: how much time is required, is self-administration an option, and does administration require mental health professional training? Does the module consist entirely of closed-response items, or are their items that would need to be coded? To give one specific example, Larson mentions that there are versions of the General Health Questionnaire with 12, 20, 28, 30 and 60 questions. What, if anything is lost by using the shorter versions? Could anything useful be learned by using an even shorter version?

Besides these operational requirements for use in the NHIS, one would want to have confidence in the validity and reliability of the different instruments or scales that might be used. Some of the other reviewers cited by Larson have identified certain instruments as being the "best" or "preferred" among a group of instruments with similar

objectives, but there is little indication of what criteria were used to make these judgements. Face validity is necessary but not sufficient. Any module for the NHIS should be thoroughly evaluated for content and construct validity and for reliability prior to use.

With regard to the author's four conclusions, I agree with his first two. Periodic measurement of mental health in national surveys is desirable, and it would be helpful if we could start with some agreement among mental health professionals about what variables should be measured. On his third point, a survey of psychiatrists and psychologists might not be the best way to find suitable measures of mental health and well-being for use in the NHIS. It might be better to form a small research team consisting of both mental health and survey research professionals to evaluate and if necessary modify existing instruments.

On the author's final point, I would need a more detailed justification to be convinced that population levels of mental health and well-being must be measured annually. Like most other health conditions or states, one would not expect levels of mental health in the general population to vary much from year to year. The purpose of the proposed minimal annual core items which I mentioned earlier was to provide explanatory variables that could be used in analyses of information collected in the NHIS supplements, which are different every year.

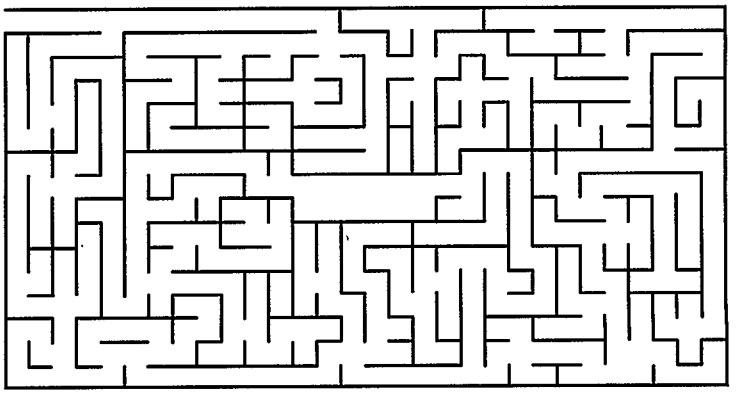
I agree with the author's overall conclusion that systematic measurement of mental health and well-being of the general public is important and that a substantial development effort will be necessary. His paper is a useful contribution to this effort.

NOTE

1. Thomas B. Jabine, assisted by Karen E. King and Rita J. Petroni, Survey of Income and Program Participation Quality Profile (Washington: U.S. Bureau of the Census, 1990).

States of mental health				
Mental disorder	Yes	No		
Psych. distress (anxiety, depress.)	Yes		No	
Absence of positive well-being	Yes			No
STATE	1	2	3	4

Appendix



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