CHALLENGES

FOR PUBLIC HEALTH STATISTICS IN THE 1990'S

PROCEEDINGS OF THE 1989 PUBLIC HEALTH CONFERENCE ON RECORDS AND STATISTICS

July 17-19, 1989

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NATIONAL CENTER FOR HEALTH STATISTICS

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

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PHCRS

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PHCRS

CHALLENGES FOR PUBLIC HEALTH STATISTICS IN THE 1990'S

Dr. Manning Feinleib, National Center for Health Statistics

It is a pleasure to welcome you to the 1989 Public Health Conference on Records and Statistics. The theme of this year's conference is "Challenges for Public Health Statistics in the 1990's," and that will be the theme of my remarks as well.

For those of us in public health statistics the challenges are coming from many directions.

First, we must address the challenges continuing from the 1980's agenda: Minority disparities in health, the health of children, the various aspects of violence, substance abuse in many forms, and the necessity to control health costs. I'm sure you all are familiar and are dealing with these challenges.

Added to these challenges, we now recognize that the public health arena is different today than it was a decade ago. The aging of America, the AIDS epidemic, the successes and failures of health promotion and disease prevention programs, the widening array of health care delivery and payment settings, and efforts to evaluate the quality and outcome of health care have made the public health scene today vastly different from that in which we operated 10 years ago.

The health statistics environment has also marked significant change. Government-wide resource constraints have come at a time when we are asked to provide important health data on a broader spectrum of health issues. Our deliberations and decisions on data collection and analysis now receive wider attention, not only from budget and management officials, but also from the constituency of data users.

We are working to meet those challenges in many ways. Setting data priorities to correspond to the current and future issues in public health may be the most important. New methods of collecting and analyzing data, new ways to present that information to match decisions that are or will be made, and the utilization of the latest technology are other ways to meet the challenges to public health statistics.

I believe that this conference continues to be the premier forum for addressing these challenges. In its 30-year history the Public Health Conference on Records and Statistics has brought together data users and producers, statisticians, program planners and evaluators to reason together. From the first gatherings of State registrars and statisticians, the conference has drawn participants from many fields over the years. Conference deliberations focused on the health service gap in the 1960's. In the 1970's a coalition was formed to determine and produce the data needed for health planning at the local, State and national levels. In the 1980's we shared the benefits of technological improvements to the health statistics systems.

Now as we enter the next decade, we have the skill and the will to turn this knowledge to helping the nation reach its health goals.

This year's conference program shows that we understand that we must provide the statistical and analytical base to formulate health goals, define obstacles, and measure progress.

With that brief overview, let's look more closely at the public health and health statistics challenges we face.

The 1987 PHCRS conference theme was data for an aging America. One in 8 Americans is now 65 and older (figure 1). In the year 2020 that will be 1 in 5, with the greatest increase for those 85 and older. We know that older Americans require a greater volume and diversity of health services. We also have learned that the over 65 population is not a homogeneous group with the same level of physical functioning and health care needs. America's senior population is a very diverse group with enormous differences in health status and health needs by age and socioeconomic status.

A different age group in the population has been struck by the Human immunodeficiency virus (HIV). Since it was first identified, some 97,000 individuals in this country have been diagnosed as having HIV; more than 56,000 have died. Spread primarily by high-risk sexual practices and sharing needles in IV drug use, AIDS has hit hardest among the young, urban, and minority populations.

In the past two decades we have been challenged by diseases which have complex interrelated causes. Heart disease, diabetes, hypertension, cancer and stroke are associated with an array of behavioral, environmental, and genetic factors. The behavioral causes of many major chronic diseases has meant that the public health community has sought to get people to examine the way they do a variety of things--what they eat, how they exercise, and even how they sleep. And that effort has been very successful.

Looking at important risk factors among adults males, we see a significant decline in such measures as elevated serum cholesterol. Hypertension is better identified and managed. And perhaps most importantly smoking is down (figure 2). And generally the same downward trends are observed for these risk factors among women (figure 3).

This decline in various risk behaviors is reflected in the mortality data. Deaths from heart disease were down 30 percent from 1970 to 1986; deaths from stroke declined by over 50 percent during that time.

Now the public health community is turning to other types of behavior. AIDS and other sexually transmitted diseases--which are also on the upswing--have meant that the programs aimed at changing or stopping disease-causing behavior have had to investigate the most intimate and personal aspects of a person's life. From the type of sexual practice to the number and type of sexual partners, the most recent surveys ask Americans to provide this information.

The health problem of the 1980's and 1990's also have their roots in societal behaviors. Substance abuse, pressure on family structure, and violence play a role. The newspapers as well as the statistical reports, show the impact of violence. In a special analysis prepared by NCHS, we examined international mortality patterns and trends for children and teens (figure 4). The homicide rate for teenagers in this country is nearly five times that in Canada and Australia, the next highest nations.

In looking at the health of infants--the persistent racial differences in mortality and morbidity are marked. Although infant mortality has declined for both groups, the mortality rate for black infants remains almost twice that for whites (figure 5). Provisional estimates show the 1988 infant mortality rate essentially unchanged from that of 1987, further evidence of the slowing in the rate of decline in infant mortality observed since the late 1970's.

For the overall population, the expectation of life at birth reached a record high of 74.9 years. However, life expectancy for black males is continuing the general downward movement observed since 1984.

The health care delivery system is changing. Only recently most surgery was performed in the hospital, most medical care delivered in the doctor's office. Today there is an array of health care settings, brought about in part by new technology and by new forms of payment and reimbursement for services. Surgi-centers, urgi-centers, hospices, and home health care now offer mainstream health services which compete with or complement the traditional health care establishments.

HEALTH STATISTICS CHALLENGES

Within the health statistics framework, events and developments have posed important challenges.

At the Federal, State and local level, resource constraints have impacted government programs across the board. Health statistics programs have struggled to maintain sufficient levels of funding just to keep ongoing data systems in operation while stretching to meet new data requirements.

Katherine Wallman, Director, Council of Professional Associations on Federal Statistics, describes declining resources as one of the major "stresses" on the Federal statistical system. She also points to other stresses we are familiar with: demands that statistical programs address a broader spectrum of health, economic and social issues; inability to divert resources from on-going data systems to support needed research and development in statistics; and a recognized limit to the burden which can be placed on the public for the sake of knowledge.

Pointing to another anomaly--while there is a concern in protecting the public from an undue burden there is a conflicting desire by the public, business, media and all data users for more information. Health information is a growth industry. Over the past two years, more health magazines than any other specialty magazine were created. Just check the local newsstand. Network and cable television consume and dispense vast quantities of health information.

So there is a public better informed, more willing and able to consider options and make choices on personal and national health issues.

MEETING THE CHALLENGES

How do we meet the challenges to public health and statistics? Luckily the problems point to the solutions--awareness to positive action.

First, we must plan, collect and analyze vital and health statistics in full awareness of the current and future public health issues. I hope this doesn't sound easy because I don't believe that it is.

The issues in public health often develop and unfold at a fast pace. AIDS is a good example. CDC established the first reporting system in 1983. From these data from locations across the country, education and prevention efforts were designed. NCHS fielded an AIDS knowledge and attitudes survey in 1987 and today there are 202 AIDS data bases in the Department of Health and Human Services. Agencies reacted quickly to the need for data on AIDS, often incorporating data items on HIV into existing surveys or questionnaires.

What is the next national health emergency? Is the past prologue to the future? How can we predict data needs when many of the public health issues are yet to be determined? We need to be studying trends and data from many sources and fields to develop our early warning system.

On the other hand, we need to be careful that the immediacy of health "emergencies" doesn't overshadow the need to deal with the long-term chronic diseases. A continuing health problem is no less important because of its familiarity than a newly-emerging phenomenon. In fact health statistics provides the best screen for evaluating previously unknown diseases and for establishing their real public health priority.

When information is available on the public health issues of the day, the next challenge is to portray and communicate that information in a way that is manageable and meaningful.

Sometimes this means developing a new analytical concept or tool. The Mortality Surveillance System developed recently at the National Center for Health Statistics illustrates this point. The MSS is a series of charts and text that each month will depict trends in provisional mortality data for selected causes of death and population groups. The topics for the MSS are chosen to represent important health problems on which current mortality data can shed light (table 1).

The goal of the MSS is to graphically present mortality data in a manner than permits timely identification of departures from mortality trends observed in the recent past. For example, looking at death rates for malignant neoplasms of respiratory and intrathoracic organs for females 45 to 54 years of age, we see that the monthly death rates have been rising slowly but steadily for the past decade and for the first 9 months of 1988 fell within the prediction intervals of a model estimated on the basis of provisional monthly death rates from 1979 to 1987.

However, the rates for all but one of the first 9 months were below the line predicted by the model (figure 6).

Let's look at the model using data for males. The trend of death rates for males 45-54 years of age for malignant neoplasms of respiratory and intrathoracic organs had been increasing steadily during this century but has been downward during the past decade. However, in most of 1988 the monthly death rates were above the line predicted by the model (figure 7). And we will have to watch whether this trend is leveling off.

Mortality data from the vital statistics system continue to be one of the most accessible means of identifying and monitoring health problems, and the new MSS will add to this system's importance as a tool for public health policy.

Helping to meet the challenges to the statistical system is automation. For example, at the Center we have automated much of the data collection in the mobile examination centers of the Health and Nutrition Examination Survey. Interviewing and examining over 30,000 Americans in 88 locations across the country and quickly producing and disseminating those findings has virtually mandated the fullest possible use of automation.

The AIDS Knowledge and Attitudes survey fielded in August 1987 was implemented by interviewers using lap-top computers. This was the first instance of a national health survey automating data collection in the household. An NCHS team is now working on automating data collection for the extensive health promotion and disease prevention survey, the major special component of the 1990 National Health Interview Survey.

Automation and the application of new technology has strengthened our capabilities to meet the demands on health statistics. So has expanding our universe of partners. We have formed cooperative ventures--collaborative arrangements so that the best teams can address health statistics and data collection issues.

Since becoming a part of the Centers for Disease Control, the number of NCHS working partners has grown. Working with programs in chronic disease prevention, injury control, and surveillance has brought new dimensions to the statistical work of NCHS and we believe new quantitative resources to other CDC programs.

The National Health and Nutrition Examination Survey is a good example of how a single survey can meet the data needs of many programs. This approach makes good use of limited data collection resources, allows individual programs to incorporate their data requirements in a state-of-the art survey planning and field operation, and promotes a synergistic relation between those who direct health research and program activities with those who direct health statistics programs. This collaboration is not without its cost. The planning process is complicated, as many data needs must be considered and integrated. Compromises must sometimes be made in the types and quantity of data which can be collected. But, on balance, working with the right set of partners is rewarding and productive.

Our partners certainly include the academic community. Publications and articles are often produced in collaboration with academic researchers. The visiting scientist program brings faculty members into the Center for special projects. The University Visitation Program--a speakers bureau of NCHS staff--offers universities an opportunity to hear about and from NCHS on a wide array of topics.

A long-standing cooperative agreement is the relationship between State vital and health statistics programs and NCHS. The Nation's vital statistics depend upon the successful maintenance and improvement of that system. Just over the past year, together we have implemented revised standard certificates to collect important new information on births and deaths. With every state participating, we have created a national file of linked birth and death records--to expand our knowledge of the causes of infant mortality. The latest development improves the quality of provisional mortality statistics, with 100 percent rather than just 10 percent reporting of death records on a monthly basis.

Sometimes the best data collection will require a new set of collaborators. Conducting a pilot study and pretest of the National Household Seroprevalence Survey, NCHS and CDC have worked closely with community advisory panels. In Allegheny County, Pennsylvania and Dallas County, Texas, the cooperative venture has expanded beyond the traditional partner--the public health department--to encompass citizen leaders throughout the community. For this survey and others which address politically and socially sensitive topics, it is not only necessary to know what constitutes good science but what is politically acceptable to the community at large and to the affected populations.

Turning to another point, many statistical agencies are finding it necessary to set priorities and closely examine the relevance of traditional data sets.

The resources for health statistics at virtually every level of government are limited. To accommodate new data needs, some long-standing data programs may be cut; some traditional data sets, dropped. NCHS made a hard decision in that light involving the marriage and divorce statistics program. Although there is ample proof of the demographic and planning uses of the marriage and divorce data, to accommodate more pressing health data needs for Fiscal Year 1990 we may have to curtail this data system for that year. An open review of the needs and alternatives for national marriage and divorce data will be held in two special sessions on Tuesday afternoon.

Hard decisions for NCHS--hard decisions for our users. But to fail to reach out and meet the new data needs, means that the health statistics system doesn't evolve, respond, or serve the best needs of our research and public health communities.

Finally the health statistics system cannot merely respond to public health data needs, but must help formulate data and program goals. The national and state agencies working to develop the Year 2000 Objectives illustrate that point. The analyses of current health status as well as the development of realistic goals provide the foundation for the Year 2000 Objectives. Not only are we responsible for

Priority Area 21 to improve surveillance and data systems, but we also have a significant role in each of the 20 health goals. Only if the expertise of health statistics programs are joined with policy makers will the full potential of this effort be realized.

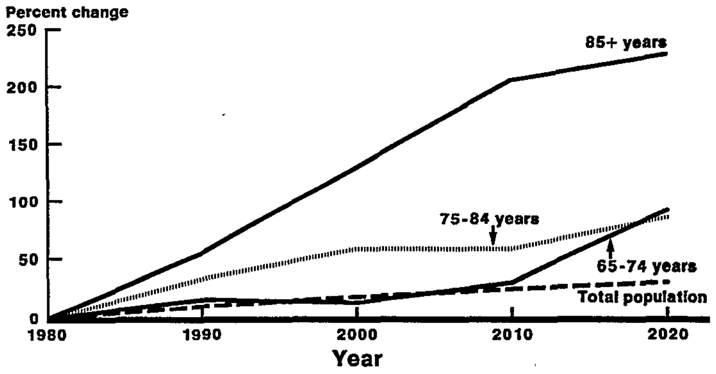
PHCRS--A FORUM TO ADDRESS THE CHALLENGES

The program of the 1989 Public Health Conference on Records and Statistics recognizes these issues. There are opportunities to assess and review the 1990 objectives and the implications for the year 2000 Objectives. There are sessions to address methodological issues in measuring quality of life and life styles. Speakers will share their research on targeting services for minorities, the disabled, the aged and the homeless. HIV, injuries, chronic disease, and infant mortality--the conference includes the major public health concerns.

We want to thank you for coming to the conference. Your participation is essential to forging the effective cooperative ventures I mentioned and to meeting the challenges for public health statistics in the 1990's.

Figure 1

Projected change in elderly population 1980-2020

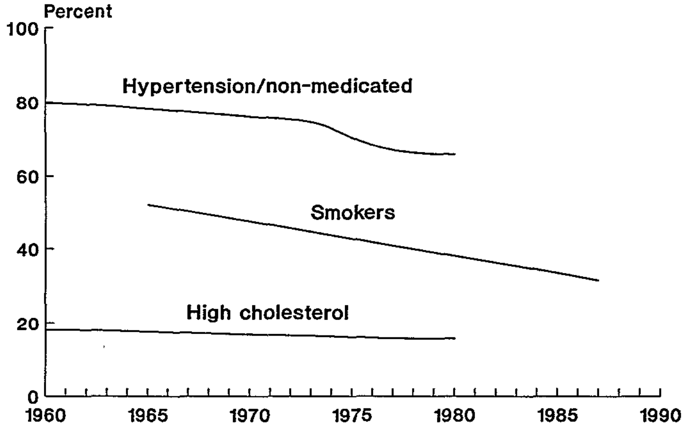


SOURCE: Joan F. Van Nostrand, "The Elderly LTC Population, Demographics and Projections," Primer Session at the National Conference on the Complex Cube of LTC.

Figure 2

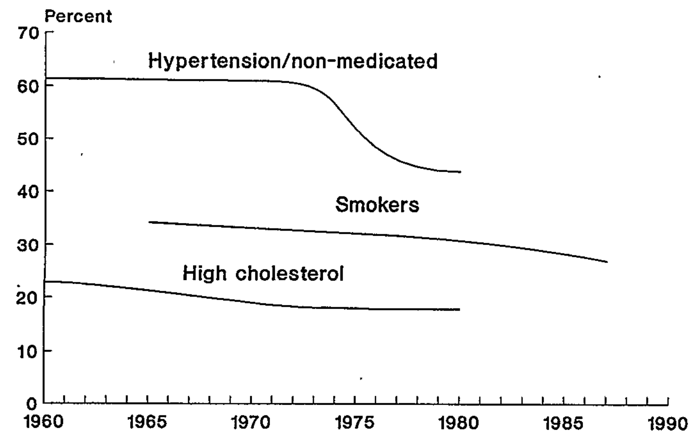
Trends in risk-factors

Adult males



SOURCE: NCHS: HES,NHANESI&II,HIS

Figure 3
Trends in risk-factors
Adult females



SOURCE: NCHS: HES,NHANESI&II,HIS

Figure 4
Death rates from homicide for teenagers 15-19 years of age, 1985

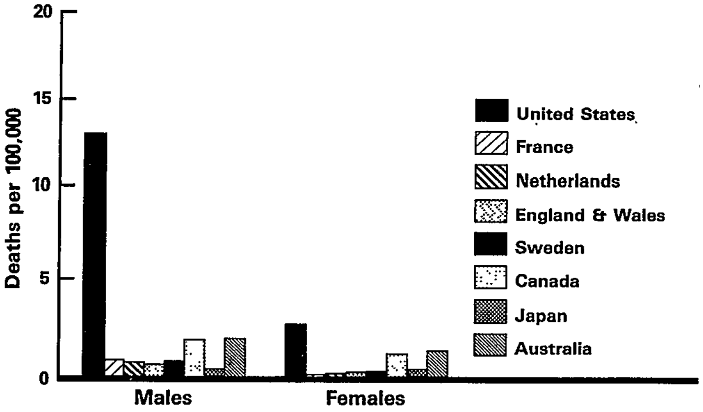


Figure 5
U.S. infant mortality rates, 1980-86

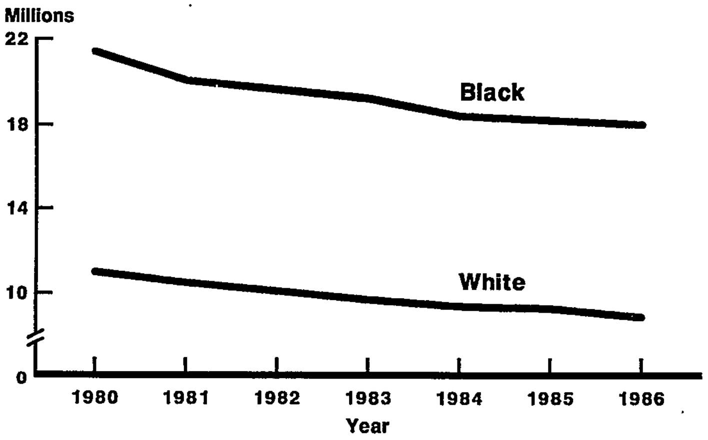


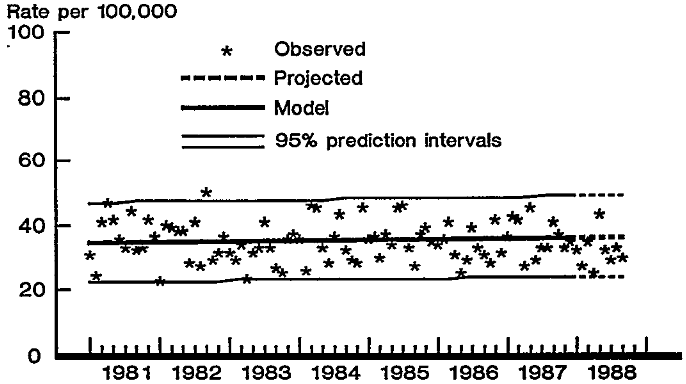
Table 1

Mortality Surveillance System

- Pneumonia and influenza
- Diabetes
- Homicide
- Cirrhosis
- Septicemia
- Genital cancers
- Breast cancer
- Heart disease
- Respiratory cancer
- COPD
- Accidents
- Digestive cancers
- Stroke
- Motor vehicle accidents

Figure 6

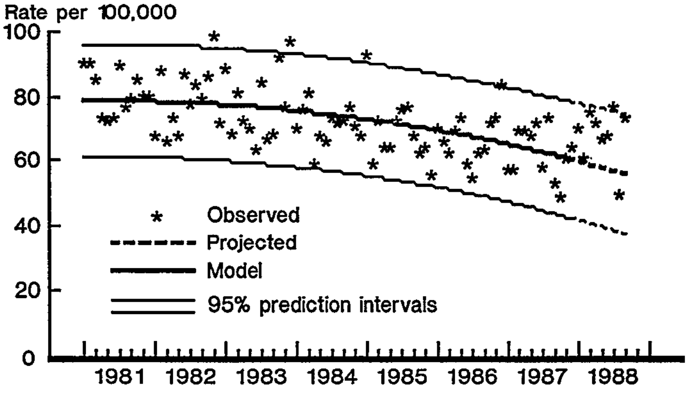
Death rates for malignant neoplasms of respiratory and intrathoracic organs for females 45–54 years of age, by month, 1981–88



SOURCE: NCHS, Provisional data from the National Vital Statistics System, 1981–88

Figure 7

Death rates for malignant neoplasms of respiratory and intrathoracic organs for males 45–54 years of age, by month, 1981–88



OPENING CEREMONY

George Hardy, Jr., M.D.
Centers for Disease Control

(Not available for publication)

THE CHALLENGE FOR PUBLIC HEALTH STATISTICS - LESSONS FROM THE INSTITUTE OF MEDICINE REPORT ON THE FUTURE OF PUBLIC HEALTH

Hugh H. Tilson, M.D., Burroughs Welcome Company

To launch the last decade of the 20th century and to prepare the Statistics and Epidemiology Community for the 21st, a series of happy convergences of efforts and energies from several sectors have occurred over the past year. None has been a more auspicious event, and clearly none has provided greater challenges and opportunities for public health than the arrival in November, 1988 of the long-awaited report of the Institute of Medicine Committee to Study the Future of Public Health. This critical effort precedes by two years the two other major landmark activities, currently underway: the reassessment and reframing of the nation's health promotion, The Objectives for the Nation for the Year 2000, coordinated by the Public Health Service; and its companion effort to develop an implementation strategy using the approach of the Model Standards for Community Preventive Health Services under the leadership of the American Public Health Association. Thus, the content of the IOM Report provides the framework and prepares the context for these two subsequent important activities. The IOM Report is noteworthy from a series of perspectives: the forum in which it was created; the approach through which it was crafted; the conceptualization upon which its subsequent contents were framed; and a series of bold recommendations which bear directly upon the statistics and epidemiology community and which should provide us with the challenge and opportunity we need to help to realize the potential of our field.

The Forum: The National Academy of Sciences was chartered by an act of congress in 1863. It represents an august group independent of, and at arm's length from, government with the specific mandate to study and make recommendations upon issues of importance to our society. The Institute of Medicine is the "Junior Partner" of the affiliated organizations of the National Academy of Sciences having been founded in 1970 with the charge of studying and making recommendations upon issues necessary for the fulfillment of our society's committment to the health of its people. The Institute Membership comprises 500 highly select leaders in the field, at least 25% of whom come from walks other than medicine and health and has conducted many landmark studies which have shaped our nation's health policies over the years. The recommendations of the Institute of Medicine come with the endorsement of some of society's greatest minds both from among the membership and from among the extraordinary diverse and well-qualified groups they assemble *ad hoc* to address specific questions.

The Future of Public Health Report is no exception. It was crafted by a committee of 22 members representing all walks of society with direct interest in and investment regarding the future of public health ranging from federal, state, and local appointed public health officials to state and locally elected officials, private practitioners, academics in health, economics, medicine, and law, and the private sector. The Committee owes a great debt to its chair, himself a well-respected member of the Statistics Community, Dr. Richard Remington and a remarkable staff from the IOM, headed by Mr. Karl Yordy.

The Approach: The Institute of Medicine Study was itself extraordinarily creative. While any number of approaches could have been used to depict the Future of Public Health for America, the Committee determined to employ political science research techniques. Site visits, involving all panel members on at least one, were conducted in six states involving over 350 participants. Site visitors were urged to use the same format in each setting and a consistent approach in each interview. Specifically, we approached the question of public health as one which remained unanswered and asked people first to describe their own concepts of public health; and then, asked them to provide specific examples from their own experience, using one or more public health conditions as a "tracer" or indicator to help us to understand how the public health system was functioning in their areas. For example, participants would be asked: "What is your area doing in the arena of adolescent pregnancy? How was it decided to use this approach? Who was involved in determining it? What else needs to be done? and How would you go about getting it done in this community?"

Six states were selected for site visiting (representing as broad a diversity as possible with such a sample), particularly including states in which there were strong or less strong local components; mostly state-centered vs. local centered managementof local public health affairs; large urban and/or rural communities. States selected were South Dakota, Mississippi, California, New Jersey, West Virginia and Washington. Fundamental agreement was reached to give site visitors full access to a broad range of potential sources of information about public health - political, professional, academic practice, citizen advocate and "non-health" alike. Exposure was requested both at the state and local level. And in return full protections of confidentiality of information were gathered and of the sensibilities potentially involved were assured.

The Committee of course, also developed information from a series of other primary and secondary sources. Regional hearings were conducted in Boston, Chicago, New Jersey and Las Vegas, to which invitations were widely distributed and which testimony from literally hundreds of persons was obtained. The Committee broadened its perspective with a site visit to Toronto to view public health under conditions of universal entitlement to medical care. Written input was also widely requested and received. The Committee itself commissioned original papers and presentations, scanned hundreds of professional articles and other secondary sources in attempting to build on an extraordinarily broad base of prior knowledge and insight into the field while still being unconstrained by prior conceptions and misconceptions.

The Impact: The emergent report is a truly remarkable document. Following its publication (after a considerable editorial review period) in

November, 1988, it became an instant media event at least in part because of some of the rather provocative observations about major problems in public health today and the threat they pose to the health of the public. After all, it is an important publication from a prestigious group, and it highlights the importance of the field of public health today and the urgency with which its problems need to be addressed. It portrays the threats to the health of the public which continued negligence and persistence of what was termed the "disarray" in public health would pose. And, it ends with an impassioned plea for "rescuing public health...now and for the sake of future generations."

In plain talk, then, this document, emerging from a respected group and highlighting problems in our field, poses an enormous opportunity for people within the field who wish to see public health improve to build their advocacy upon a shared and credible perception.

The Content: The report is not long (6 chapters, 4 technical appendices, and a total of 225 pages altogether). And, it is certainly not complicated! While it was the Committee's original intent to come up with three or four simple direct and memorable recommendations, the more we looked the more things we found which needed to be addressed.

In the interests of time (and space in this publication), let me resist the temptation to try to be encyclopedic. Every one of the recommendations is important and worthy of your consideration. Therefore, my fundamental recommendation is that anyone concerned with the future of public health, from any perspective - government employee, legislator or policy-maker, public or private advocate, or citizen concerned about preserving health and dignity - should have a copy of this report. Everyone will find in the report inspiration for action. While the report contains literally hundreds of "nuggets" of recommendations based upon literally thousands of similarly priceless findings, they all boil down to one fundamental message which needs to be telegraphed again and again by all who are concerned: "This report conveys an urgent message to the American people. Public health is a vital function that is in trouble. Immediate public concern and support are called for in order to fulfill society's interest in assuring the conditions in which people can be healthy. History teaches us that an organized community effort to prevent disease and promote health is both valuable and effective. Yet public health in the United States has been taken for granted, many public health issues have become inappropriately politicized, and public health responsibilities have become so fragmented that deliberate action is often difficult if not impossible." (page 17)

- Public Health is Vital: The report contains a well-crafted and thorough chapter on the history of public health as well as an extensive outline in the Appendix of the features of the US public health system. The first chapter presents in detail, case after case of the success stories which document just how important public health functions are.

- Public Health needs Governance: Public health is an essential component of a civilized society's responsibilities to govern and protect itself; and public health in America is inextricably intertwined with American governance. While many of us had originally conceived this report as a broad call for collaborative action among many contributors in all sectors, what became clear early in the development of the report was that an even more urgent call was needed for action to restore the fundamental principles of government which, for a series of reasons over the past 50 years have been eroded and, in the process, have eroded public health. These are presented in considerable detail in the report, but boil down to an evolving current mistrust of and disdain for government and, with it, a lack of constituency for many of its most vital and venerated institutions, public health among them.

- Public Health is in Disarray: Here is the "punchline" of the report. And you can bet it wasn't entirely popular, particularly with people who have spent their entire professional lifetimes trying to hold together this vital and fragile apparatus and to build in the face of adversity. Most of us fall into that category. And I am proud, despite the fact that my salary is currently paid by the private sector, to be able to call myself, to this day, a fulltime Public Health Worker. Public health is an honorable and vital profession, one of which we all must be proud. But it is important not to let that cloud our objectivity. The system which is so vital to help society to fulfill its promise to its citizens of creating the context in which they can be healthy, certainly is in disarray. While you could quibble with whether the IOM Committee actually saw a real cross-section in the six states and among the thousands of people interviewed and/or presenting their perspectives at four public hearings, the "evidence" was really quite overwhelming despite the notable exceptions to the contrary - centers of brilliant excellence also visited by the Committee. We saw in case after case, in place after place, on face after face, the tell-tale signs of disarray - inadequate financing; high turnover and too few properly trained professional staff; inadequately prepared staff among those trained; weak and ambivalent community support and a political apparatus fragmented by non-public health issues and intimidated by a tax-weary electorate. Using our participant anthropology approach, asking people inside and associated with, as well as outside the flow of public health apparatus for their own definitions and visions, we repeatedly found an absence of crispness of definition of vision. Again and again we heard explanations of how this state of affairs could have happened - presented only in its most superficial detail even in the report - trends such as: progressive reduction of federal financial support and technical assistance; increasing Medicare and Medicaid budgets draining residual financing capacity and will; and redefining what public health does as services responsive to where the money is, in this case, direct personal medical services for those with third-party reimbursement; and with this, an increasing perception from outside the public health sector, that public health is "just another provider" in direct competition with the private sector. Particularly compelling were views that mental health and environmental health, two critical dimensions of community health services (after all, they do have the same last name) had split off from the public health family and formed their own separate constituencies, bureaucracies and funding basis - the health and preventive aspects of which had also suffered under similar circumstances in recent years.

- Government Has Roles Which Can't Be Delegated: The Committee found that most public health services and protections are provided not by government, but by a complex fabric involving many factors and many actors in many corners of society. The way these aspects manifest will differ in every community based upon the unique mix of available resources and the unique manifestations of problems inherent to public health. What is absolutely unambiguously clear in the report is the Committee's conviction that certain aspects of public health represent the unique contribution of government - functions which must be available to every citizen in every community; and functions which cannot be delegated! The report presents a new conceptualization of government's role in public health, with extensive theoretical and practical justification and definition beyond the scope of this presentation. In summary, however, three basic functions of public health which are the responsibility of government are presented, defined and described in the report. These three functions are essential to the reconceptualization of public health and they are commended to every person reading my words. The essential functions of government are: assessment, assurance, and policy development. The renewed call for an "assessment" function redefines basic public health surveillance and vigilence activities understood and embraced by everyone in the public health statistics community. Let me come back to that in a minute. "Assurance" means that while it is not possible and, in our culture, not desirable for government to be the provider of all health services for all people, it is nevertheless vital that government occupy the role of ensuring that all people in all communities have access to the necessary services to secure their health - everything from the basic preventive services of immunization, family planning and health education, to the necessary access to early medical intervention to prevent progression of disease. The third function which only government can provide is the development of policy at the community level. The need for enlightened policy, and the policy development apparatus which must underly it, is so fundamental to the public health statistics community that it scarcely requires any further discussion. In describing and analyzing, reporting, interpreting, and applying public health statistics, communities are enabled to develop appropriate strategies to address real problems and establish priorities across conflicting objectives.

- All Levels of Government Count: The report also revisits a reality similarly clear to the public health statistics community - that public health at the national level is different from that at the state and local levels; that each level of government has its own unique contribution to make and role to play; and that the tri-partite model of assurance, assessment, and policy development has its own applicability, but plays out uniquely at each level. The report revisits the fundamental concept that the United States is a confederation of states which, under the Constitution, bear primary responsibility for fulfilling these functions. And, again, with considerable detail, the report rejustifies the need for national leadership in the conduct of affairs of national concern - research; national syntheses and direction; provision of unique resources, including technical assistance; and redistribution of resources. The last of these is especially important to the statistics community. The report validates the concept of the creation of national objectives and the allocation of national financial resources to state and local delivery systems to enable the nation to progress towards those objectives. Particularly poignant to an old "public healther" like myself, was the remarkable validation in visit after visit of the extraordinary role which the Centers for Disease Control play in providing unique resources in the area of statistics and technical assistance in epidemiology! And, finally, in this brief overview, while states have prime responsibility for assuring that necessary public health services are in place, the report reaffirms that public health must be delivered at the community level. The report recognizes that "because of great diversity in size, powers, and capacities in local government, generalizations must be made with caution." (page 9). It then issues as strong an advocacy for local public health delivery as possible: "no citizen from any community, no matter how small or remote, should be without identifiable and realistic access to the benefits of public health protection, which is possible only through a local component of the public health delivery system."

The Special Relevance to the Statistics Community: While all of public health should revel in this rediscovery of the basic importance of our field and the clarion call for new constituencies and the rekindling of old flames of support, none should be more enthusiastic than the statistics community. For the report is replete with reaffirmation of everything we believe in. The rediscovery of one of the three vital components of public health which must be provided by government and must be available to every citizen in every community - the "assessment" function - is fundamental and far-reaching. The report is unambiguous in its call for assessment: "The Committee recommends that every public health agency regularly and systematically collect, assemble, analyze and make available information on the health of the community, including statistics on health status, community health needs, and epidemiologic or other studies of health problems." (page 7). While recognizing that that does not necessarily involve a fulltime statistician in every tiny local community public health department, the Committee nevertheless unambiguously endorses that no agency is "off the hook"; "Not every agency is large enough to conduct these activities directly; intergovernmental and interagency cooperation is essential. Nevertheless, each agency bears the responsibility for seeing that the assessment function is fulfilled. This basic function of public health cannot be delegated." (page 7)

Several specific constructs of central interest to the public health statistics community are embraced in the report. The report emphasizes the need for creation of measurable objectives at the national level, translated into objective-setting, work planning and policy development efforts at the state and delivery with similarly measurable - and measured - objectives at the local levels. Rather than attempting to "rediscover the wheel," about just what services public health includes, the report recognizes the extraordinary body, over more than a decade of work, conducted by the Working Group on Model Standards for Community Preventive Health Services, currently convened under a cooperative agreement between the CDC and the American Public Health Association. In verifying the need for standards, once again the Committee underscores the role of the statistics community in helping society to deliver on its promise, with such specific recommendations as: "that each state establish standards for local public health functions, specifying what minimum services must be offered, by what unit of government and how services are to be financed. States (unless providing local services directly) should hold localities accountable for these services and for addressing statewide health objectives using the Model Standards: A Guide for Community Preventive Health Services as a guide." Therefore, in the interest of space, let me simply refer you to the two additional documents which are currently under revision - The Objectives for the Nation for the Year 2000 (revisiting those dimensions already presented in "healthy people" and updating our vision for the Year 2000) and the Model Standards: A Guide for Community Preventive Health Services, (which is being revised as a direct parallel implementation compendium for the Objectives 2000, to be reissued at the same time as the new objectives book as "Volume II"). These two documents, currently under development, will provide the statistics world outline for implementation of the IOM report.

There is much else of interest and relevance to the statistics community in the report but time simply prevents discussion. For example, there is an extensive consideration of education for public health; a consideration of "special linkages" with health-related activities, often relegated to other corners of government; and, of course, some suggestions about financing and capacity-building. But I would be remiss if I did not call to this group's attention another unambiguous endorsement for the development of rigorous and useful statistical system in every corner of this new public health enterprise. The report, recognizes that part of the "disarray" has resulted from the loss of a constituency; this has resulted from a lack of clear indicators which can be understood, valued and embraced by those who would otherwise support the development of a strong public health enterprise. Therefore, the report calls for: "A uniform national dataset should be established that would permit valid comparison 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 Services." (page 13). And, as if that weren't enough, the need for an organizational framework for such activities (if you wanted to call that the CDC and State Centers for Health Statistics, it would be okay by me) is also recognized: "There should be an institutional home in each state and at the federal level for the development and dissemination of knowledge, including research and the provision of technical assistance to lower levels of government and academic institutions in voluntary organizations." (page 14)

The Challenge for the Health Statistics Community: The Institute of Medicine report on "The Future of Public Health" provides an opportunity which the field of health statistics has not seen in decades. Issued by a highly respected and impartial group bearing the support of the Public Health Service and the Kellogg Foundation, and carrying a forceful message to multiple constituents of the need to support public health services, the report should provide basis for program and capacity-building, resource allocation and the establishment of priorities at every level of society and for many years. It may be entirely without precedent that a report from the "outside" has provided such strong support for the essential role which the "assessment function" - the embodiment of statistics and epidemiology in public health application - has received in this report.

However, it is <u>only</u> a report. Action and implementation planning have already begun at the national level among prestigious organizations within the public health sector. However, finding a way to develop a similar implementation support in every state and locality by every group involved will require the concerted and thoughtful efforts of everyone reading this summary. But, look around you. You will not be alone. Your response to this report has been gratifying so far and it has only just begun. And, you won't have to look very hard to find me in the ranks either - pursuing the shared mission - a new mission articulated for the first time in this landmark report: "fulfilling society's interest in assuring conditions in which people can be healthy".

HEALTH PROMOTION AMONG MINORITIES

Herbert W. Nickens, Association of American Medical Colleges

When I was in medical school in the early 70's we were trained that race was presented as a part of a good history and physical. We always led off with a phrase like "...this is the 3rd University Hospital admission for this 57 year old Black male ..." It was never explained well why race was significant and I always felt uneasy about the relevance of the information. No one in Philadelphia in that era worried much about other races or ethnic groups. The world was white and non white (i.e. Black).

Of course studies have now been done that show that racial data in a case presentation is very powerful and that if you present the same facts but just change the race, diagnostic and disposition decisions by clinicians also change.

When I first travelled to Europe I was often asked about my heritage. I would explain that I was American, and then if further questions were asked, that I was a Black American. To most Europeans this made little sense since I didn't look like their notion of an African American and yet despite the phenotype, being a Black American was, and is, a reality for me.

I offer this preamble because this concept of "minorities" is a highly charged yet problematic one in America. It means not of the majority, not white, that is, not of stock from Ireland, England, France, Italy, countries of Eastern Europe etc.

And who are our U.S. minorities? Well, they are from the "other" stocks, and are sometimes referred to as "people of color".

Our current "crazy guilt" of racial and ethnic classifications draw their current, their power, from the worldview generated during the rapid expansion over the past few hundred years of Europeans into Africa, South America, the East and into the Americas. That's why it was particularly ironic that during that trip to Europe people there didn't understand that by my being there, confusing them, I was just closing the circle they began.

Now why am I going through all of this? The reason is that our whole American enterprise of health program design, data gathering, and analyses is shaped by considerations such as I've just described. Categorizing our populations by race has been an important and all too often invidious preoccupation throughout our national history. We cannot sensibly discuss disease or its prevention among minorities without keeping all of this heavy baggage in our minds.

We have four generally recognized minority groups in the U.S.: Asian/Pacific Islanders, Blacks, Hispanics, and Native Americans. These four groups are highly different from one another, there is extreme diversity within them, and within some groups there is much more diversity than others. For example, there are hundreds of Indian tribes, in some cases genetically and culturally very different. A discussion of the diversity among minorities is itself sufficient to take up an entire conference. What minorities in the U.S. generally have in common is some history of bias and exclusion directed toward them, some degree of economic and social powerlessness, social marginality, generally a lower median income, and lower educational attainment.

Minority health status is also on average poorer than that for White Americans, though again diversity is the rule. The definitive work on minority health status remains the 1985 Secretary's Task Force on Black and Minority Health (Table 1).[1]

Table 1. Net Excess Deaths by Minority Group[1]

	BLACKS	HISPANICS	NATIVE AMERICANS	ASIANS
U.S. Population[a] (% of total)	26.1 (11.5%)	14.5 (6.5%)	1.5 (<1%)	3.7 (1.6%)
Excess Deaths[c]	58,942	≈ 7,000[b]	1,042	-819
Excess/Total Deaths(%)[c]	42%	≈ 10%[b]	22%	-14%

a) 1980 U.S. Census Population in millions.

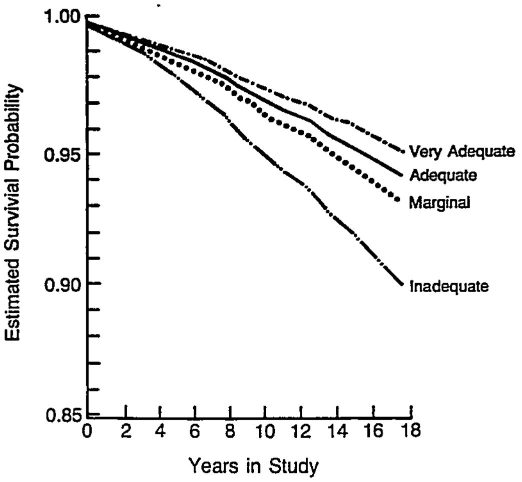
b) These are rough estimates made from Texas surname data, and Mexican/Cuban born data. They are provided to give some idea of the order of magnitude of excess deaths in Hispanic populations ≈ = approximately.

c) Excess deaths are calculated as an average of the years 1979-1981. Excess deaths = (the number of deaths actually observed prior to age 70) minus (the number of deaths which would be predicted when age and sex specific death rates of the U.S. white population are applied to the minority population)

One of the variables that talking about minorities leaves out is social class. As one of my sociology professors used to say: "social class is the most variance gobbling factor we know". Poverty kills. It's always been true (Table 2).[2]

We have never been entirely comfortable with social class distinctions in our avowedly egalitarian country. I was not trained to begin

Table 2. Eighteen-Year Survival of Alameda County, California, Residents by Family Income[2]



medical case presentations by, "this is a 57 year old social class IV male", and yet that would have made a lot of sense.

Class and race/ethnicity must both be considered and neither is a simple phenomenon. You will recall the dramatic difference in Black vs Hispanic health status yet Blacks and Hispanics have similar poverty rates.

What does all of this have to do with health promotion/disease prevention? A lot.

There is a great deal we don't understand about minority health status. Low birth weight and infant mortality among Blacks is a good example.

But here I must make a distinction between politics and science. There is a great deal that we could do based on current knowledge to improve minority health status. What we lack is the political and moral fiber to do so. It is inconceivable that we have infant mortality rates compared to those in third world countries within hailing distance of the U.S. Capitol. Our national failure to act is not lack of money, it is our decisions about how to spend that money.

Yet I would also say that the extent to which we as a nation have extended and continue to extend eligibility for maternal and child care, particularly under Medicaid, is because of the overwhelming biostatistical case that has been made that maternal and child health services work and that they save money.

I also could go through a variety of risk factors and preventive services and describe how we have failed to enact behavior change campaigns and have failed to enable access to health care which would reduce disease rates among specific minority populations. I am not suggesting that improving minority health status would be easy, but we also have not tried hard enough or consistently enough .

Overall, I must confess I am pessimistic about the likelihood about making substantial progress in minority health by the Year 2000. As you know death rates for Blacks are moving in the wrong direction, with death rates <u>increasing</u> in the past two years for which we have data.[3] Our data for Hispanics are so inadequate, I'm not sure we'd detect change should it occur.

And now AIDS, of course, is hitting Blacks and Hispanics at about 3 times the rates of whites, forcing us to wrestle not only with race/ethnicity, and social class, but also with variance by HIV transmission categories: homosexual, heterosexual, IV drug users, and perinatal.

One final point: it is critical that the number of minorities who are "card carrying" epidemiologists and biostatisticians increase. Simple equity requires this. Beyond simple equity, however, the formation of research questions is an intensely personal and culture-dependent enterprise. The fiasco a year ago in which the Federal HIV household serosurvey in Washington, DC had to be withdrawn was ultimately because of insufficient sensitivity in the way the enterprise was organized and implemented. Beyond this one example, there are many studies that are never done because the world-view and preoccupations of the researchers are elsewhere. Diversity among researchers, like randomization in a clinical trial, is protective against bias. I would speculate that our severe data limitations regarding minority populations (particularly non-Black minorities) would not exist if we had racial/ethnic diversity among those responsible for data collection systems.

Similarly, it is critical that those who design and execute health promotion/disease prevention programs for minority populations include minorities in decision making positions. AIDS has made this more clear.

Given the demographics of the world and our country, pluralism in the final analysis, is the future. If you live in areas such as California that pluralistic future is now.

Our only real decision is whether our future racial/ethnic diversity becomes richness or strife.

1. Report of the Secretary's Task Force on Black and Minority Health: Vol. 1, Executive Summary, Washington, D.C., U.S. Department of Health and Human Services, August 1985.

2. Kaplan, George A. et al. Socioeconomic Status and Health. In: Amler RW, Dull HB, eds. Closing the Gap: The Burden of Unnecessary Illness. New York:Oxford University Press,1987:125-129.

3. National Center for Health Statistics: Health United States, 1988. DHHS Pub. No. (PHS) 89-1232. Public Health Service. Washington. U.S. Government Printing Office, Mar. 1989.

HEALTH STATUS AS A MEASURE OF HEALTH PROMOTION AND DISEASE PREVENTION

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During the past 20 years the measurement of health status or health related quality of life has progressed from measures of disease-specific morbidity, and activity limitations and bed disability days to multi-dimensional health profiles and indexes that permit the integration of health-related quality of life across a variety of domains. These indexes can provide an overall measure of health of a population or of an individual. They are now being widely used in the clinical and clinical research arenas. But they have yet to be applied in the general assessment of the health of populations though many of them were designed for that purpose. So, before we proceed to discuss the usefulness and applicability of health status measurement to health promotion and disease prevention we should all be aware that these measures have yet to be used to determine the health status of the general population where the focus of interest is on the more traditional assessment of burden of illness and not on health promotion and disease prevention.

Overall health status includes a number of concepts. Some are well measured while others still present challenges for the future. As you can see from Figure 1, health status includes duration of life, impairment, functional status, health perceptions, and opportunity. We have reliable and valid measures of health status based on function, impairment, and death; but have much to do in the areas of opportunity and fitness. These areas may be especially important for assessment of health promotion and disease prevention.

I will focus my presentation on three issues related to the use of health status measures for assessment of health promotion and disease prevention, and I will conclude by discussing problems that may be especially pertinent for the next decade. The three issues I will focus on to start with are:

* Combining quantity and quality of life

* Measuring positive health

* Linking process and outcome

<u>Combining quantity and quality of life</u>. A major challenge in the next decade will be to forecast and monitor the health and quality of life outcomes influenced by prevention and health policy in general. These outcomes must combine <u>quantity</u> and <u>quality</u> of life so that remaining years of life are adjusted for positive or negative health. Two methods are currently used to integrate quantity and quality: active life expectancy and quality adjusted life years.

Active life expectancy is a calculation of life expectancy at a particular point in time reduced by the number of years of expected disability. Thus it provides the number of years of life free of disablement. The appeal of this measure is its ease of calculation. Its disadvantage is that it assumes that once disability occurs there is not return to disability-free life or some less-impaired functional state. And, we know that many impairments and disabilities are time limited. Thus, this index may be most appropriate for those relatively close to the end of their lives - the very old and those with diseases that are known to shorten life expectancy substantially.

Quality-adjusted life years (QALYs) is an index that discounts remaining years of life by the amount of dysfunction experienced. The discount rate is a weight that can be derived in a number of ways including empirical studies of preference, expert judgements, and literature reviews. QALYs are appealing because they permit the "discount rate" or weight to vary with the impairment, they can incorporate social preferences or individual preferences, and they allow each year or time period to be valued or weighted separately.

Nonetheless, there are problems with QALYs. First, if QALYs are to be used to compare different programs or policies, then the preference weights used to calculate the QALY must be the same for the different programs. Second, weights must be based on actual preferences not on assumptions. Many of the publications that use QALYs to estimate the cost-effectiveness of health promotion or disease prevention <u>assume</u> a weight. For example, Hatziandreu, in an article published in the AJPH last year, <u>assumed</u> that each year following a non-fatal form of coronary heart disease was equal to .8. The data on which he based that assumption is scant and the weight could have affected his conclusion. Third, QALYs must be calculated for several time periods subsequent to an index event so that the weights applied to each year accurately reflect the pattern of dysfunction or impairment. Someone with Alzheimer's disease will have a quite different pattern than someone with arthritis or chronic lung disease. And, these patterns determine the overall QALYs score. In assessment of health promotion and disease prevention, these differing patterns become critically important. Modeling patterns of

Figure 1
CONCEPTS AND DOMAINS OF HEALTH-RELATED QUALITY OF LIFE

Concepts and Domains	Disadvantages
OPPORTUNITY	
Social or cultural handicap	Disadvantage because of health
Individual resilience	Capacity for health; ability to withstand stress; reserve
HEALTH PERCEPTIONS	
Satisfaction with health	Physical, psychological, social function
General health perceptions	Self-rating of health; health concern/worry
FUNCTIONAL STATUS	
SOCIAL	
Limitations in usual roles	Acute or chronic limitations in social roles of student, worker, parent, household member
Integration	Participation in the community
Contact	Interaction with others
Intimacy	Perceived feelings of closeness; sexual
PSYCHOLOGICAL	
Affective	Psychological attitudes and behaviors, including distress and general well-being or happiness
Cognitive	Alertness; disorientation; problems in reasoning
PHYSICAL	
Activity restrictions	Acute or chronic limitation in physical activity mobility, self-care, sleep, communication
Fitness	Performance of activity with vigor and without excessive fatigue
IMPAIRMENT	
Subjective complaints	Reports of physical and psychological symptoms, sensations, pain, health problems or feelings not directly observable
Signs	Physical examination: observable evidence of defect of abnormality
Self-reported disease	Patient listing of medical conditions or impairments
Physiologic measures	Laboratory data, records, and their clinical interpretation
Tissue alterations	Pathological evidence
Diagnoses	Clinical judgments after "all the evidence"
DEATH AND DURATION OF LIFE	Mortality; survival; longevity

ADAPTED FROM PATRICK AND ERICKSON (1988B)

change based on longitudinal studies or prudent analysis of cross-sectional studies is one of the activities we must begin.

Measuring positive health. Measures of health status traditionally concern distinctions between "normal" conditions that are most generally distributed, and "pathological" deviations from the norm.

As health care, and society in general, places more emphasis on health promotion and disease prevention, there is increasing need for measures that incorporate the positive benefits that may result from health promoting environments or behaviors and preventive interventions. These "positive" measures are especially relevant for the assessment of changes in relatively well individuals that may result from health promoting influences and activities. At present, the only mechanism for assessing the effects of health promotion is subsequent reduction in illness or lengthening of life. Yet, these two outcomes may not be the only outcomes or the most important ones. Even if morbidity and longevity are unaffected, health promotion may enhance health by increasing energy, stamina, feelings of well-being, and productivity.

Positive health, or the upper end of the health-illness continuum, is not easy to define. There tends to be wider disagreement about what is "good health" than what is "bad health". One approach would be to define positive health as desirable deviations from expected or usual functions, activities, or perceptions that constitute daily life. This approach would be consistent with the concept of physiologic reserve. Physiologic reserve represents the unused capacity of the organism that can be called upon in times of stress, crisis, or increased activity. Evidence of reserve exists in observations of lowered susceptibility to health threats such as hassles and life stresses and of rapid recovery from illness.

Another approach to positive health focuses on feelings of well-being, and may be based on theories of personality, social learning, personal control, or specific phenomena such as happiness, elation, or optimism.

Both the notion of physiologic reserve and feelings of well-being can be encompassed by the concept of resilience or the ability to recover from adversity. Positive health may be viewed as capacity rather than performance. In 1957, Halbert Dunn, then Chief of the National Office of Vital Statistics, concluded that freedom from illness or high level wellness was a largely uncharted and undifferentiated area of good health. Developing health measures separate from illness measures is a challenge that remains today.

Linking process and outcome. The main objective of preventive services, health promotion, and health protection is to improve health-related quality of life outcomes. Increasing the potential for health and elimination of influences that detract from health are assumed to improve health-related quality of life outcomes.

But, evaluation of personal and community preventive efforts cannot be based solely on measurement of health resources or health risks. The existence of legislation, environmental protection, positive attitudes and healthy habits are measures of effort and process. These efforts must be linked to consequent changes in health and quality of life outcomes. Mortality measures, particularly infant and all-cause mortality, are appropriate outcome measures for large population-based interventions, although these outcomes may occur long after the preventive intervention is instituted and/or evaluated. Functional status is important, particularly for the evaluation of interventions that are meant to reduce the chronic limitation of activity. Measurement of positive health, as mentioned earlier, will be needed as we focus more and more on interventions that improve capacity, potential and opportunity.

One problem that may be particularly pertinent to the 1990s is access to health care. Access to health services for everyone continues to be a major policy goal based on the assumption that improved access to health, including disease prevention and health promotion, will lead to improved health status.

Equity in access to health care, however, is a substantially different goal than equity in health status. Equity in access is presumed to lead to "equity" in health status. Yet, decades after the National Health Service was introduced in Great Britain to reduce inequity in access, social inequities in health status persist. The effect of equity of access on health status has been examined primarily with mortality rates or measures of chronic activity limitations and bed disability days. Further work is needed to incorporate multidimensional measures of health status, measures that include mortality, disability, and subjective well-being in the examination of inequities in health and their association with access and use of services. Progress in achieving equitable access must be monitored with a range of health outcomes.

In conclusion, I would like to make a prediction and propose a challenge. The prediction is that the use of health-related quality of life measures will increase over the next decade but that the increase will be in clinical research and clinical practice not in policy research.

This prediction is based on the observation that policy research tends to rely on available national data, that these data provide limited information about health status, and that there appears to be insufficient interest and resources to broaden data collection or to develop methods that incorporate a broad spectrum of health outcomes (e.g. death, impairment, functional status, and perceptions) into a single measure of health.

This state of affairs is particularly unfortunate as we face a decade in which available health and medical care may become more limited and social inequity in access and health status may become more marked. The effect of social inequities and restrictions to health care on the health of the nation cannot continue to be determined with reference only to the structure and process of the health care system. Health and quality of life outcomes are what counts. And, these outcomes cannot be determined without appropriate and inclusive measures of health-related quality of life.

Of course, I hope this prediction is wrong. But to be wrong, two things have to happen. Those who collect national data - data that is used to formulate health policy - must be convinced that broader measurement of health status will enhance our understanding of the health of the nation, and will not jeopardize the longitudinal data that has been useful to examine trends over the years. And, those who appropriate and those who allocate resources must put more of these resources into improving measurement of population health status and quality of life. The effects of improving accessibility, providing disease prevention and health promotion programs, and improving the quality of health care delivered to the nation can only be assessed adequately in terms of the health-related quality of life of the nation.

Session A

Assessing Progress Toward the 1990 Objectives

PHCRS

THE EFFECT OF MORTALITY TRENDS ON THE ATTAINABILITY OF THE 1990 OBJECTIVES

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In 1979 the Surgeon General published "Healthy People" proclaiming goals for reduced mortality among major ethnic and age groups in the nation. "Objectives for the Nation" appeared in 1979 in which committees of health care professionals further defined these goals. While these publications noted that mortality rates were declining at every stage of life, the history of these reductions were not used in setting the levels of the goals. To draw an analogy from seamanship, the captains of the enterprise hoped for favorable winds but did not measure the strength nor direction of the currents. A consideration of these trends is not only important in setting goals with a reasonable chance of attainment, but also in providing a baseline from which progress toward the goals can be measured. It is important to know whether declines in mortality represent a continuation of ongoing progress, or an improvement in addition to the established trend.

This paper describes a method by which such an analysis can be made. This methodology was used in an evaluation of mortality trends in states in Public Health Service Region III in 1981 which was described in the publication, "Healthy People in the Mid Atlantic Region". While the methodology was applied to several groups in that study, our limited time will only allow me to discuss an analysis of the trends of infant mortality and its causes.

The process consists of establishing trends for the decade preceding 1978 when the goals were set and projecting them to 1990. Demographers and biostatisticians recommend transforming mortality rates to log linear values or logits to meet the assumption that as rates change, further improvements are increasingly difficult. When declines are linear, log linear projections are also linear. When trends are curved, the projections continue the curve. Rates which rise and fall use a logit transformation and quadratic function to project the pattern but within limits.

An evaluation of these trends will answer two questions; first, whether the goals were reasonable, and second, whether progress toward the goals represents the success of new efforts or a continuation of established trends.

Trends established from 1960 to 1978 indicate that children, youth and adults were forecast to reach their goals when they were set in 1978. Both youth and adults had trends which required logit transformations and the inclusion of curvilinear factors to best fit their distributions. (Mortality trends for children, youth and adults are shown in the Appendix).

In addition to evaluating the trends of total mortality for white and nonwhite infants, (male and female rates at this age are nearly identical for each group), a separate analysis will be presented to show trends for each of the leading causes. This makes it possible to re-evaluate our strategies for reducing infant mortality and to focus on the causes in which little improvement has been achieved.

This process can be demonstrated by showing the trends of infant mortality from 1968 to 1978 (Figure 1). In 1968 at the beginning of the War on Poverty, infant mortality was 22 per 1000 live births. That rate declined to 13.8 by 1978, by about a third. (All figures will show deaths per 1000 live births). Assuming that improvements in nutrition, medical care and other social determinants of infant mortality would continue to 1990, the slightly curvilinear trend projects a level of less than 8. In other words, by simply continuing the progress of the 1970's, the goal of nine deaths per 1000 would be reached with no additional effort. The same goal for white infants (Figure 2) was predicted to be surpassed more easily with a trend falling to 6.5 by 1990.

FIGURE 1
TOTAL MORTALITY

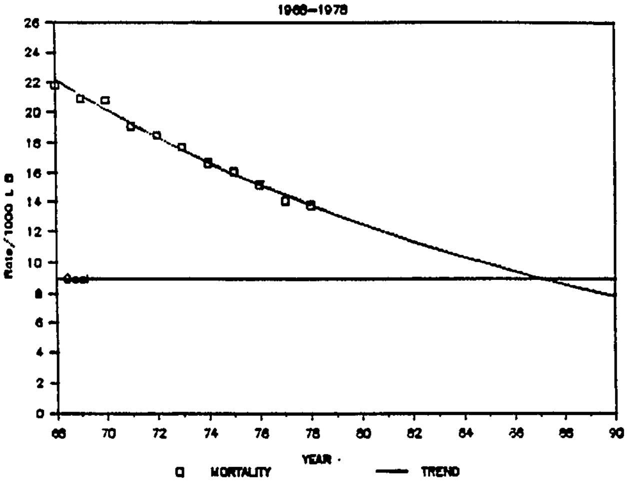
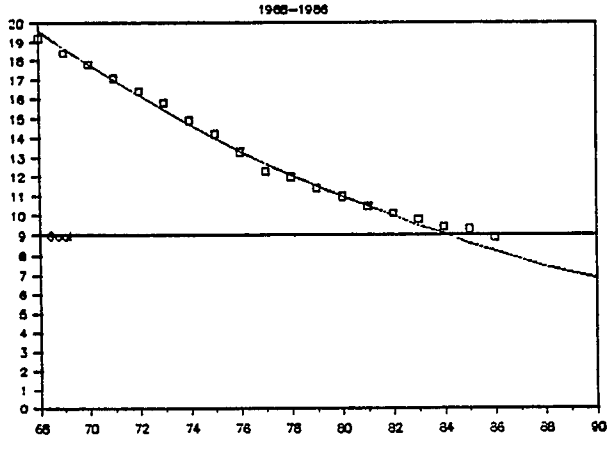
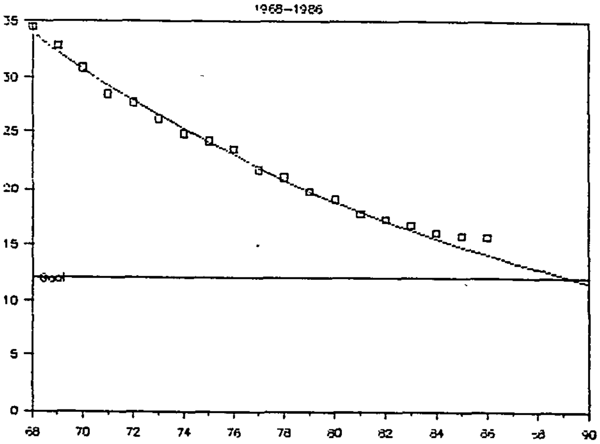


FIGURE 2
TOTAL WHITE MORTALITY



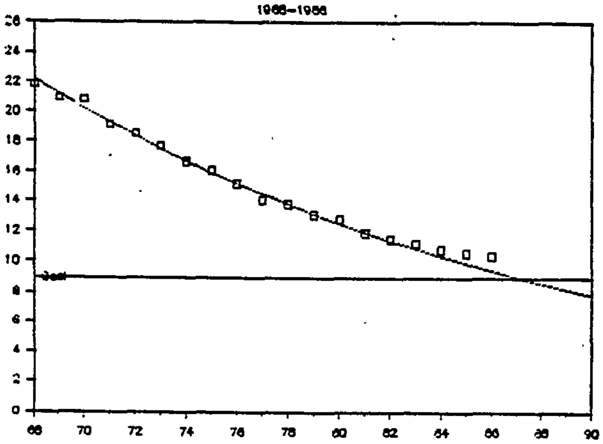
Nonwhite infant mortality (Figure 3) has historically been nearly twice the rate of whites, but the goal of 12 deaths per 1000 live births was also attainable without additional efforts.

FIGURE 3
TOTAL NONWHITE MORTALITY
1968–1986



What is our success in reducing infant mortality since the goals were set? It is clear (Figure 4) that the conditions which led to a steady decline in the previous decade have not continued into the 1980's. Instead, the rate of decline is slowing until the current projection predicts a 1990 rate just beyond the goal.

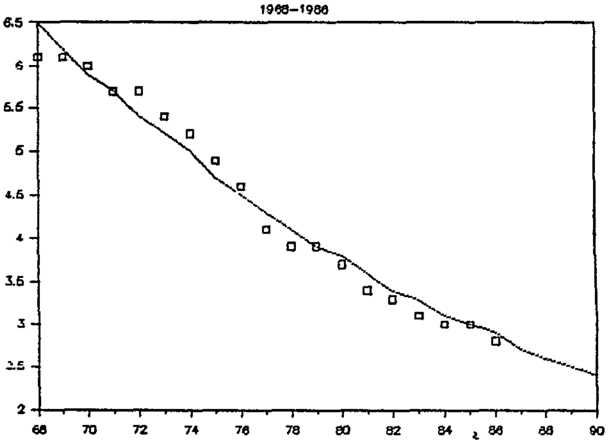
FIGURE 4
TOTAL MORTALITY
1968–1986



While mortality rates have continued to decline for white infants (Figure 2), the decline falls short of the established trend although the group met its goal in 1986. Nonwhite infants (Figure 3) have not fared so well. The trend since 1978 appears to be leveling out and is now probably going to barely meet the 1990 goal of 12 deaths per 1000.

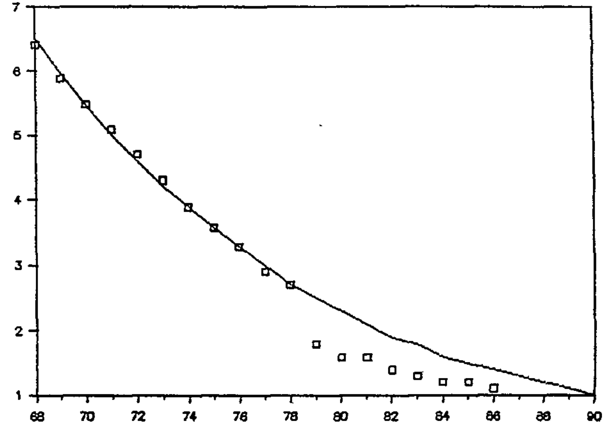
It is useful to conduct a similar evaluation of trends for the major causes of infant mortality. In 1968 these were, in descending order, immaturity, birth injuries, birth defects, SIDS, lung diseases (pneumonia and influenza), accidents and all other causes. Immaturity was the leading cause of infant deaths in 1968 (Figure 5) as it is today. The International Classification of Diseases (ICD) codes were changed from the eighth to the ninth version in 1979, and will be changed again to the tenth version this year. Some of the decreased rate of immaturity subsequent to 1979 may be attributed to these changes. (A complete description of ICD codes for all leading causes is available on request). While immaturity has continued to decline, it has followed a course parallel to the 1968-1978 trend, indicating no substantial improvement in the conditions leading to deaths from immaturity.

FIGURE 5
TOTAL IMMATURITY
1968–1986



Mortality from birth injuries (Figure 6) made dramatic declines during the ten years preceding the goals, and declines following 1978 have continued apace, but on a parallel track at a much lower level.

FIGURE 6
TOTAL BIRTH INJURIES
1968–1986



Dramatic declines after 1978 are apparently the result of changes in ICD codes. Birth defects (Figure 7) fell prior to 1978, but while the rates then rose, the cause cannot be explained by changes in ICD codes because the same codes were used for both versions. SIDS (Figure 8) was identified as a cause of mortality in the early 1970's and with its rapid increase during that decade, was projected to increase to 2.7 by 1990. This would have made it the leading cause of infant mortality. Happily, that trend has slowed to an almost constant level and the current projection is for a rate of 1.8 by the

FIGURE 7
TOTAL BIRTH DEFECTS
1968–1986

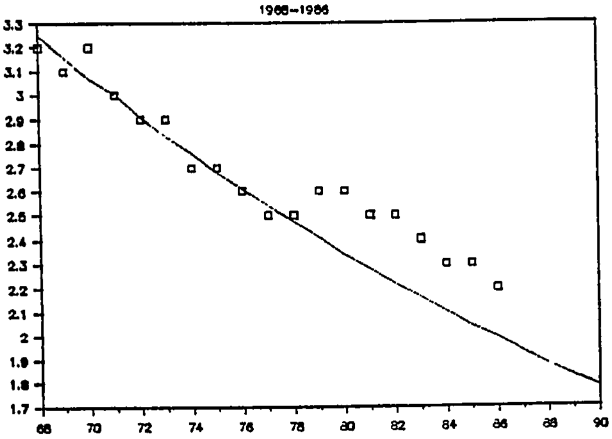
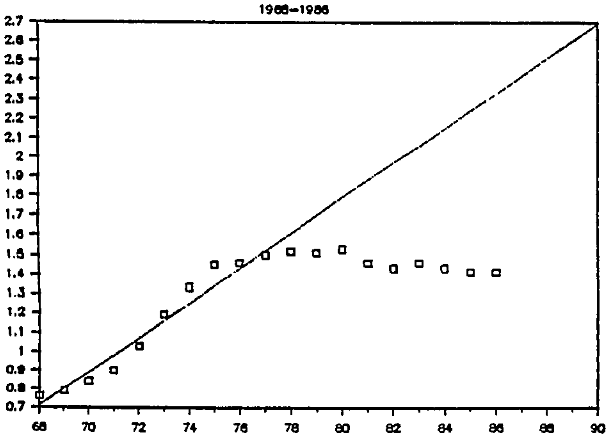
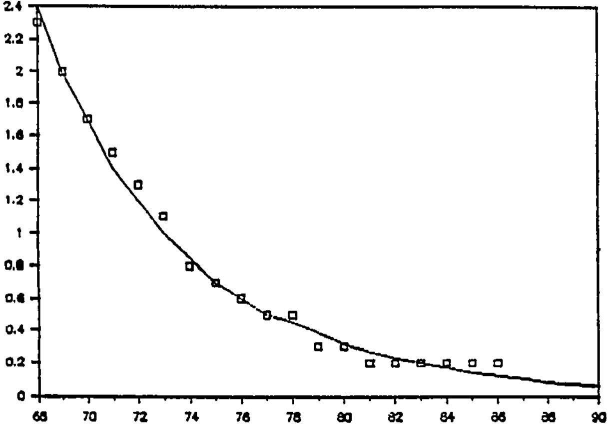


FIGURE 8
TOTAL SIDS
1968–1986



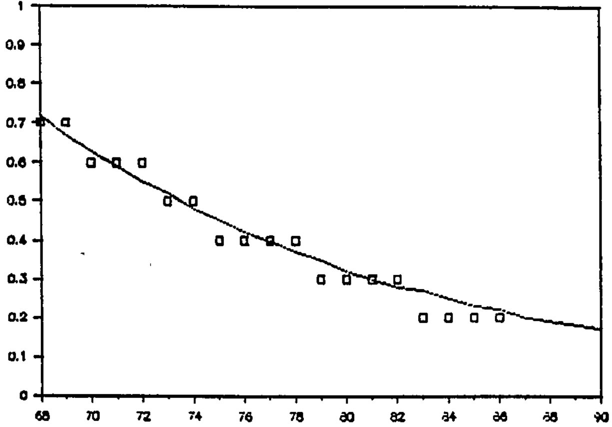
end of this decade. Improvements in deaths from pneumonia and influenza were dramatic between 1968 and 1978 (Figure 9) and subsequent rates have declined to nearly zero by 1986.

FIGURE 9
TOTAL LUNG
1968–1986



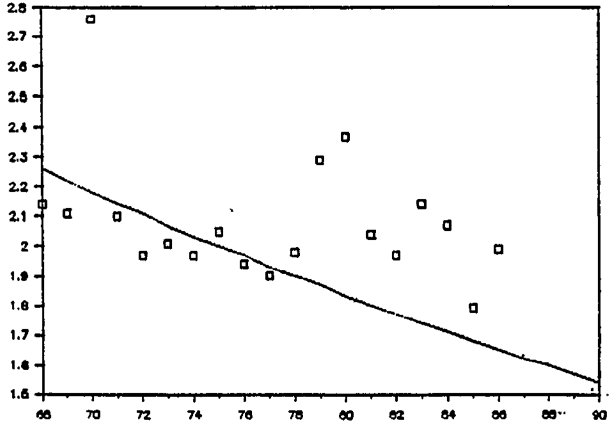
Accidental deaths (Figure 10) occurred at less than one per 1000 live births in 1968 and have since fallen steadily on the predicted track.

FIGURE 10
TOTAL ACCIDENTS
1968–1986



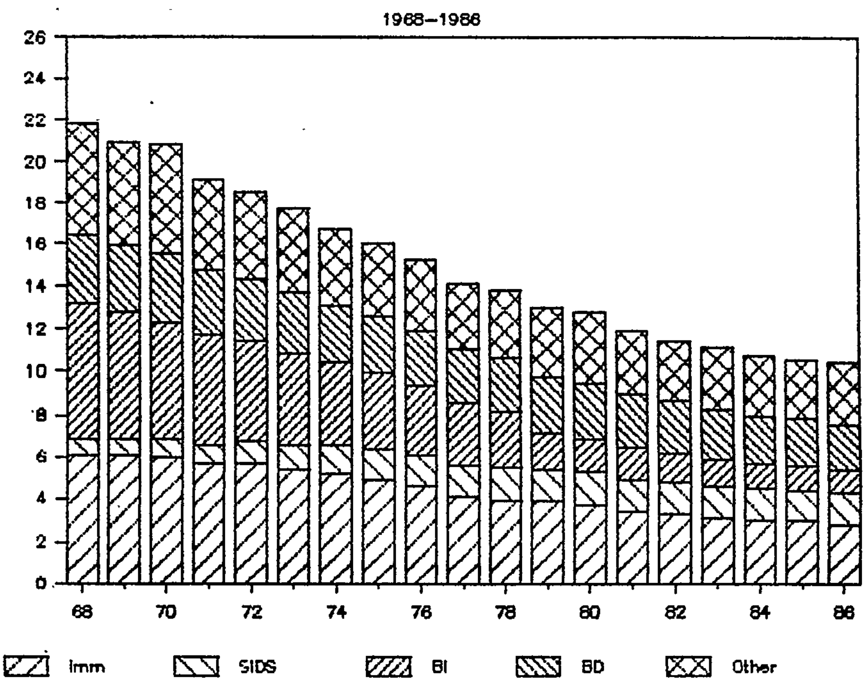
Before 1978, deaths from all other causes (Figure 11) followed an erratic pattern but due to one unusually high value in 1970, the trend was projected to decline. It is likely that much of the increase following 1978 was due to changes in the ICD codes in immaturity and birth injuries.

FIGURE 11
TOTAL OTHER CAUSES
1968–1986



Finally, I would like to consider the contribution of combined causes of total infant mortality to identify those with the greatest potential for further declines (Figure 12). This analysis also offers the advantage of examining the effects of changes of one trend on others. While immaturity has fallen from 6 per 1000 in 1968 to 4 in 1986, SIDS rose by 40% from 1973 to 1986. Considering that low birthweight infants contribute heavily to both groups, it is likely that there has been little real improvement in deaths from low birthweight with declines in immaturity balanced by increased deaths from SIDS. Improvements in birth injuries have been more dramatic, from a rate nearly equal to immaturity in 1968 to about a

FIGURE 12

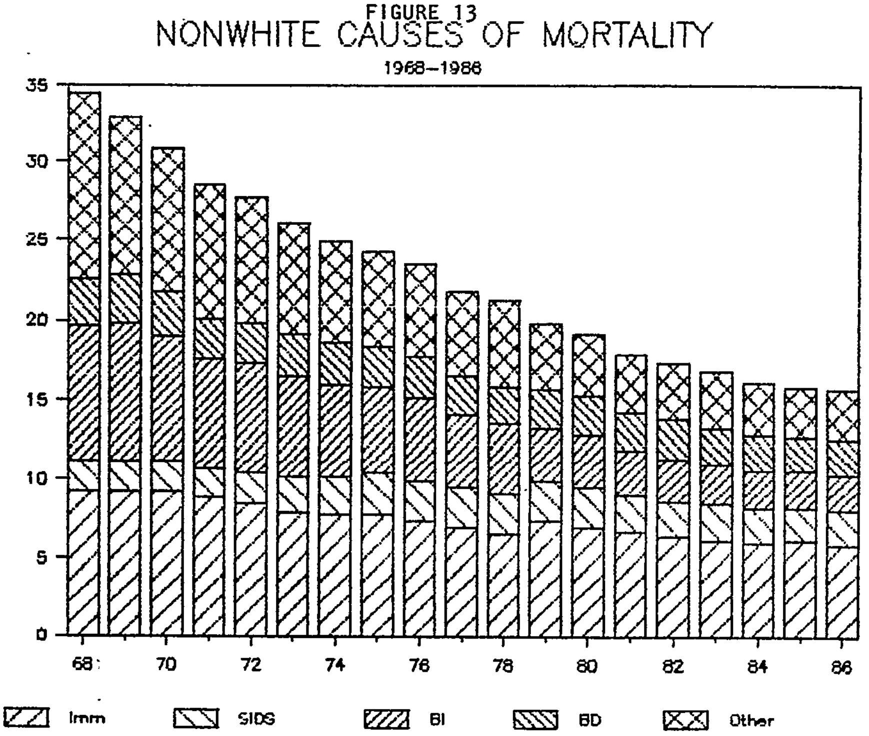


fourth of that rate in 1986. Deaths from birth defects do not show any noticeable improvement over the past 18 years. Lung diseases, accidents and other causes of infant deaths have experienced substantial declines.

Causes of white infant mortality (not shown) have patterns similar to total mortality, as they should since whites comprise nearly 90% of the total group. Immaturity and SIDS rates have declined slightly and birth injuries have fallen enough to leave birth defects as the second leading cause of mortality in 1986.

Nonwhite birth defects (Figure 13) as a cause of mortality has always trailed white rates, but the combined immaturity and SIDS rates have declined more slowly.

FIGURE 13



So what does this analysis of the tide tables of mortality suggest? First, it is apparent that the original goals were modest in the context of prevailing trends. All that was required to meet the goals was to continue what we were doing in 1978.

When we evaluate the causes of infant mortality, two (if you combine immaturity and SIDS) stand out. Low birthweight rates along with deaths from immaturity and SIDS have declined slowly, highlighting an area of opportunity. The limited success of early prenatal care in lowering low birthweight, suggests that the problem should also be addressed through encouraging high risk women to delay or avoid delivering infants who are conceived when risks are greatest. Perhaps the focus should be on pre-pregnancy risk reduction along with increased prenatal care.

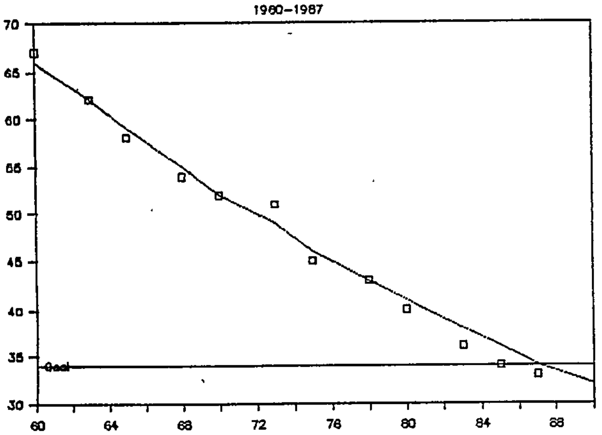
A second opportunity for lowering infant mortality is in the area of birth defects. While equally controversial to programs directed at reducing immaturity, it may be more amenable to medical intervention. Couples with a family history of genetic diseases, or women who suspect that they may be bearing an infant who carries a defect, can currently seek an amniocentesis. This procedure is effective during a small part of the pregnancy when the amniotic fluid and placenta are sufficiently mature, but before the pregnancy has reached a stage where termination is unsafe. White women who are at risk (those over 35), seek this procedure much more often than black women and while the gap is narrowing, only about half as many black women (17% vs 30%) had an amniocentesis in 1980. Fortunately a new procedure (Chorionic Villae Sampling), identifies genetic problems during the first weeks of pregnancy. The procedure is not yet broadly used nor accepted. The costs are high limiting its use by the poor. Nonwhite women have fewer infants who die of birth defects but these rates may rise if deaths from immaturity decline.

Limited time has not allowed us to examine the causes of mortality at the life stages of other groups. The application of this analysis can highlight intractable causes of mortality for each subgroup of the population. These causes should be targeted in establishing new goals and programs for the year 2000.

APPENDIX

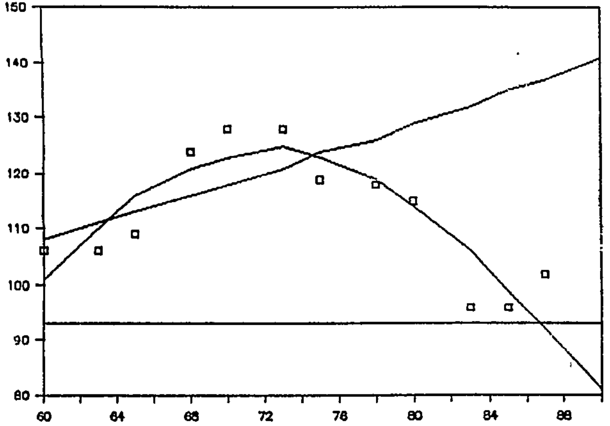
CHILD MORTALITY

1960–1987



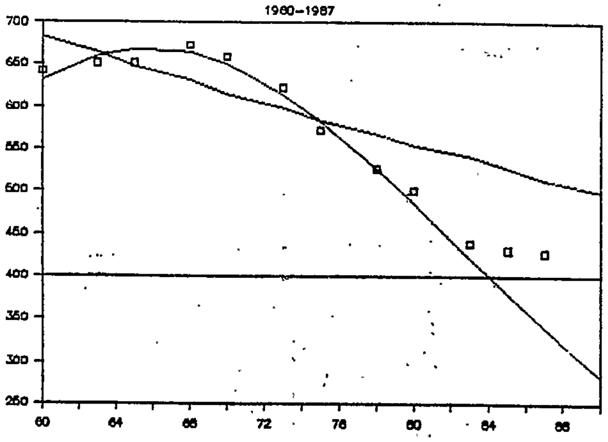
YOUTH MORTALITY

1960–1987



ADULT MORTALITY

1960–1987



APPLICABILITY OF THE 1990 HEALTH OBJECTIVES FOR THE NATION TO THE PREVENTION OF DISABILITIES

Sara L. White, Office of Disease Prevention and Health Promotion

The U.S. Public Health Service has a long history of promoting better health practices and preventing disease through research, education of health professionals and the public, and direct medical treatment in underserved areas. In 1979, the PHS undertook an additional national initiative — development of national goals and objectives for health promotion and disease prevention addressing all age groups, and specific strategic health targets. This first Surgeon General's report on health promotion and disease prevention, Healthy People, announced five national health goals for 1990:

- a 35% reduction in infant mortality
- a 20% reduction in deaths of children aged one to 14, to fewer than 34 per 100,000
- a 20% reduction of deaths among adolescents and young adults to age 24, to fewer than 93 per 100,000
- a 25% reduction in deaths among the 25 to 64 age group
- a major improvement in health, mobility, and independence for older people, to be achieved largely by reducing by 20% the average number of days of illness among this age group

From these five national health goals, 15 strategic targets were identified by assessing the risk factors involved in the leading sources of morbidity and mortality for each age group -- and determining those which could be most effectively addressed by available public health services. The 1990 health objectives evolved out of this process — a total of 226.

A careful review of the 1990 national health goals and objectives reflects a primary orientation towards prevention of premature death and temporarily debilitative morbidity resulting from communicable diseases, chronic diseases, and injuries. However, as many as 33 million Americans also are estimated to have disabilities resulting from disease, injuries and/or lifestyle practices which affect health. A number of studies indicate that many of the causes of these disabilities are preventable.

How applicable, then, are the 1990 health objectives to the prevention of disabilities? In preventing morbidity and premature mortality, are we also having an impact on disabilities?

These questions have been raised over the past several years as interest grows in expanding health promotion and disease prevention to include the prevention of disabilities — particularly to include disability specific objectives in the Year 2000 National Health Objectives.

The ODPHP undertook an analysis of the 1990 health objectives to determine:

1. how many of the objectives also applied to the prevention primary disabilities,
2. how many applied to the prevention of further complications in people with disabilities, and then, finally,
3. to identify gaps between the existing 1990 objectives and those that would be required to develop a comprehensive national strategy for the prevention of disabilities.

While other forums are more appropriate for a discussion of how to define disability — for our purposes here let me summarize the categories of disabilities that were considered:

- visual impairments;
- physical disabilities affecting use of hands, arms, legs, and movement;
- hearing impairments;
- speech and language disorders;
- mental retardation;
- learning disability;
- mental illness or psychopathology; and
- atypical appearance.

The following evaluation criteria were used for this subjective analysis:

- If the objective was explicitly targeted only to mortality reduction, it was judged not applicable.
- If the objective was explicitly targeted only to general health status improvement, it was judged not applicable.
- If the disease or event does not usually result in permanent morbidity (i.e., chronic disease) with usual and customary medical diagnosis and treatment, the objective was judged not applicable.
- If the disease or event could directly lead to disability — or if prevention activities were known to be effective in reducing the onset of disability — the objectives were judged applicable.

This approach assumed that medical treatments are usual and customary as provided by a licensed medical doctor, are reasonably successful, and that normal access to adequate medical care is available and obtained. To assume otherwise would result in excess disability.

Of the 226 objectives, 81 percent were judged applicable to the prevention of disabilities. An additional 5 percent could apply if restated. That left only 14 percent -- or 31 objectives — that did not also serve to prevent disability, along with morbidity and premature mortality. Objectives deemed inapplicable generally had to do with infant mortality and certain infectious diseases.

From the perspective of what the 1990 objectives did have, they seemed to be working toward the prevention of disability — even if they did not explicitly state a disability target. However, the analysis also showed significant gaps that would need to be included for the objectives to become a comprehensive approach to preventing disability.

Gaps were found in some of the existing 15 areas. However, many of the gaps are apparent only now because of developments that have been made over the past decade. For example, one 1990 objective sets the target that virtually all newborns should be provided neonatal screening for metabolic disorders for which effective and efficient tests and treatments are available — without further specificity about the targeted conditions. In other instances, risks such as radon or diseases such as AIDS have only recently been identified.

In our analysis, additional areas were identified that extend the prevention of disabilities beyond those target areas addressed by the original 1990 objectives. These are vision disorders, hearing disorders, improvement of mental health, maintaining health and functioning in older persons, and learning disorders. Since a major assumption that must be made is that the etiologic factors of the disease or condition have not only been identified, but that they are also amenable to efforts to prevent disability from occurring, each of these areas will not be affected equally by public health interventions.

Vision Disorders: Blindness and vision impairments could be reduced by several different types of prevention strategies including early identification of disease, protection from injury, and protection from exposure to toxic agents.

Hearing Disorders: Similarly, hearing loss could be reduced by environmental, as well as some behavioral, prevention strategies.

Mental Health: Mental health status could be improved by identification of disorders and access to services, for children in schools through older persons in the community.

Learning Disorders: Since the causes of learning disorders are by and large unknown, prevention efforts are limited. Furthermore, diagnosis and treatments are unclear. Nevertheless, it would be appropriate to target a greater awareness by teachers and other professionals about the identification of learning disorders, effective classroom techniques, and how to gain cooperation and involvement from parents.

Maintaining Health and Functioning in Older Persons: Although most of the 1990 health objectives would also apply to older people, the special health concerns of this high risk population were not carefully addressed. Older people are more likely to have multiple chronic diseases and impairments, creating a wide range in health status. The goal, then, is not simply primary or secondary prevention of specific diseases, but to maintain health and independence. A prevention strategy would be one that identifies the major factors in the loss of independence, the risk factors for those conditions, and the appropriate interventions.

Beyond the scope of our analysis, but similar conceptually, is the prevention of further complications in people with disabilities — at each of the different stages of life.

The conclusions reached were that, for the most part, the 1990 health objectives had not only the potential for having an impact on morbidity and mortality trends, but also for disability. However, to track such trends in prevention of disabilities would have been nearly impossible using the data systems available for the 1990 objectives.

The PHS is now in the process of setting new health objectives for the year 2000. Attention is being given to the prevention of disability, alongside the prevention of disease and premature mortality. Some areas will be easier to target than others. As in 1979, with respect to certain disabilities — and certainly with respect to the prevention of further complications in people with disabilities — we are looking through the mirror darkly. Much needs to be learned. Relevant to this conference, one of the major challenges over the next decade will be to collect the necessary incidence and prevalence data for disabilities so that an epidemiology of disability prevention can be developed.

One of the 21 priority areas in the year 2000 health objectives will specifically target older people. Another will address mental health. Vision and hearing disorders are addressed in the prevention of chronic diseases. In addition, disabilities are being targeted along with mortality, with head injuries from motor vehicle accidents, for example. Many of the gaps will be filled. Further discussion about the year 2000 health objectives can be found in subsequent sessions.

Thank you.

ESTABLISHING NATIONAL AND STATE HEALTH OBJECTIVES

Michael A. Barry, Public Health Foundation

INTRODUCTION

In 1979, results from an analysis of the ten leading causes of death in America and the elements contributing to these deaths were documented by the Department of Health and Human Services in the landmark report, *Healthy People: The Surgeon General's Report on Health Promotion and Disease Prevention*. The results supported a powerful theory: The majority of deaths in the United States are preventable. Using this finding as an impetus, the Surgeon General and the Department of Health and Human Services established national goals to be reached by 1990 for improving the nation's health status by promoting healthful lifestyles, reducing environmental hazards, and improving health care services.

Although the 1990 objectives are intended to be national in scope, their acceptance at the state level, where individual states' priorities varied, was critical to the attainment of the goals. In *Status Report: State Progress on 1990 Health Objectives for the Nation*, results from a study conducted by the Public Health Foundation examining each state's progress toward meeting selected 1990 objectives is presented. This paper will:

- Provide an overview of what was covered in the study;
- Focus on results from a 1987 Public Health Foundation survey soliciting information from state health agencies on the establishment of health objectives in their states and the degree to which states used the national health objectives as a guide in formulating their own state-specific objectives;
- Give examples of how organizers of the year 2000 objectives are using what was learned from the 1990 objectives to guide the process of setting the new objectives; and
- Examine why public health constituents have become more focused on health outcomes and efforts to measure the impact of services on those outcomes.

OVERVIEW OF FOUNDATION'S STUDY

Status Report: State Progress on the 1990 Health Objectives for the Nation is unlike previous reports such as *The 1990 Health Objectives for the Nation: A Midcourse Review*, which examined the nation's progress toward attaining the objectives. The report provides insight into differences in state and regional progress toward meeting the objectives. While these differences are apparent in a state-by-state analysis, they are not apparent in national, aggregate data.

The Public Health Foundation's study utilized data gathered primarily from the Centers for Disease Control and the National Center for Health Statistics. It addressed nine of the 15 priority areas identified by the Surgeon General's report: family planning; pregnancy and infant health; immunizations; sexually transmitted disease; accident prevention and injury control; surveillance and control of infectious disease; smoking and health; misuse of alcohol and drugs; and control of stress and violent behavior. For each priority area, the study examines several objectives and national and state progress toward meeting each objective. The Foundation was able to project for several of the objectives whether or not each state will meet the objective by 1990. These projections were based on states' progress from 1980 through 1985 (or 1986 where data are available) using a linear regression formula. These projections are not absolute predictors of the future, but merely indicate what may happen based on recent trends. They do not take into account external events that may affect the course of a disease (e.g., the effect of AIDS on tuberculosis).

Although the Foundation was able to present an in-depth analysis of states' progress on meeting 29 of the 226 objectives, it would have been desirable to assess their progress on many more. The problem is that reliable state-specific data on other objectives, especially objectives such as those that call for public and professional awareness of a health problem, were generally unavailable.

STATE DISEASE PREVENTION AND HEALTH PROMOTION ACTIVITIES

In the *Status Report*, information gathered from a 1987 Public Health Foundation survey of the nation's state health agencies is also presented. The survey attempted to determine if states had established or planned to establish disease prevention/health promotion objectives and, if so, did they use the national health objectives as a framework for setting their own objectives.

States Are Establishing Objectives

The Public Health Foundation found that, although the degree to which the national health priorities were applied varied from state to state, nearly every state embraced the concept of health objectives and was focusing on disease prevention activities. Establishing disease prevention/health promotion objectives has become an accepted part of states' health agendas across the country. According to the survey, 54 of the 55 state and territorial health agencies responding reported that their state or territory had established their own objectives for at least some of the 15 national objective priority areas or had begun the process of establishing them. Of the 54 states, 46 had established objectives and eight others had begun the process.

State Objectives Often Reflect National Health Priorities

The 1990 objectives were not intended to be applied, unchanged, in all states; their purpose was to guide state and local decision making. However, many states, in fact, have used the priority areas of the national objectives to formulate their objectives, while some established their own priority areas. Twelve of the 46 states that have them, set objectives for each of the 15 priority areas, while another 20 states set objectives for at least two-thirds of the priority areas. Most of the 46 states established objectives for some priority areas, while other priority areas were addressed by only about half the states.

An analysis of state objectives-setting within the 15 priority areas provides a clear picture of where public health agencies are concentrating their efforts. For example, 43 of the 46 states established objectives for pregnancy and infant health. At least 40 states established objectives for high blood pressure, immunizations, sexually transmitted disease, dental health, and nutrition. At the other extreme, only 22 states established occupational safety objectives.

A detailed table displaying which states established objectives for which of the 15 priority areas can be found in the Foundation's *Status Report*.

Objectives Usually Are Time-limited, Quantifiable, and Measurable

In *Promoting Health/Preventing Disease*, the Department of Health and Human Services, pointed out that reliable data, continuously reported and coded according to universally accepted definitions and conventions, are essential for documenting the true nature of the problems preventive measures should address. Reliable data are also essential for charting trends toward achieving the objectives. The Public Health Foundation survey found that, in general, states are setting objectives that are time-limited, quantifiable, and measurable.

For each priority area, most states have set a timetable for attaining their health objectives. With the national objectives being the primary impetus for states to establish objectives, the year 1990 has become a target date for many states. The Foundation found that for 14 of the 15 priority areas, the majority of states with established objectives in those areas set objectives to be accomplished by 1990.

The survey also found that states have set objectives that are usually quantifiable. In other words, the objectives can be quantified in terms of rates, number of cases, or whether or not the objective has been implemented. For all but one priority area, the majority of states with established objectives in that area reported that at least 75 percent of the objectives are quantifiable.

Finally, the survey gathered information on the degree to which states' objectives were measurable, i.e., the state will have data to assess whether or not the objective has been met when the target date has been reached. The objectives' measurability varies widely from state to state as well as across priority areas. At one extreme, two-thirds of the states with objectives in the area of immunizations reported that more than 75 percent of their objectives are measurable. At the other extreme, just over one-fourth of the states with objectives in the area of occupational safety reported that more than 75 percent of their objectives are measurable. Thus, as was the case with the establishment of the national health objectives, some states chose to establish objectives where no data were available to measure accomplishment of the objectives.

A copy of the survey and its results can be found in the appendix of the Foundation's *Status Report.*

FORTHCOMING YEAR 2000 OBJECTIVES

The process of setting the 1990 objectives excluded persons from a large sector of the health community, primarily state and local level health officials who are responsible for administering health programs to communities nationwide. Because of that, some of these officials did not initially take ownership of the objectives and did not support the objectives-setting process. Learning from this experience, the Department of Health and Human Services is making efforts to increase the number of people involved in the year 2000 process to include health and other officials from every level of government working with representatives from the private and nonprofit sector to establish the objectives.

Inaugural Hearing on the Year 2000 National Health Objectives

In May 1987, the Office of Disease Prevention and Health Promotion, Department of Health and Human Services (the agency coordinating the objectives-setting process) along with the Public Health Foundation cosponsored the inaugural hearing on the establishment of the national health objectives for the year 2000. The hearing was held in conjunction with the annual meeting of the Association of State and Territorial Health Officials and was intended to generate input from state health officers on the year 2000 objectives-setting process. Hearing participants developed three major themes to guide the objectives-setting process.

First, health officers called for a broad base of support for the process through cooperation and active participation of both the public and private sectors, including federal, state, and local health officials, elective office holders, industry, educational institutions, and private nonprofit organizations.

Secondly, the group emphasized the importance of establishing baseline data wherever possible to measure progress and evaluate outcomes and also that the year 2000 objectives should be linked to the 1990 objectives where appropriate to preserve continuity of monitoring the health status of the nation. Presenters addressed the difficult question of whether objectives should be set if data do not exist to measure their achievement. The group was divided, some stating that objectives are valuable as a means of focusing public health efforts even without data to measure progress, while others contended that objectives serve little purpose if progress toward meeting the objectives cannot be measured. The group agreed that entities responsible for carrying out activities to attain the objectives will have to strike a reasonable balance between the costs and benefits of maintaining or establishing data systems versus using valuable resources for service delivery.

Finally, members urged a commitment from all levels of government as well as private industry to accept the objectives-setting process and provide the necessary resources for establishing and achieving those objectives. Because more people and organizations are involved in the objectives-setting process, they should share the responsibility for assuring the attainment of the objectives by providing the necessary resources.

National Survey of States

Because the availability of data to measure the national health objectives has been an ongoing issue of debate since the establishment of the 1990 objectives, the Office of Disease Prevention and Health Promotion is working closely with the Public Health Foundation to survey the nation's state agencies on the availability and retrievability of data related to proposed priority areas for the year 2000 objectives. This effort will be conducted simultaneously with the distribution of the draft objectives for public review. The hope is that the results of the survey, i.e., the availability of data in the states, will be considered before the objectives are finalized.

Both the hearing of state health officers and the national survey of states demonstrate a desire on the part of the objectives setters to improve upon the process of setting national health objectives, taking into account states' ability to measure the progress toward achieving those objectives.

OUTCOME APPRAISAL

In the past, public health agencies have been hampered by the lack of descriptive data illustrating the impact of their activities on the health status of our communities. Part of the problem has been that public health agencies provide such a wide array of services and were sometimes compelled to try to collect data describing all of their activities. This bean-counting approach is cumbersome and ineffective in marketing public health initiatives. National and state policymakers are not interested in public health activities per se. They are interested in the impact those activities are having on the health status of American citizens. Efforts such as the setting of national and state health objectives have given public health agencies a more well-defined focus on which outcomes are of high priority. Public health officials can now use objectives to try and measure the impact of the services they provide on the most pressing public health issues. This outcome appraisal approach focuses on end results, providing administrators with evaluation feedback necessary to make decisions on improving health services.

The Public Health Foundation has collected information on the services and expenditures of state health agencies since 1970. In keeping with its mission of strengthening national, state, and local public health activities in order to improve the health status of all Americans, the Foundation is taking steps to refocus its data collection efforts on a more outcome-oriented approach. Using the national health objective priority areas as a guide, the Foundation is revising its core data set to begin to assess health departments' progress toward achieving important health goals. But because many health interventions are temporally removed from their outcomes (sometimes by decades), linking interventions to outcomes would be problematic, at best. Hence, the Foundation, through the guidance of a panel of health data experts, has decided to collect information on public health interventions where a definable relationship has been established in the scientific literature between the interventions and health goals or outcomes. Panel members agreed that it is appropriate to infer outcomes from data on the interventions that have already been medically proven to impact the outcomes. For example, it is well established that early prenatal care is an intervention strategy that can reduce infant mortality by decreasing the associated risk factors (such as low birthweight, tobacco and other substance abuse by the mother, and poor maternal nutrition). Information about the number of women receiving adequate prenatal care through the health department will help health professionals begin to assess health departments' impact of reducing infant mortality.

CONCLUSION

It is obvious that the 1990 objectives have had a significant impact on public health activities nationwide. Widespread agreement exists in the health field that establishment of 1990 national and state health objectives has helped the federal government and many state and local governments to focus their health-related activities in the areas of greatest importance. A midcourse review of the 1990 objectives showed that more than half of the objectives have already been achieved or are well on their way to being accomplished by 1990.

As the health community eagerly awaits the forthcoming year 2000 objectives, the hope is that lessons learned during the development of the 1990 objectives will enable the organizers of the objectives-setting process to refine and improve the process. The emphasis for the year 2000 objectives has been on increasing the number of people involved in the process.

Much national attention has been devoted to the 1990/year 2000 national health objectives, but objectives-setting activity at the state level has often been overlooked. The establishment of national health goals has been important to improving the health status of the American people, but states will undoubtedly continue to set their own objectives to accommodate the health priorities unique to their own state.

ASSESSING PROGRESS TOWARD THE 1990 OBJECTIVES FOR CALIFORNIA'S DIVERSE POPULATIONS

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Sheila Dumbauld, Cynthia Schmidt, Sherry Fujii,
Michael Pearson, and Charles Chan

California's population is as diverse as it is large. Statistics show that one in nine children in the United States are Californians, while one in three Hispanic American children, and two in five Asian American children live in California.[1] These diverse sub-populations are reflected in the million vital records that are registered annually in California. In 1987, less than half (48.1%) of California's 503,376 births were White, non-Hispanic, 33.0 percent were Hispanic, 8.7 percent percent were Black, and 10.3 percent were Asian and Other, including American Indian.[2]

Considerable ethnic and cultural diversities can be found within each of these main sub-populations. For instance, about one out of three of the Asian births were Filipino, almost one out of five were Chinese, one in eight were Vietnamese, one in ten were Japanese, and one in eleven were Korean.[3] Notable variations can be found among California's Hispanics as well. In addition to Mexican Americans, who account for almost 30 percent of the State's births, California has sizable sub-populations from most Central and South American countries. Less than two percent of California's Hispanic births are of Puerto Rican or Cuban origin.[4]

The demand for more race/ethnic detail in California's vital and public health statistics is increasing. This detail is critical for more effective health status assessment, including tracking California's progress toward the 1990 National Objectives.[5]

In order to better meet this demand, the race/ethnicity coding structure for California's vital records has been expanded to 30 codes, including very detailed Asian and Spanish/Hispanic origin categories.[6] Nevertheless, efforts to provide more detailed vital statistics have resulted in a number of problematic issues. First, in order to calculate race/ethnic-specific rates, appropriate population denominators are needed. Since 1985, California has produced statewide population estimates for four groups: Hispanics; White, non-Hispanics; Blacks; and Asians and Others.[7] These denominators limit the State's ability to analyze the health status of more specifically defined sub-populations.

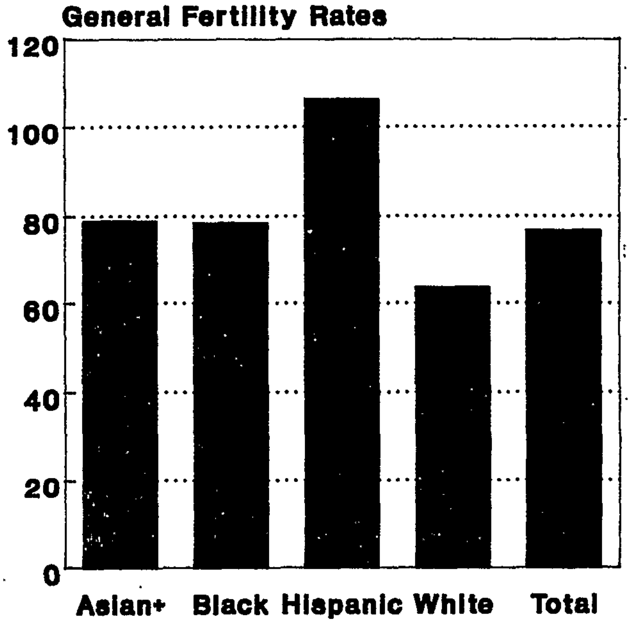
Second, even with a population of almost 29 million--- and a million vital events a year---small cell sizes can limit detailed analyses of vital statistics for particular California sub-populations. Third, recent analyses of linked birth and infant death certificates showed that a significant number of Hispanic and American Indian infant deaths were incorrectly reported as White.[8] The degree to which race/ethnicity is misreported on California's vital records for older ages and for specific race/ethnic groups is unknown.

Since no cause-specific population data are available, it is not possible to age-standardize cause-specific mortality rates by race/ethnicity. Differences in cause-specific rates due to variations in the age compositions of these sub-populations are not adjusted in this paper. Age-standardization could be applied only to "All Causes" of death.

FERTILITY RATES

California's general fertility rate (GFR) (Births per 1,000 women ages 15-44), was 76.6 in 1987.[9] This was the highest since 1970, and was 16.6 percent higher than the national rate of 65.7. At 106.3, the Hispanic GFR was almost 40 percent higher than the statewide rate. In contrast, Whites at 63.5 were almost 20 percent lower. (See Figure 1.)

Figure 1
General Fertility Rates by Race/Ethnicity California, 1987



Sources: See Footnotes 3 and 7.

Interesting patterns emerged by analyzing the age-specific birth rates by race/ethnicity. Among teens, Blacks have the highest rate. For Blacks under 15, the fertility rate was 3.3 and for those ages 15-19, the rate was 87.5. For women in their 20's, Hispanics have the highest rates. For Hispanic women 20-24, the rate was 187.8 and for Hispanics 25-29, it was 155.9. Among women in their 30's and 40's, Asian and Other women have the highest rates. For Asian and Other women 30-34, the rate was 118.6. For Asians and Others 35-39, the rate was 51.4, while for those 40-44, the rate was 12.1. For all of these race/ethnic and age groupings, fertility rates are rising. (See Table 1.)

A complementary pattern emerges for low fertility rates. For teens through age 24, Whites, and Asians and Others have the lowest rates. For women 25-44, Blacks have the lowest rates. For women 45 and older, Whites have the lowest rates, followed closely by Blacks, as shown in Table 1.

Table 1
Age-Specific Live Birth Rates[1] By Race/Ethnicity Of Mother
California, 1982-1987
(By place of residence)

YEAR	GENERAL[2] FERTILITY	UNDER 15	15-19	20-24	25-29	30-34	35-39	40-44	45 & OVER
				HISPANIC					
1982	106.4	1.8	89.7	173.0	141.9	91.3	46.5	13.2	0.9
1983	101.6	1.6	85.1	166.1	135.0	89.2	46.2	12.3	1.0
1984	101.3	1.7	83.9	167.9	137.8	88.5	44.1	12.7	0.8
1985	105.2	1.6	84.9	176.9	147.3	92.5	46.9	12.6	0.7
1986	104.9	1.5	85.0	182.1	149.3	91.1	46.3	12.1	1.0
1987	106.3	1.6*	86.5	187.8*	155.9*	91.9	46.9	11.9*	0.9
				WHITE					
1982	59.0	0.4	36.2	101.1	102.6	60.6	21.2	3.2	0.1
1983	59.7	0.4	35.6	101.4	104.4	64.7	22.9	3.6	0.1
1984	60.3	0.4	34.6	100.0	109.2	67.5	24.3	3.7	0.2
1985	62.0	0.4	35.6	100.2	115.8	72.0	25.9	4.0	0.1
1986	62.0	0.5	35.5	98.5	119.5	74.1	27.3	4.4	0.2
1987	63.5*	0.5*	36.7	97.7*	124.8*	79.0*	29.8*	5.3*	0.2
				BLACK					
1982	72.8	2.5	76.1	128.2	98.4	54.2	19.2	3.7	0.3
1983	72.6	2.5	75.0	125.1	100.0	56.0	21.5	3.9	0.2
1984	75.0	3.0	78.9	128.0	104.5	58.2	23.0	3.6	0.1
1985	76.1	3.2	80.1	128.2	107.7	60.1	24.5	3.6	0.2
1986	76.7	3.0	83.8	127.9	108.6	62.7	24.4	3.8	0.2
1987	78.3*	3.3*	87.5*	131.2	112.1*	63.8*	25.8*	4.5	0.3
				ASIAN PLUS OTHERS					
1982	81.6	0.4	31.8	102.8	148.4	103.9	45.1	9.4	1.2
1983	81.9	0.8	30.3	102.5	150.3	107.4	46.1	9.6	1.2
1984	81.0	0.7	28.0	96.8	150.2	110.4	49.1	11.3	1.5
1985	79.7	0.6	27.7	91.7	149.1	113.9	49.4	11.3	1.7
1986	76.5	0.8	27.4	86.5	142.4	113.5	48.5	11.7	1.6
1987	78.8*	0.8	28.1*	88.1*	149.9	118.6*	51.4*	12.1*	1.7*

* Using regression analysis, the change in the rate from 1982 to 1987 was found to be statistically significant at the 95% confidence level.

[1] An age-specific live birth rate is the number of live births per 1,000 women in a specific age group. For women under 15, the rate is calculated using the female population 10-14 years of age, and for women over 44, using the female population 45-49 years of age.

[2] The general fertility rate (GFR) is the total number of births, regardless of age of mother, per 1,000 women of childbearing age (15-44 years).

Sources: See Footnotes 3 and 7.

MORTALITY RATES

Unadjusted, or crude, death rates for all races and the four race/ethnicity groups are presented in Table 2.

Table 2
Age Standardized and Crude Death Rates[a]
California, 1987

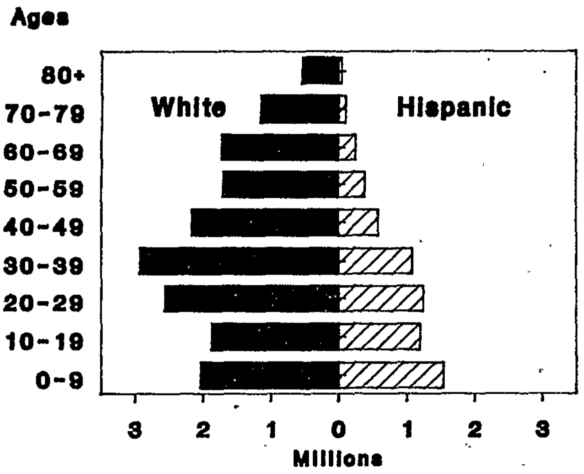
Race/Ethnicity	Standardized	Crude
Asian & Others	3.3	3.3
Black	8.5	8.0
Hispanic	3.8	2.8
White	5.3	10.0
Total	5.2	7.6

a: Deaths per 1,000 population.
Sources: See Footnotes 7 and 13.

The differences between the unadjusted Hispanic (2.8) and White (10.0) rates, in particular, are quite striking. The differentials lead to questions about the age composition of the respective populations. The age structures of the young Hispanic population and the much older White, non-Hispanic population vary considerably, as shown in Figure 2.

Also, Table 2 compares the crude and age-standardized "All Cause" death rates for California by race/ethnicity. The rate for Asians and Others remained fairly constant with the standardization based on the U.S. standard 1940 population. However, rates for the younger Black and Hispanic populations increased, while those for the older White population dropped dramatically. This decline also was reflected in the "All Races" rate.

Figure 2
White and Hispanic Populations
California, 1987



Source: See Footnote 7.

Though the cause-specific rates are not standardized, it is important to consider the potential impacts these age variations in population composition may have on the respective rates. For instance, causes of death most common among older Californians may show inflated rates for Whites, while injury death rates may be inflated for the younger Hispanic and Black populations.

TEN LEADING CAUSES OF DEATH

Using race-specific data for 1987, pneumonia was the fifth leading cause of death for Whites (41.6), and for Asians and Others (11.7), while it was sixth for Blacks (23.0), and eighth for Hispanics (8.6).[10] Chronic Obstructive Pulmonary Disease (COPD) ranked fourth for Whites (47.7), sixth for Asians and Others (10.3), and eighth for Blacks (19.9). COPD was not among the ten leading causes of death for Hispanics. (See Table 3.)

Unintentional injuries were the third leading cause of death for Hispanics (32.5), fourth for Asians and Others (23.5), and fifth each for Blacks (46.3) and Whites (41.6). Suicide was the seventh leading cause of death for Asians and Others at 6.7, and also for Whites with a rate of 18.8. It was not among the leading causes for Blacks or Hispanics. Homicide, on the other hand, was the fourth leading cause for Blacks at 47.8, and the fifth for Hispanics at 13.5. Homicide was not among the ten leading causes for Asians and Others, or for Whites, as shown in Table 3.

Table 3
Ten Leading Causes of Death
Rates[b] by Race/Ethnicity
California, 1987

Cause:	Asian/ Other	Black	His-panic	White
Heart Disease	92.2	238.3	67.6	346.3
Malignant Neoplasms	80.3	167.9	48.9	232.3
Cerebrovascular Disease	30.3	56.3	16.3	76.4
COPD	10.3	19.9	a	47.7
Pneumonia and Influenza	11.7	23.0	8.6	41.6
Unintentional Injury	23.5	46.3	32.5	41.6
Suicide	6.7	a	a	18.8
Liver Disease	5.0	16.9	11.6	16.2
Diabetes	6.1	19.6	7.7	13.4
Atherosclerosis	a	a	a	13.0
Homicide	a	47.8	13.5	a
Perinatal Cond.	5.1	20.6	9.0	a
Congenital Anom.	a	a	6.5	a
All Other	53.0	145.0	56.4	151.8
Total Causes	329.1	801.6	278.6	999.0

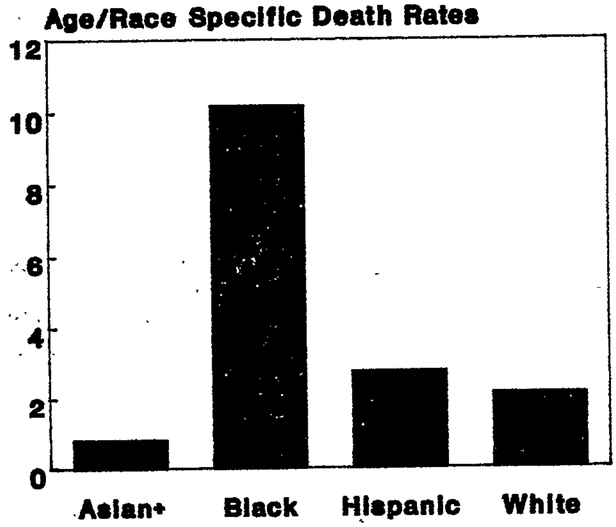
a: Not among the Ten Leading Causes.
b: Deaths per 100,000 population.
Source: See Footnote 2.

California's five leading causes of death by sex, age, and race/ethnicity provide a great wealth of health status data.[11] For instance, in 1987, the homicide rate of 10.2 deaths per 100,000 Black children under age five was more than three times as high as the rate for all races (3.0), almost five times higher than the White rate (2.2), and more than 12 times higher than the rate for Asian and Other children (0.8). (See Figure 3.)

Figure 3

Homicide: Children <5 Years Old

California, 1987



Sources: See Footnotes 3 and 7.

For California males ages 35-44, AIDS was the second leading cause of death, accounting for over 15 percent of all deaths, while it was fifth for Asians and Others, and third for Blacks and Hispanics. (See Table 4.)

Table 4
AIDS: Percent Deaths and Rank
California Males Ages 35-44, 1987

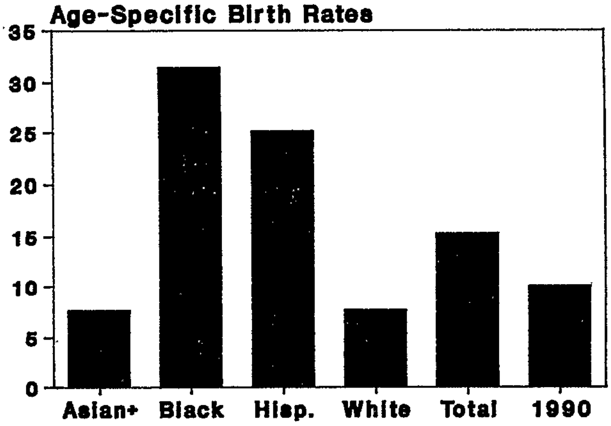
Race/Ethnicity	Percent	Rank
Asian+	7.2	5
Black	13.4	3
Hispanic	10.8	3
White	17.4	2
All Races	15.4	2

Source: See Footnote 3.

NATIONAL OBJECTIVES FOR 1990

The data for the 1990 National Objectives[12] shows varied achievements when sub-populations are analyzed. For instance, as Table 5 shows, the National Objective of no more than ten births per 1,000 females 15 years of age has been met by California's Whites (7.7), and Asians and Others (7.6). However, Black teens aged 15 experienced more than three times the target fertility rate with 31.4 and Hispanic 15-year olds followed with a rate of 25.1. (See Figure 4.)

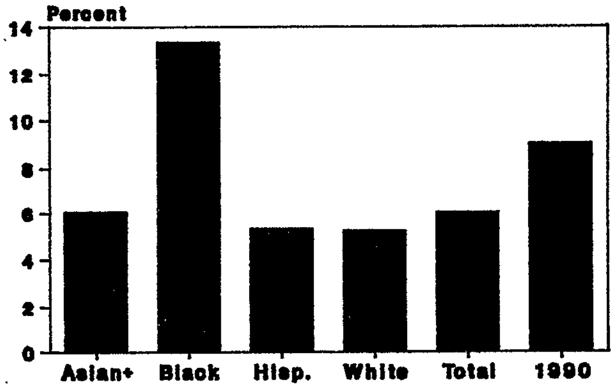
Figure 4
Birth Rates for 15 Year Olds
California, 1987



Sources: See Footnotes 3 and 7.

Asians and Others, Hispanics, and Whites have met the 1990 objectives of no more than nine percent of births that were low birth weight. However, Blacks experienced more than twice the proportion (13.3%) of low birth weight babies when compared to Whites (5.2%), Hispanics (5.3%), or Asians and Others (6.0%), and well over the target rate of 9.0. (See Figure 5.)

Figure 5
Percent of Births <2500 Grams
California, 1987



Sources: See Footnotes 3 and 7.

The objective for motor vehicle deaths for all ages of 18.0 deaths per 100,000 has been met only by Asians and Others with a rate of 14.9. The remaining race groups all had rates above 20.0. The objective for motor vehicle deaths for children under 15 (at 5.5 per 100,000) has also been met by Asians and Others. However, for this objective, Black children have a rate of 11.0, which is more than one and a half times that of any other race/ethnic group.

The 1990 Objective for fatalities due to falls is 2.0. Note the varied mortality experiences for the four sub-populations, compared with the trend for the total population. In 1987, Whites showed the highest rate of deaths per 100,000 population compared with the objective of 2.0. Hispanics, and Asians and Others have already met the objective with rates of 1.7 and 2.0.

Only Asians and Others have met the objective (2.0 deaths per 100,000 population) of deaths due to drugs with a rate of 1.7. The White drug death rate of 7.0 is more than four times that of Asians and Others, and the Black rate of 12.2 is more than seven times that of the Asians and Others rate.

The 1990 National Objective of reducing deaths among persons ages 15-24 to 93 per 100,000 has been met only by Asians and Others with a rate of 60.7. The highest rate of 189.7 is for Blacks while the Hispanic rate is 108.6 followed by the rate of 101.4 for Whites.

Though California is expected to meet the 1990 Objective of reducing total deaths in the age group 25-64 to 400 per 100,000 population by 1990, each sub-group has shown varied progress. Both Asians and Others (198.4), and Hispanics (237.2), have long met the target rate for this age group. However, it is unlikely that either Whites at 433.9 or Blacks at 683.6 will meet the objective by 1990. (See Table 5.)

Table 5
Selected 1990 National Objectives
Data by Race/Ethnicity
California, 1987

National Objective	Goal by 1990	Rates For Each Objective by Race/Ethnicity Total	White	Hispanic	Black	Asian/Other
Fertility rate for 15 year-old girls[a]	10.0	15.3	7.7	25.1	31.4	7.6
Percent low birthweight[b]	9.0	6.0	5.2	5.3	13.3	6.0
Motor Vehicle Deaths, All ages[c]	18.0	21.0	22.0	20.6	20.5	14.9
Motor Vehicle Deaths, less than 15 years[d]	5.5	6.8	7.1	6.0	11.0	4.0
Deaths due to Falls[c]	2.0	3.8	4.9	1.7	3.4	2.0
Deaths due to Drugs[c]	2.0	6.2	7.0	4.0	12.3	1.7
Death Rates for Persons Aged 15-24[d]	93.0	107.8	101.4	108.6	189.7	60.7
Death Rates for Persons Aged 25-64[d]	400.0	391.2	433.9	237.2	683.6	198.4

a: Births per 1,000 women aged 10-14.
b: Low birthweight live births are those under 2500 grams.
c: Deaths per 100,000 population.
d: Deaths per 100,000 population of the specified ages.

Source: See Footnotes 3, 13, and 14.

In summary, a review of California's vital statistics by race/ethnicity points to great variations for the State's sub-populations. Based on these experiences, we are actively exploring more effective ways to collect and to assess vital statistics based health status indicators and to monitor California's progress toward the 1990 National Objectives for these diverse populations.

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Note: "Asians and Other Races" includes American Indians and all other races not included in the other three categories. For brevity, this group will be referred to as "Asians and Others".

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10. Ibid.

11. Ibid.

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Session B

Modeling of HIV Infection

PHCRS

THE COST OF DELAY IN PREVENTING THE SPREAD OF HIV

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Mathematical models of the spread of HIV and AIDS can help to forecast the future burden of illness and to evaluate potential intervention strategies. The models that have been developed so far range from relatively simple statistical extrapolations to epidemiological and demographic models that represent demographic and behavioral subgroups and their interactions in great detail. A new model, presented in this paper, combines some of the best features of the existing models and can both accurately track the available AIDS surveillance data and explore the implications of various interventions.

The new model shows that currently available data are not sufficient to distinguish whether the HIV epidemic is dying out or increasing dramatically. Despite this, it is possible to arrive at robust conclusions about the relative effects of behavioral prevention and vaccines. In particular, a 20 percent reduction in "infectiousness" (to be defined more precisely later) starting in 1990 will prevent as much as 50 percent of the HIV infections that would otherwise occur, and is equivalent (in terms of HIV infections averted) to a vaccine that is 100 percent effective and fully applied around 2005.

HIV/AIDS epidemic models

A continuum of models have been proposed and developed to assess the spread of HIV and AIDS[1,2]. At one extreme, statistical models that are extrapolations of one sort or another work with the most aggregate statistics and make almost no assumptions about behavior. The well-known CDC projections use this approach[3]. Such models might be good for forecasting the magnitude of the future burden of illness, at least in the short range, but have nothing to say about the value of potential interventions. These models make minimal demands on the data, relying primarily on AIDS surveillance data. Although these data are not as complete and accurate as most investigators would prefer, they represent some of the most reliable information currently available.

At the other extreme, epidemiological and demographic models disaggregate the population in terms of demographic, behavioral, and other variables, and describe interactions within and among these groups. Such models demand large amounts of disaggregated data, and make many assumptions about sexual behavior and IV drug use. Because these models require the estimation of so many parameter values (or assumptions about other potential parameters) they often demand more of the data in terms of precision and availability for subgroups than the data can provide. For instance, one model has over 900 population subgroups[4], so counting a small number of parameters for each subgroup and many more for interactions among the groups, there are many thousands of parameters that must be fit (or values assumed). Since not that many independent, reliable bits of data on AIDS in the United States exist, and there are no data at all on many of the aspects of the model, models of this sort are not good for short term predictions. In some cases, however, the qualitative results of these models may be robust, and if so, can help evaluate the relative effects of various interventions.

Clearly, a balance must be struck between these two approaches. As one attempt to strike this balance, the model proposed in this paper uses features characteristic of models at both ends of the continuum: (1) as in epidemic models, the number of newly infected individuals in a given time period is proportional to the product of the numbers infectious and susceptible; (2) the latency period from HIV infection to AIDS diagnosis has a realistic, right-skewed distribution consistent with epidemiological data; (3) the model is simple enough so that it can be fit statistically, and transparent enough to be understandable; and (4) the model contains the explicit features necessary to compare and contrast potential intervention strategies.

Model definition

The model is defined in terms of three mutually exclusive populations that together make up the entire population of people ever at risk of HIV infections. At time t let

S_t = the number of individuals susceptible by their behavior patterns to HIV infections, but not yet infected,

I_t = the number of people infected with HIV, but not diagnosed with AIDS,

C_t = the number of AIDS cases alive.

To simplify notation, let P_t be the proportion of the population infected, that is, $P_t = I_t/(S_t+I_t+C_t)$.

The major epidemiological assumption of the model is that, in a given time period, the number of newly infected individuals equals the number susceptible to infection at the beginning of the period (S_t) times a variable that describes the "average" number and kind of sexual and IV drug use contacts with others (β_t), times the proportion of these contacts that are themselves infectious (P_t). In mathematical terms, this is expressed as

$$(1)\ I_{t+1} - I_t = S_t * \beta_t * P_t\ .$$

This model does not assume that the population is homogeneous or that all cases are equally infectious. Rather, β_t sums up a number of behavioral factors, and is an average figure in the sense that equation (1) holds in the aggregate. β_t is a measure of infectiousness in the sense that it summarizes, in one parameter, all of the behavioral and biological factors that intervene between the numbers of susceptible and infectious individuals. The model also makes the simplifying assumption that the numerator in P_t, the proportion infectious, is I_t not I_t+C_t, that is, diagnosed cases are not infectious. This is primarily a behavioral, not a biological, assumption.

Because every variable in equation (1) varies with time, the model is perfectly general. It is not, however, very useful unless the variation in the parameters is restricted in some way that will allow projections into the future. As one possible restriction, the model assumes that β_t declines over time according to a logistic formula,

$$(2)\ \beta_t = \beta_L + (\beta_H - \beta_L)(1 + e^{a+bt})^{-1}$$

in which β_H is the upper asymptote at negative infinity and β_L is the lower asymptote at plus infinity. The parameters a and b control the point of inflection (where $\beta_t = ((\beta_H+\beta_L)/2)$ and the slope of β_t at that point.

Because there is currently not enough reliable data to disaggregate the population into groups defined by risk behaviors, demography, or geography, and still fit the model parameters empirically, β_t must reflect all of behavioral and biological heterogeneity in the model. The decline in β_t represented by equation (2) reflects both the spread of the epidemic from the initial high risk groups to a broader population and changes in sexual behavioral and IV drug use. The particular mathematical form of equation 2, however, was chosen for its simplicity and its ability to reproduce the observed AIDS surveillance data, as described below. Because none of the variables in equation (1) have been observed, there is no epidemiological information on the shape of β_t other than can be obtained by fitting this model.

To accurately represent the latency distribution, the group of infectious individuals, I_t, is broken down into four stages that correspond to increasing levels of symptoms, following the method developed by Bongaarts[5]. In each time period, all newly infectious individuals, as calculated by equation (1), are assigned to the first stage of I_t. Also in each period, a constant proportion k of the individuals in each stage move on to the next stage, or on to AIDS, and k is the same for all stages. Thus the distribution of the latency period is the sum of four Exponential random variables and thus has a Gamma distribution, which is close to empirically observed distribution[5]. The mean latency period is 4/k. This model has two major benefits. First, it simplifies computer calculations because the model remains Markov. Second, although not attempted in this paper, the model could be used to simulate more specific, stage-targeted interventions, or to investigate the effect of differential infectiousness by stage.

The model assumes that all who are infected eventually progress to AIDS, and that the death rate is a constant 0.25 per half year for AIDS cases and 0 for others. It also assumes that there are initially 40 million susceptible individuals, and that the number of new susceptibles per year is increased by 0.4 million each half-year. Sensitivity analyses indicated that, over a wide range of these parameters, the model estimated similar numbers of HIV infections and AIDS cases.

Model fitting and parameter estimation

When compared to the available data--AIDS incidence by half-year through 1988--the model is still relatively complex and the number of parameters is large. Therefore, parameter estimation was carried out in an exploratory fashion. The model described above was programmed in a Lotus 1-2-3 spreadsheet on a personal computer, and the parameters were varied and the projected and actual AIDS cases were compared graphically and in terms of the average absolute relative error.

Because the data are affected by late reporting, under reporting, and a change of definition in 1987, two different data series were used: all cases reported to CDC through March 1989 and all "consistent definition" cases at that time, that is, those that met the pre-1987 CDC case definition[6]. These two figures probably bracket a consistent series of AIDS diagnoses. In recent years, the "all cases" figure is probably too high to represent a consistent series because of the expanded definition. The "consistent definition" cases, on the other hand, are probably too low because some of the extra cases will eventually meet the consistent definition, or could meet it if physicians had to perform extra diagnostic tests to confirm. According to a recent report, however, there may be systematic underreporting of AIDS cases that is not represented in either of these two data series.[2] Parameter estimation is based on the average of these two series. Furthermore, because pediatric cases generally do not lead to new infections, they were excluded from the calculations.

To explore the goodness of fit, Figures 1 and 2 show the actual AIDS incidence data and three sets of projections plotted by half-year on logarithmic and linear scales. The marked curvature in the logarithmic scale indicates that the number of AIDS cases is growing at a rate that is less than exponential. Assuming the epidemic model represented by equation (1), this means that either β_t has been decreasing over time or that the number at risk for HIV infection is substantially less than one million. There are no direct estimates of HIV prevalence in the United States, but indirect evidence suggests that the number is approximately one million, but perhaps as low as 500 thousand or as high as 2 million[7]. Thus, it seems likely that β_t has been decreasing over time.

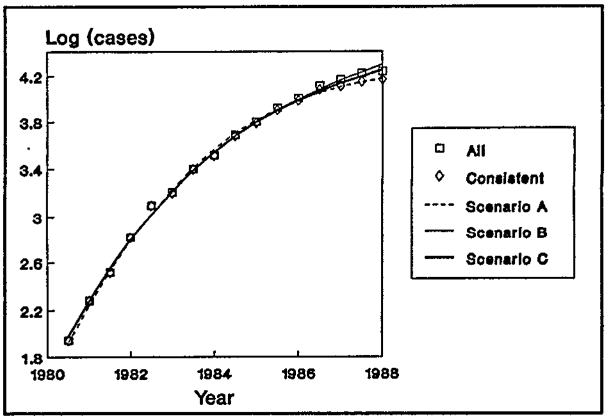

Figure 1. AIDS surveillance data by half year (all cases and "consistent definition" cases) and estimated values under three scenarios on a logarithmic scale.

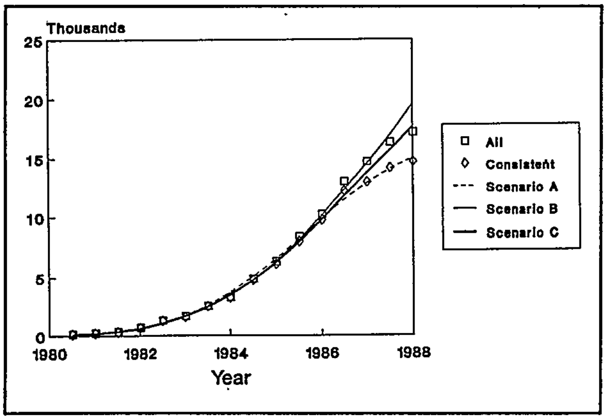

Figure 2. AIDS surveillance data by half year (all cases and "consistent definition" cases) and estimated values under three scenarios on a linear scale.

Table 1 gives the fitted parameters and average absolute relative error for each model. As Figures 1 and 2 indicate, three different parameter sets fit the data almost equally well for '81-'86. In terms of the average error, the fit for the first scenario is slightly worse than the others, and its predicted values fall off faster than the observed data in 1988. The results also indicate how sensitive projections are to minor changes in the AIDS reporting system. The difference between the most extreme models in 1988, seen most clearly in Figure 2, correspond roughly to the difference between the two case definitions. Changing reporting delays adds an additional component of uncertainty.

Table 1. Model parameters and results under three scenarios

		Scenario	
	A	B	C
<u>Parameters</u>			
Number infected in 1981	84,184	78,375	129,838
$ß_H$	1.5	1.5	1.5
$ß_L$	0.005	0.12	0.006
Midpoint year for ß	1979.5	1979	1979
Rate of change in ß (see text)	2.0	1.94	2.0
Latency period (years)	9.0	9.0	10.70
<u>Average absolute relative error</u>	6.05%	4.32%	4.58%
<u>Results</u>			
Number infected in 1989	233,539	863,202	686,580
Cumulative AIDS cases by 1991	189,228	280,224	240,522

The major differences between the scenarios can be found in the number of people infected with HIV at the end of 1981, the ultimate value of $ß_t$, and the average length of latency period. All three scenarios have $ß_t$ starting out at 1.5 and decreasing through its midpoint in 1979 or 1979.5. Furthermore, the parameters of the Equation (2) are such that $ß_t$ falls through two-thirds of its range (noted as "rate of change" in Table 1) in 1.94 or 2.0 years, suggesting that most of the drop in $ß_t$ occurred even before AIDS was discovered. Other values were tried, but the parameters of Equation (2) had to be roughly similar to this in order for the projected AIDS cases in the 1980s to exhibit the downward slope evident in Figure 1. This early drop in $ß_t$ suggests that the changes mainly reflect heterogeneity in the population infected with HIV rather than behavioral changes in response to the epidemic.

The scenarios also differ with respect to what they say about the number of people infected with HIV in 1989. This ranges from 234 thousand in Scenario 1 to 863 thousand in Scenario 2. Given the current estimates of 0.5 to 2 million people infected with HIV as mentioned above, the estimate from Scenario 1 is somewhat low. Together with the graphical analysis, this suggests that this is the least likely of the three scenarios. Taken together, however, the results from the three scenarios suggests that total number of people infected with HIV in 1989 is on the low end of the 0.5 to 2 million range.

Over the next two decades, the three parameter sets lead to very different projection results. Figures 3 and 4 show the projected HIV and AIDS incidence through 2010. The most critical parameter value is $ß_L$, which describes the rate of growth of the epidemic into the future. In Scenario A, with $ß_L = .005$, HIV incidence has already peaked in the early 1980s, AIDS incidence peaks around 1990, and the epidemic dies off soon. With $ß_L = .12$ as in Scenario B, the epidemic grows dramatically, and neither HIV nor AIDS incidence peaks before 2010. In this scenario, there are over a million new AIDS cases per year by 2010. Finally, with $ß_L = .06$ in Scenario C, intermediate results obtain. The course of this epidemic is shown in more detail in Figure 5. In terms of AIDS, more than 100,000 new cases are diagnosed per year by 2010 under this scenario. HIV incidence peaks in the early 1980s, falls off by about 20 percent, than increases again and continues to do so at least through 2010. This pattern suggests a situation in which the epidemic peaked in a relatively small high-risk population, but continued to spread to a lower risk, but considerably larger population.

The main result of this analysis is not the particular projection from any of the three scenarios; rather it is the difficultly in distinguishing between them on the basis of the observed data. Because of the long and variable latency period, the number of current AIDS cases tells us primarily about HIV infections four or more years ago. Thus projections made in 1989 are really extrapolating not from 1989, but from 1985 or earlier. Because the AIDS incidence data can be fit by very different, but equally plausible, parameters sets, we can not have much confidence in any particular projection.

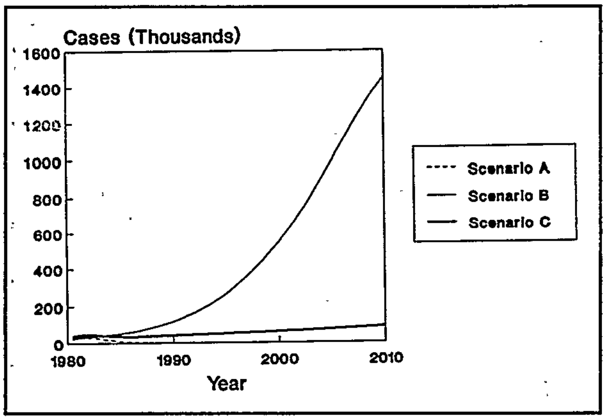

Figure 3. HIV incidence by half-year under three scenarios.

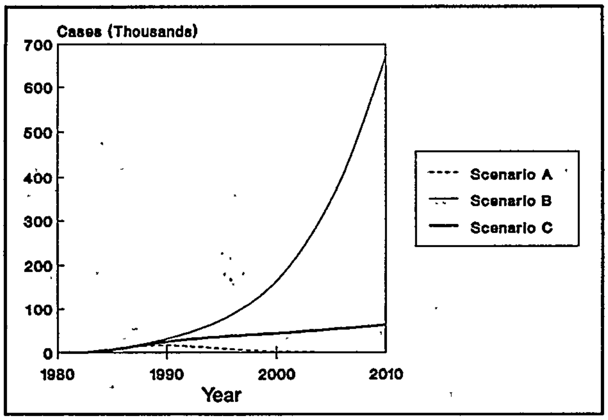

Figure 4. AIDS incidence by half-year under three scenarios.

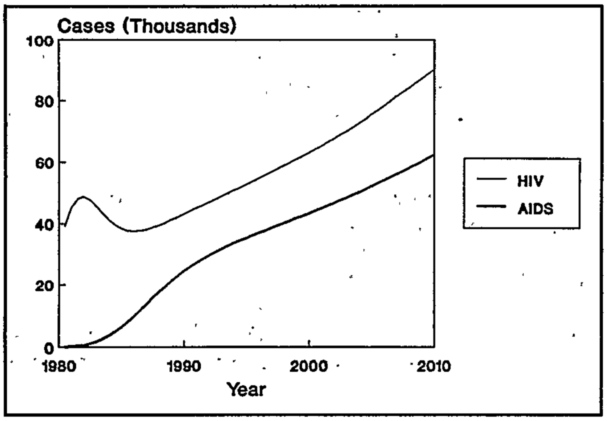

Figure 5. HIV and AIDS incidence by half year under Scenario C.

Interventions

Despite the uncertainty about which parameter set best describes the HIV/AIDS epidemic, it is possible to derive relatively robust qualitative results. In this paper, two general approaches are explored, primarily to study the result of delay in introducing prevention efforts.

The first approach corresponds to behavioral interventions to change sexual behavior and IV drug use. It is assumed that β_t is reduced to $(1-p)\beta_t$ starting in 1990. For the purposes of the model, it does not matter whether this is brought about by changes in the number of sexual partners, use of condoms or other changes in sexual behavior, reduction in needle sharing, or other factors. The changes can be large ones for a small subset of the susceptible population or small ones for the entire population. The only constraint is that the number of new infections for a given level of susceptible and infected individuals, in the sense of equation 1, declines by p percent.

The second approach is the introduction of a vaccine that is p percent effective starting in year t^* in the future. Specifically, it is assumed that the new value of β_t equals $(1-p)\beta_t$ for $t \geq t^*$. Presumably, the value of p would be larger than that for behavioral interventions, but a vaccine will not be available until considerably after 1990. A vaccine could be less than 100 percent effective because of its biological properties or because of less than complete application to the population at risk.

The results of these two interventions are compared in terms of the number of new HIV infections for 1991 to 2010. This has the effect of devaluing prevention efforts later in time, but the epidemic and our knowledge of the biology of HIV and potential medical treatments are changing so rapidly, projections beyond this point cannot be regarded as realistic.

Continuing with scenario C, Figure 6 compares prevention effectiveness as a function of the level of prevention (p) and time of introduction (t^*). In this scenario, the largest absolute effect is from the first prevention efforts, increasing p from, say, 0 to 20 percent. Also, largest absolute reduction in cases is from the earliest introduction of the intervention; a one year advance in the 1990s saves more lives than a one year advance in the 2000s.

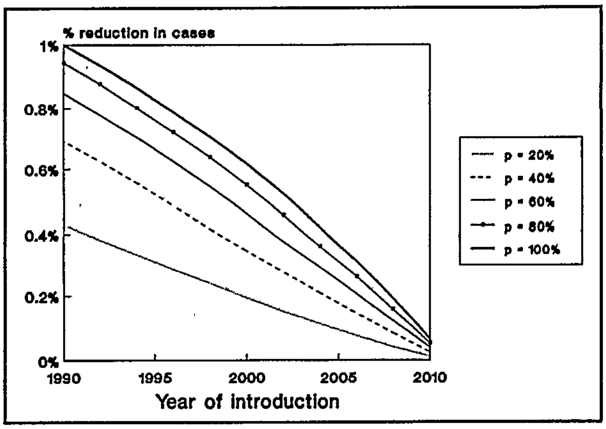

Figure 6. Percentage reduction in the number of future HIV infections as a function of the effectiveness of the intervention (p) and the year of introduction (t^*).

Figure 6 also shows the tradeoff between behavioral and vaccine-based prevention efforts. In particular, a 20 percent behavioral change in 1990 is equivalent to a 100 percent effective vaccine available in about 2004. Given the difficulty of developing a vaccine, testing it for safety and efficacy and getting FDA approval for its use, and administering it to all of the appropriate target population, a 20 percent behavioral change seems at least as likely.

Figure 7 compares the effect of a behavioral change in 1990 in the three scenarios. Despite the differences in the scenarios, the effect is qualitatively the same: an X percent reduction in β_t reduces future cases by more than X percent. For instance, the reduction in the number of new infections caused by a 40 percent reduction in β_t ranges from 42.2 percent in Scenario A to 81.6 percent in Scenario B. This "multiplier effect" arises because, in the epidemic model, preventing an infection in one year results in a reduction in new infections in future years. The effect is greater when the epidemic is still growing, as in the Scenarios B and C, but only marginally present when in scenario A in which HIV incidence has already peaked. The qualitative conclusion is robust, however, despite the differences between scenarios: even far from perfect prevention efforts early on can make a big difference to the total number of future cases.

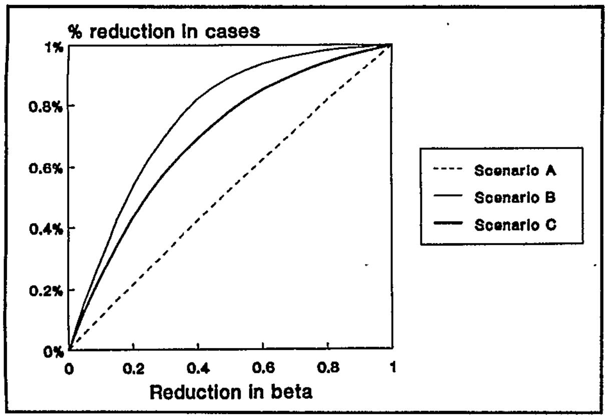

Figure 7. Percentage reduction in the number of future HIV infections as a function of the effectiveness of the intervention (p) under three scenarios.

Figure 8 shows the effect of delay in the introduction of a vaccine under the three scenarios. The horizontal axis is reversed to indicate that an earlier introduction requires more effort. Scenarios B and C are similar in shape; a 50 percent reduction in the number of new infections requires a vaccine to be fully in place by 2006 or 2003 respectively. Because the number of HIV infections has already peaked in Scenario A, however, the vaccine is needed by 1993 to have this same effect.

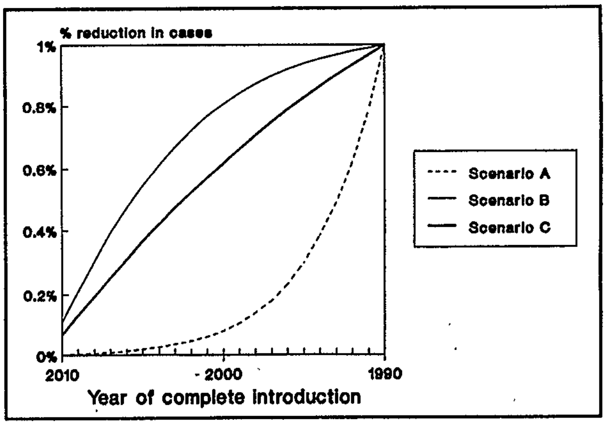

Figure 8. Percentage reduction in the number of future HIV infections as a function of the year of introduction (t.) under three scenarios.

Discussion

Clearly this is a very simple model, and has only limited usefulness for forecasting the future HIV epidemic. The analysis does, however, exhibit two important things. First, it shows that the currently available AIDS statistics are not able to differentiate between very different HIV epidemics, and hence it is very difficult to accurately predict the future course of the epidemic over the next two decades. Second, the analysis shows that, despite the uncertainty about the future level of the HIV epidemic, some qualitative conclusions about preventive interventions can, nevertheless, be robust.

One implication of this modeling exercise is the realization that relatively small behavioral changes, if affected early enough, can have results similar to those of more effective vaccines that are fully applied around 2005. This would suggest that behavioral research and research aimed at the development of a vaccine should be roughly on a par. In fact, however, much more is being spent on vaccine development[8].

Despite its flexibility, the model presented in this paper is only one of many possible models for the HIV epidemic. Some might disagree with some of the choices that have been made in an attempt to develop a simple and understandable model. The main result, however, is that even with a very simple model many different long range outcomes are consistent with the current AIDS surveillance data. The fact that other modeling choices might have been made supports this paper's main conclusion about the inability of the currently available data to distinguish between very different future scenarios.

As currently structured, the model assumes no medical interventions for people infected with HIV. With the recent discovery that AZT can help delay or prevent the development of AIDS symptoms, this assumption will become increasingly unrealistic. The model can, however, be used to study the effect of such interventions. In particular, the impact of delay in the progression of HIV disease can be modeled by varying the parameters that specify transitions through the four stages of infected period and the AIDS death rate. One particularly interesting question is, if people remain infectious while being treated with AZT, whether the increase in the number of infectious people caused by delays in the transition to full AIDS lead to an increase in the number of new HIV infections.

One important weakness of the model in this paper is that it does not account for heterogeneity other than through a changing β_r. Future modeling efforts need to consider the effectiveness of more specific interventions, especially (1) targeting population subgroups for testing and counseling, other interventions and (2) increased condom use and other behavioral changes by only a part of the population. Efforts are needed to look in more detail at heterogeneity in risky behavior and HIV incidence. For example, is it possible for the epidemic to sustain itself by heterosexual transmission alone (given U.S. conditions), or does there need to be a subpopulation that engages in high-risk behavior? Knowing the answer to this would have important effects on planning an intervention campaign. If the second hypothesis were true, it would mean that effort should be concentrated on the high-risk populations and actions that transmit the epidemic from these groups to others.

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SIMULATION OF HIV TRANSMISSION IN A STRUCTURED INTRAVENOUS DRUG USING COMMUNITY

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The spread of HIV infection between intravenous drug users (IVDUs) who share injection equipment is the second most common mode of transmission of the HIV virus (1). Infected IVDUs are the most common source of HIV into the heterosexual population and of HIV infected newborns (2). Clearly, control of this epidemic is a priority for public health.

Control of the spread of HIV infection among IVDUs has focused on changing behaviors to reduce the risk of exposure and on increased treatment to reduce the number of users. Because both of these goals may be approached using a wide variety of actual interventions, public health officials are faced with the task of deciding which approach is best for a specific community. This decision is complicated by the wide variation in IVDU communities. New York City has a prevalence in its IVDU population of between 55% and 60% while many other U.S. cities have prevalences less then 5% (3).

We have addressed this analytic policy need by developing a stochastic model of HIV transmission in an IVDU population. The model was developed as an exploratory tool for the purpose of evaluating factors affecting the dynamics of IV drug transmission of HIV and intervention strategies designed to reduce this transmission.

I. Methods

Our model is a micropopulation model since it is populated with discrete members who are followed throughout a simulated period of ten years. These members are characterized by the extent of their IV drug habit and by their social networks, shared drug usage and HIV status. The structure of our model is best described as three interacting models: a model of IV drug abuse, a model of HIV progression within an infected individual, and a model of the social networks that describes the amount of equipment sharing by drug users.

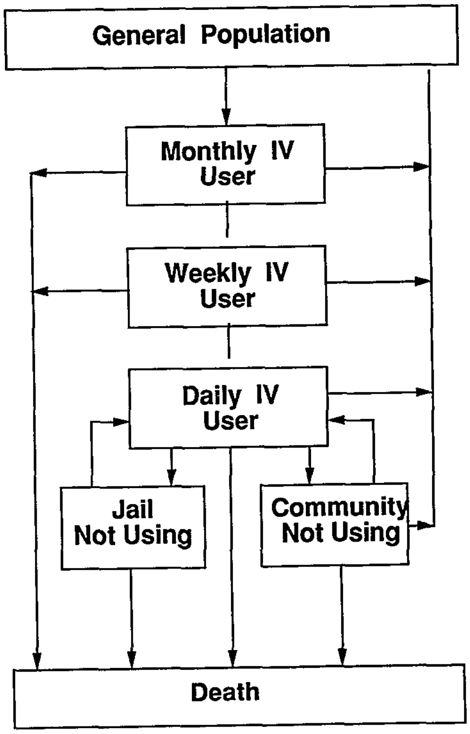
Figure 1 is a depiction of our IV drug usage model; it is based on the substance abuse literature and describes the "careers" of IV drug users (4,5,6). In this model drug users are divided into 3 stages of use: monthly users, weekly users, and daily users. Users can progress from monthly to weekly to daily usage during the course of a simulation; this process is referred to as recruitment.

Because of greater knowledge concerning daily users, they are more completely described than either weekly or monthly users. The literature indicates that daily drug users move in and out of usage states as a result of enrollment in treatment programs and incarceration (7). Both are represented in the model.

During the course of a simulation new users enter the model from the general population, progress through the stages of addiction, and, once they reach the daily user level, may use or not use drugs for the reasons indicated. Finally, they may leave our drug addiction model because of death or recovery.

Figure 1.

IV Drug User Dynamics



The social network of IVDUs is described by three structures in our model (Figure 2). One is the drug user's circle of acquaintances. It has been reported to include 15 members of which approximately 7 use drugs (8,9). We simulated this by assigning each member to 2 social groups of size 10, in which approximately half of the members are currently using drugs.

Two other social behaviors that affect an IVDUs risk of exposure to HIV are sharing drug equipment with strangers and participating in shooting galleries. These structures are also included as part of our social network modeling approach.

Figure 2.

Needle Sharing Behaviors of IV Drug Users

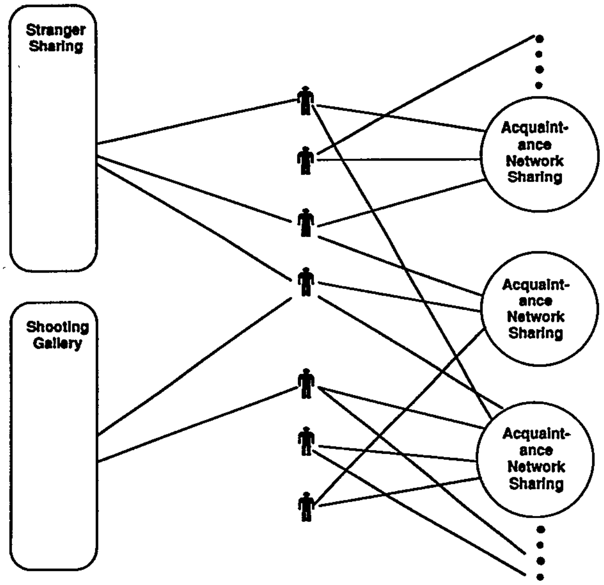


Table 1 lists the monthly exposure rates for the three drug use types by the three sharing behaviors: sharing with members of their acquaintance group, sharing with strangers and visiting shooting galleries. Only daily users are stipulated to share with strangers or visit shooting galleries. In the simulations reported, we stipulate that 10% of the daily users visit shooting galleries and 15% share with strangers.

Table 1. Needle Exposure Rates

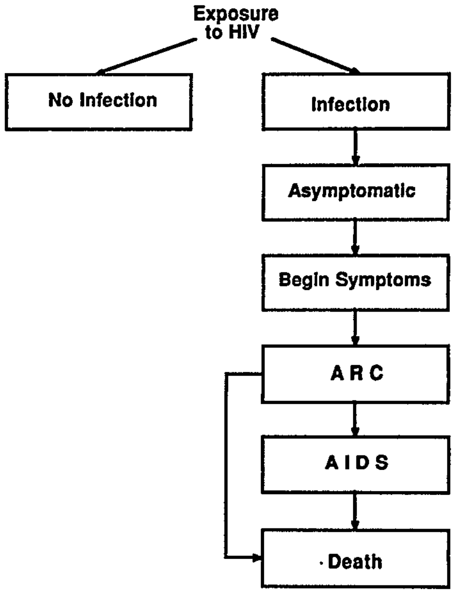
	Total Monthly Needlesticks	Shared Needlesticks (25%)	Types of Sharing
Daily users	30	7.5	Social Network Stranger/Shooting
Weekly users	4	1.0	Social Network
Monthly users	1	.25	Social Network

Each member of the population is also classified as susceptible or infected with HIV. If a member is infected, then the HIV progression model shown in Figure 3 is used to simulate the course of the disease. This model is based on progression through identified disease states, beginning with infection and proceeding to the asymptomatic state, the pre-AIDS symptomatic state, AIDS, and death due to AIDS.

Each state of the disease has an associated distribution of durations and a level of infectiousness, based on the best estimates of these parameters available in the AIDS literature. The length of time that an infected IV drug user spends in a state is determined by Monte Carlo methods from the distribution of times for a specific state. (10,11)

Figure 3.

HIV Infection Progression Model



Our model was run to simulate ten year periods in one month intervals. For each month the risk of HIV infection is calculated for each non-infected member currently using drugs. This risk has two components. The first is the probability that the equipment used in that month is comtaminated, which depends on the needle cleaning history and the current prevalence of HIV infection in the mixing group where the needle was used. The second component is the probability of becoming infected from contaminated equipment. This is determined by the number of needle sticks that are used. Alpha has not been determined specifically for needle exposures associated with IV drug use. An estimated value of .004 can be derived from the studies of accidental needle stick exposures to Health Care Workers (12).

Once a member's risk is calculated, Monte Carlo methods are used to determine if the member was infected. During each iteration Monte Carlo methods are also used to determine how IVDUs progress through the IV drug usage model and how HIV infected users progress through the HIV transmission model.

The model was developed using the Micropopulation Simulation Resource, which is located in Health Computer Sciences at the University of Minnesota. The Simulation Resource has developed a stochastic modeling system based on a set of core programming modules. These routines can be adapted to a range of biomedical problems in infectious, chronic and genetic diseases. The simulation model described here was developed from these modules.

II. Results

The following results illustrate some of the possible uses of simulation models of this type. In all of these simulations the ordinate axis is HIV prevalence. The abscissa, in years, represents 10 years. The population simulated includes 1600 heavy drug users distributed among the three daily using states and 1000 occasional users, both monthly and weekly users.

Alpha was set to .005 for all of these simulations. Five cases of HIV were introduced into the sub-populations of daily users to begin each simulation. Results are based on 100 replicates.

In Figure 4 the median number of infected users is plotted for both the heavy and occasional IV drug user sub-poulations. Also plotted are the 5 and 95 percent bounds for the distribution of results, the ability to generate which is one of the important advantages of Monte Carlo simulation models.

These simulations show the large variability in the time path prevalence in different types of drug users. This variability results in overlapping confidence bounds for occasional and heavy users many years into the simulation.

It should also be noted that after 5 years--the length of time to date of many outbreaks among IV drug users in US cities--the confidence interval of HIV prevalence even for heavy users barely exceeds zero, and may be unrecognizable. The difference between heavy and occasional users points to the importance of accurately documenting the type of drug user being surveyed when population specific HIV prevalence rates are given.

Figure 4.

User Categories with 5 and 95 percentiles

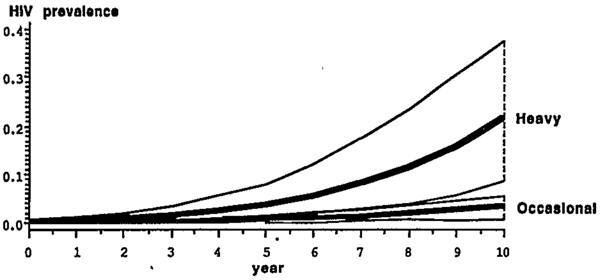
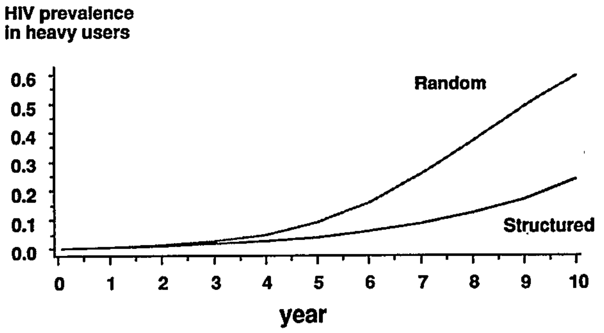


Figure 5. shows the results of sensitivity studies that we performed to begin to examine the effect of mixing structures on the transmission of HIV. Results from the simulated population with small acquaintance groups described above are compared with those from a simulated population with random mixing. The large discrepancy between the two results illustrates the importance of accounting for social mixing when constructing HIV transmission models. Even the modest social network that we have included results in a 50% reduction in prevalence when compared to a random mixing scheme.

Figure 5.

Random Sharing Model vs. Social/Behavioral Sharing Model

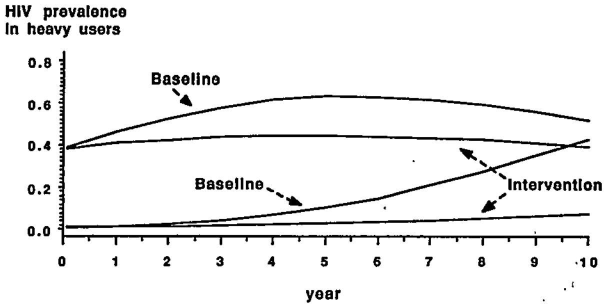


One use such a model can be put to is in studying the effect of interventions on the transmission of HIV. We illustrate this by implementing an intervention that effects a 50% reduction in needle sharing by all users. The intervention was simulated in two populations with initial underlying prevalences of .01 and .4. The results were compared to baseline simulations without interventions as shown in Figure 6.

The dramatic effect of underlying prevalence is easily seen in these simulations. In the low prevalence population, after 10 years there is an 80 percent reduction in prevalence. In the high prevalence population a more complicated interaction occurs. We can see from our baseline simulations that saturation effects begin at HIV prevalence above .6, resulting in a much less dramatic effects for interventions.

Figure 6.

Simulated Intervention 50% Reduction in Needle Sharing



III. Discussion

The population used for these simulations was based on a collection of parameter distributions and data value estimates found in the HIV and IV drug literature. Table 2 lists the source of these values. Many of these values came from studies that did not include IV drug users.

This, of course, is only appropriate when there is no difference between drug users and the population studied for the variable of interest. But future studies may reveal a difference in needle transmissibility and HIV progression for IV drug users.

The data we used to model IV drug user behavior was obtained from a wide range of studies conducted in a number of different cities. Different locations may have different rates of needle sharing, organization of social mixing, and availability of shooting galleries, as well as underlying HIV prevalence. Because of this, it is important when developing such models to have as much data as possible collected from the specific population being modeled.

Table 2. Sources of Parameter Values

Parameter	Population	Reference
HIV progression	Hemophiliacs	11
	SF Gay Men	10
IVDU state dynamics	Baltimore	6,7
	Chicago	5
IVDU networks	West Coast	8
IVDU needle behavior	New York	13
	Minneapolis	14
HIV transmission following needle sticks	Health Care Workers	12

IV. Conclusions

The core modules of the Micropopulation Simulation Resource allowed the rapid development and testing of a range of models aimed at understanding mechanisms of disease and its control. The flexible structure of the models allows simulation and investigation of a large range of factors important in the study of transmission of HIV.

Monte Carlo methods illuminate the variability inherent in the processes involved in disease transmission. Sensitivity studies help test the interactions of specific features of transmission and their effect on the results. The simulations of HIV in intravenous drug using populations can be used to examine a number of pressing policy questions.

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THE NATIONAL SURVEY OF HEALTH AND SEXUAL BEHAVIOR

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(Not available for publication)

METHODS FOR SHORT-TERM PROJECTIONS OF AIDS INCIDENCE

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Session C

Data Sources

PHCRS

IS THE MEDICAL RECORD AN EFFECTIVE EPIDEMIOLOGICAL DATA SOURCE?

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INTRODUCTION

For many years epidemiologists have used the medical record to compare specific patient characteristics to the occurrence of disease. However, in this case-control study that examined risk factors suspected of being associated with epithelial ovarian cancer, the majority of the risk factors were not documented in the medical record.

BACKGROUND

Ovarian cancer is the most lethal of all gynecologic cancers. It is an insidious disease in a deep-seated organ that defies early detection. In fact, the appearance of vague, nonspecific symptoms (pelvic unrest, backache, aching legs, bloating, nausea, etc.) may already be a manifestation of advanced disease. Epithelial cancers predominate (incidence rate of ovarian cancer is 18,000 cases per year and epithelial ovarian cancer comprises 65% of that amount) and the majority are asymptomatic. Presently, ovarian cancer claims half the deaths due to female genital malignancy, and although mortality rates for gynecologic cancers are declining, those for ovarian cancer are slowly increasing. (1,2)

A number of risk factors are suspected of being linked with epithelial ovarian cancer. Some of these include: nulliparity, infertility, menstrual tension, abnormal breast swelling, marked dysmenorrhea, greater than two abortions or miscarriages, early menopause (50 years), group A blood, irradiation of pelvic organs, exposure to asbestos, exposure to talc, high socioeconomic status, social habits (smoking, alcohol, coffee), breast cancer, cervical fibroids, endometrial cancer, obesity, resistance to mumps parotitis, gallbladder disease, stilbestrol use, oral contraceptive use, and member of an ovarian cancer-prone family. (3,4,5,6,7,8,9,10)

A pilot study was performed in which risk factors for 20 ovarian cancer cases were compared to 40 randomly-selected, age-related controls. Interpretation of the data was very limited because 30% of the risk factors were not found in the medical record for the cases or controls. These results may be due to the small sample size and collection of data from only one hospital. (11)

SPECIFIC AIMS

This research study was designed to evaluate 150 epithelial ovarian cancer cases newly diagnosed with the disease with 300 age-matched controls. The specific aims were to: 1) narrow the number of risk factors suspected of being linked to ovarian cancer by providing evidence that a specific risk factor is found more in the cases than in controls; and 2) determine whether the medical record is a useful tool for collecting risk factors and other health history information.

METHODOLOGY

Ten hospitals' medical record departments or tumor registries were contacted (after IRB approval had been obtained) to obtain the number of patients diagnosed with epithelial ovarian cancer during July 1, 1987 - June 30, 1988. Patients newly diagnosed with the disease were used because the medical record should provide a more complete past history of medical information when a patient is newly diagnosed with a condition. Once the diagnoses were validated, the attending physician was contacted to obtain approval to contact his/her patients. Once the physician approval was obtained, the consent forms were sent to the case to seek their participation. Once the case agreed to be a part of the study, the case's medical record was abstracted, the interview conducted, and a control was randomly selected from a population of women undergoing surgery or hospitalization for reasons unrelated to cancer. Each control was matched with the case on age, discharge date and hospital. In order to solicit participation by the controls, the same procedures were performed as with the cases in relation to physician approvals and consents.

Research assistants abstracted data from the medical records and interviewed cases and controls over the telephone. Each research assistant was either a graduate or undergraduate student in the health records administration department at the University of Pittsburgh. All research assistants were trained in abstracting the medical record. The major emphasis in these training sessions was that the entire medical record was to be reviewed, and in order for the abstractor to record a "no" on the abstract, the documentation in the medical record must state, for example, "No history of hypertension, no history of cervical fibroids, etc." If there was no mention of the risk factor, then it was considered not documented. Each record was abstracted three times in order to determine levels of agreement. The same questionnaire was used for abstracting and interviewing. It consisted of demographic items and the risk factors associated with epithelial ovarian cancer, as listed above. Research assistants were trained on interview techniques by listening to a tape-recorded session of a mock interview. Questions were then discussed among the research group. The interviews were hypothesized as being able to render the most accurate data and were compared with the data from the medical record.

RESULTS

Of the 58 cases and 104 controls eligible to participate in the study, only 23 cases and 23 controls (40% cases and 22% of the controls) were interviewed and had the medical records abstracted for the risk factor data. However, since one hospital refused to allow interviews of any of their patients but did allow us to abstract the medical records, a total of 34 cases and 45 controls had their medical records abstracted. The others were not interviewed or medical records not abstracted because of physician refusals (10% for cases and controls); patient refusals (26% for cases and 45% for controls); death (5% for cases and 2% for controls); and hospital refusals (19% for cases and 21% for controls.)

As seen in Table 1 below, demographic and other health characteristics of cases and controls (date of birth, marital status, race, nationality, education, occupation, income, height, and weight) were documented in the medical record 79% (occupation of cases) to 100% of the time (marital status of cases, and race of cases and controls.) The agreement level between abstractors was between 72 and 100% for all the characteristics mentioned and the kappa statistics ranged from 0.67 to 1.00. Other characteristics such as date of diagnosis, stage and histology, were documented 88, 67, and 91% of the time for cases with agreement levels between 86 and 99%, and kappas ranging from 0.68 to 0.98.

In Table 2, the risk factors associated with epithelial ovarian cancer were documented from 4 to 94% of the time. Family history of ovarian cancer and the relation with that cancer were documented 26% of the time for cases and 4% of the time for controls. Family history of any type of cancer and the relation with that cancer were documented 47 to 50% of the time for cases and 20 to 24% of the time for controls. Other risk factors: (age of menopause, number of pregnancies, number of miscarriages, blood type, irradiation of pelvic organs, hypertension, smoking and alcohol use) were documented in the medical record from 50 to 94% of the time for cases and 29 to 98% of the time for controls. Age menses began, whether one was ever pregnant, age at first pregnancy, hypothyroidism, history of measles, history of ovarian cysts, dysmenorrhea, talcum powder use, oral contraceptive use, history of cervical fibroids, and coffee use were documented 0 to 24% of the time for cases and 0 to 40% of the time for controls. The agreement level between abstractors for the risk factors ranged from 76 to 100%, and the kappas ranged from 0.49 to 1.00.

Table 1: Percentages of Demographic and Other Health Characteristics Documented in the Medical Record

Characteristics	Case (n=34	Control (n=45)	Agreement	Kappa
Date of Birth	97%	97%	100%	1.00
Marital Status	100%	98%	96%	0.93
Race	100%	100%	99%	0.67
Nationality	0%	0%	100%	1.00
Education	0%	0%	100%	1.00
Occupation	79%	80%	52%	0.40
Income	0%	0%	100%	1.00
Height	91%	93%	72%	0.69
Weight	88%	93%	57%	0.49
Date of Diagnosis	88%	-	86%	0.68
Stage	67%	-	99%	0.98
Histology	91%	-	86%	0.78

Table 2: Percentages of Risk Factors Documented in the Medical Record

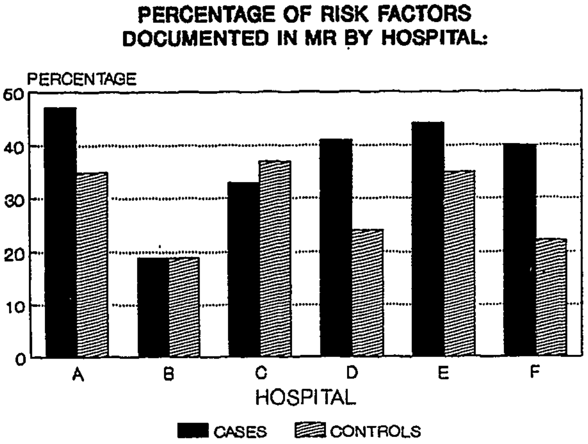
Risk Factor	Case (n=34)	Control (n=45)	Agreement	Kappa
History of Ovarian Cancer	26%	4%	86%	0.49
Relation	26%	4%	86%	0.54
History of Any Cancer	50%	24%	84%	0.67
Relation	47%	20%	94%	0.75
Age Menses	18%	47%	71%	0.60

Table 2: (continued)

Risk Factor	Case	Control	Agreement	Kappa
Age of Menopause	68%	47%	71%	0.60
Pregnant	15%	40%	86%	0.73
No. of Pregnancies	85%	49%	84%	0.79
Age first Pregnancy	24%	18%	85%	0.54
Ever have Miscarriages	76%	31%	77%	0.61
Number of Miscarriages	76%	29%	76%	0.59
Blood Type	94%	33%	86%	0.81
Irradiation Pelvic Organs	65%	22%	81%	0.60
Cervical Fibroids	3%	13%	92%	0.54
Hypertension	50%	71%	78%	0.68
History of Measles	0%	9%	99%	0.85
Hypothyroidism	18%	20%	86%	0.63
History of Ovarian Cysts	3%	8%	92%	0.54
Dysmenorrhea	3%	7%	94%	0.52
Talcum Powder	0%	0%	100%	1.00
Oral Contraceptives	15%	4%	96%	0.71
Smoking	94%	98%	86%	0.69
Alcohol	94%	76%	80%	0.68
Coffee	3%	4%	99%	0.79

As seen in Figure 1, documentation practices across hospitals did not vary extensively. However, all of the hospitals had the risk factors documented less than 50% of the time for both cases and controls. Hospitals B, C, E and F had a very low number of records reviewed (n=15) and this may account for the low percentage of documentation of the risk factors. Hospitals A and D had the majority of records reviewed from their hospitals (n=64).

Figure 1



Overall, even the most significant risk factors such as family history of ovarian cancer or any cancer that are known to be related to ovarian cancer were documented less than 50% of the time. This may be occurring because a physician or other health care provider will not state, for example, "no history of ovarian cancer in family or no history of any cancer" when the risk factor is not present in the patient. The difference in the number of risk factors documented for cases compared to the number documented for controls was large. However, with some risk factors, (hypertension, hypothyroidism, history of ovarian cysts, smoking, history of measles), the controls had higher percentages of documentation than the cases.

Although one can state patterns or trends in the data, one must also consider limitations of the study design. The abstractors could distinguish between the records of cases and those of controls and may have looked for the risk factors more in the cases than the controls. Also, some of the kappas (agreement beyond that expected by chance) were lower than the 0.60 standard and therefore the usefulness of the data for these risk factors could be limited. Because of the lack of information obtained from the medical record, patient interviews were necessary. Conducting the interviews limited the sample size since some patients could not participate due to the extent of their illness. One hospital refused to allow us to conduct patient interviews although a review of the medical records was permitted. Since the sample size was smaller than anticipated, many of the patterns may result from sampling variability or chance.

DISCUSSION

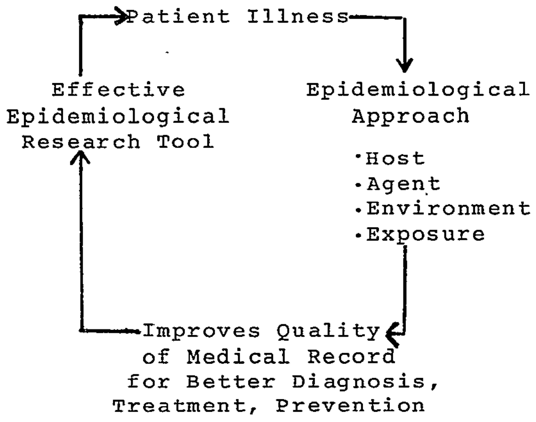
The major purpose of every health care facility is to provide the highest level of care to their patients. The major purpose of the medical record is to accurately document information about the overall health status of the patient in order to provide the best possible care. In order to determine the health status of the patient, the health care provider collects information on the health history as well as present illnesses, treatments and procedures. Information about the patient's diet, occupation, social habits, environmental factors and exposure factors.

should also be collected since these factors also play a significant role in the occurrence of disease.

In order to collect these factors, all health care providers should include an epidemiological approach in assessing health status, as outlined in Figure 2. This approach encourages the health care provider to think about the epidemiological factors associated with the patient's disease. This approach improves the quality of the documentation in the medical record which in turn leads to better diagnoses, treatment and prevention.

Figure 2:

Epidemiological Approach in
Assessing Health Status



This approach can be facilitated by collecting the epidemiological factors concurrently. This should be easily obtained because the patient or family member is available to answer questions about the past exposures, pre-existing diseases, and social habits related to the disease. Since the patient is being asked questions near to the time when the disease occurred, the patient should have better recall than when asked during an interview that may be conducted six months to one year later. When the risk factor data is collected as part of the patient care process, the cost and time of collecting the risk factors for research purposes is reduced. The medical record professional should be a part of this process by becoming aware of the risk factors that are associated with the disease and work toward collecting these factors. This is not an easy process but can begin by discussing the epidemiological approach in assessing a patient's health status with new residents, during Quality Assurance and Medical Record Committee meetings and with physicians and other health care providers during the daily completion of the medical record.

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A COMPARISON OF RESPONSES TO TELEPHONE AND FACE-TO-FACE INTERVIEWS IN A LONGITUDINAL STUDY

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The rapidly rising cost of the face-to-face interview has forced investigators to consider other means of gathering data. One approach that is gaining popularity in longitudinal, or panel, surveys is to alternate face-to-face interviews with contacts by other modes. In one study, for example, face-to-face interviews alternated with telephone interviews [1].

One potential difficulty for such a strategy is that the choice of mode might affect responses to key items in the study. Mode-related response variation has been examined primarily in cross-sectional surveys. In some, nonrespondents to one mode were contacted by other modes [2,3] while in others, two or more random samples of subjects were contacted by different modes [4]. In general, investigators have concluded that identified differences are too small to materially affect the results of the studies.

These cross-sectional investigations have focused on the effects of survey mode on response differences between subjects. Longitudinal investigations tend to focus instead on differences between contacts within subjects. Within-subject changes can often be measured with much greater precision than between-subject differences. The variance in responses that would arise from a change of mode could therefore constitute a larger share of total variance in the longitudinal comparison than in the cross-sectional comparison. Thus, the longitudinal study may be more sensitive than the cross-sectional study to changes in survey mode. This would imply that the cross-sectional studies of mode-related response variation provide little information on the effects of variation in survey mode on responses in a longitudinal study.

This paper examines responses in a longitudinal sequence of telephone interviews and a subsequent sequence of face-to-face interviews with the same subjects. The effects of survey mode on within-subject response variation are examined by comparing changes in responses between interviews that were conducted by different modes with changes between interviews that were conducted by the same mode.

METHODS

The Massachusetts Women's Health Study consists of two longitudinal investigations of the health of mid-age women. Study I began in 1981-82 with a cross-sectional survey of a random sample of Massachusetts women who were 45-55 years old [2]. This survey produced 8050 responses, giving a response rate of 77%. As one part of the survey, each woman's menstrual status was determined, so that premenopausal women could be recruited for a longitudinal study of health and the menopause [5]. A total of 2569, or 93.7% of those who were eligible, were successfully recruited. The longitudinal study consisted of six telephone interviews at nine month intervals. In 1987, as this study was ending, a cohort of approximately 400 women who had not yet completed the menopause and who lived in the Boston metropolitan area, were recruited for Study II. This study consisted of a baseline survey and a sequence of face-to-face followup interviews, again at nine month intervals. To date, the first two followups of Study II have been completed. However, data from the second followup are available for only 243 of the subjects. The responses of these 243 subjects in Studies I and II form the basis of this investigation.

The interviews in both studies explored diverse aspects of physical and mental health, utilization of health care, social circumstances, stress and other areas. Items were included in this analysis if they had exactly the same form in Studies I and II.

Three measures of physical and mental health status were included: health-related activity restrictions, recent symptomatology, and an index of depression. Each subject was asked if her health had caused her to restrict her usual activities in the last two weeks. She was also asked if she had experienced each of 20 common symptoms (e.g. headache, backache) in the prior two weeks. A binary index of depressive symptoms was derived from the CES-D scale. This scale explores the frequency with which a respondent experienced each of 20 depressive symptoms in the preceding week. Item scores, which are based on the reported frequencies, were summed (range: 0-60) and the sum was dichotomized (≤ 15, ≥ 16) to obtain an indicator of depressive symptoms [6,7].

Six measures of utilization of health care were included in the analysis. Each respondent was asked if she had had a PAP test or breast exam in the prior nine months. She was also asked if she had consulted a physician, nurse, mental health professional or relative in the last two weeks regarding a problem with her health.

The analysis also included five aspects of social circumstances: current employment status and the presence or absence of parents, children, other persons or pets in the respondent's household.

Finally, four measures of stress were included. Each respondent was asked if anyone close to her had been ill, died, been especially demanding or caused her special worry in the prior nine months.

The overall approach to the analysis involved estimating rates of response variation between interviews. If survey mode constitutes an added source of variation, then the rate of response variation between two interviews conducted by different modes should be greater than the rate of variation between two interviews conducted by the same mode. To test this hypothesis, data were taken from the last two followups of Study I (hereafter I-5 and I-6) and from the first two followups of Study II (II-1 and II-2). Using these data, the rates of variation of responses between a telephone and a face-to-face interview (I-6 vs. II-1) were compared with rates of variation between two telephone interviews (I-5 vs. I-6) and between two face-to-face interviews (II-1 vs. II-2).

To accomplish this, the responses to a given interview were crosstabulated against the responses to the succeeding interview. These crosstabulations were then compared across pairs of contacts to see if the level of systematic variation was associated with the sequence of modes employed in the surveys.

The analysis involves comparisons of pairs of observations on binary variables that were obtained from the same subjects. Thus, McNemar's test for pair-matched designs was used to analyze the data [8]. This test focuses on the discordant pairs of responses and seeks to determine whether the rate of change of responses in one direction (e.g. 'yes' to 'no') is greater than the rate of change in the other.

RESULTS

The results of the 117 statistical tests (37 items by 3 interview pairs) are summarized in Table 1. The overall impression is one of much greater variation in responses between two interviews conducted by different modes that between two interviews conducted by the same mode. The comparisons of two telephone interviews, I-5 and I-6, produced only four statistically significant differences, all of which involved recent symtomatology. Two symptoms were reported with greater frequency and two with lower frequency at I-6. The comparisons of two face-to-face interviews, II-1 and II-2, produced only six statistically significant differences, including four symptoms, one measure of utilization and a measure of social circumstances. One symptom was reported with greater frequency at II-2 but the other five items were answered affirmatively less frequently at II-2 than at II-1.

Table 1. Associations between Responses at Two Followups. Table entries are the numbers of statistically significant associations.

	Comparison		
Subject (Number of Items)	I-6 vs. I-5	II-1 vs.I-6	II-2 vs. II-1
Symptoms (20)	4	10	4
CES-D Scale (1)	-	-	-
Restricted Activity (1)	-	-	-
Utilization (6)	-	2	1
Social Circumstances (5)	-	1	1
Stress (4)	-	3	-

In contrast to this, the comparisons of responses to telephone interviews at I-6 with responses to face-to-face interviews at II-1 produced 16 statistically significant differences: 10 symptoms, two utilization measures, one aspect of social circumstances and three measures of stress. In all but the measure of social circumstances, affirmative answers were obtained with much greater frequency in the face-to-face interviews than in the telephone interviews. Consider for example, reports of recent backaches (25.2 % at I-6 vs. 37.5% at II-1), headaches (29.3% at I-6 vs. 46.9% at II-1) and, under the stress measures, reports of special worries (48.8% at I-6 vs. 62.2% at II-1).

In using recent symptomatology as a measure of health status, analyses often focus on the number of symptoms reported, rather than on the individual symptoms themselves [6,9]. The consistent increases between interviews I-6 and II-1 in the frequencies with which individual symptoms are reported results in a substantial increase in the proportion of subjects who reported relatively large numbers of symptoms (Table 2). Such changes did not occur between interviews I-5 and I-6 or between interviews II-1 and II-2.

Table 2. Frequency Distributions of the Number of Symptoms Reported At The Four Followups

	Followup			
Number of Symptoms	I-5	I-6	II-1	II-2
0	16.7%	18.8%	8.2%	5.4%
1-2	34.2	32.1	21.4	22.6
≥3	49.2	49.1	70.4	72.0

Some of the differences in these comparisons are undoubtedly attributable to real changes in this population, rather than to changes in survey mode. For example, responses to questions regarding recent menstrual history and menopausal symptomatology indicated that, as of interview I-6, the subjects in this analysis were either premenopausal or they were in the earliest stages of the menopause. The premenopausal subjects had reached ages at which the menopause was imminent. Thus, the rapid changes in menopause status that were taking place over these four contacts were expected to bring about increases in reports of menopausal symptoms (hot flashes and night sweats) and decreases in reports of menstrual problems. Indeed, changes in the frequencies with which these symptoms were reported account for much of the variation in responses to individual items between interviews I-5 and I-6 and between II-1 and II-2. However, these three were not among the symptoms for which reporting frequency varied between I-6 and II-1. Possibly, the effects of changing survey mode obscured the effects of changing menopausal status. In any case, setting these symptoms aside does not alter the patterns described above: the proportion of subjects who report relatively large numbers of symptoms still increased between I-6 and II-1 but did not change between I-5 and I-6 or between II-1 and II-2.

It is important to recognize, however, that some women find the experience of the menopause uncomfortable and that such discomfort could lead to increased reporting of symptoms, other than menopausal symptoms themselves. Such discomfort could also lead to increased reporting of other sources of stress. This would imply that the changes in reporting between I-6 and II-1 were caused by changes in menopause status, not by changes in survey mode. However, when the analyses in Table 1 were repeated, including in a given crosstabulation only those women whose menopausal status did not change between those two followups, essentially the same results were obtained. Thus, changes in menopause status do not explain the abrupt increases between I-6 and II-1 in reports of common symptoms or sources of stress. It therefore appears that the switch from telephone to face-to-face interviews was accompannied by substantial changes in responses to some key items in this study.

In most epidemiologic investigations, inferences are based on associations among variables, not on the distributions of individual variables. It is therefore important to consider the impact of survey mode on these associations: if responses to two items vary with survey mode, a change of mode could affect the association between them. This problem was investigated by examining the association between stress, as measured by the item regarding special worries, and health, as measured by the number of symptoms reported. These measures were chosen in part because both have been employed in prior analyses of the data from this study [6,9]. A measure of stress could be constructed from the four items described above but responses to the four are so highly correlated that a single item carries most of the information in the four.

The effects of survey mode on the associations between stress and health were examined both cross-sectionally and longitudinally. In the cross-sectional investigations, the average number of symptoms reported at a given followup, by subjects who reported special worries at that time, was compared with the number reported by subjects who reported no such worries at the same time. At all four followups, those who reported that someone had caused them special worry reported more symptoms than did those who did not report such worry (Table 3). However, the difference in symptom reporting between these two groups varied only slightly across the four followups, which indicates that the difference was not affected by the method of contact employed at a followup. Thus, the cross-sectional association between these measures of stress and health was unaffected by survey mode.

The longitudinal analysis focused on the effects of changes in special worries on changes in symptom reporting. This was accomplished using linear regressions of symptom reporting at a followup on worries at that contact and symptoms at the prior contact, using data only from those who did not report worries at the prior contact. In effect, these regressions focus on the effects of the onset of stress on symptom reporting.

Table 3. The Effect of Self-Reported Special Worries on the Mean Number of Symptoms Reported At Each Followup

	Followup			
Special Worries	I-5	I-6	II-1	II-2
yes	4.7	4.2	5.4	5.3
no	2.7	2.7	3.7	3.8
difference	2.0^{***}	1.5^{***}	1.7^{***}	1.5^{***}

***$p< 0.001$

The results of these regressions are presented in Table 4. As expected, the number of symptoms reported at interviews I-6, II-1 and II-2 is strongly associated with the number reported at the preceding interview. However, the number of symptoms reported varies with stress only at interview II-1. That is, the onset of special worries appeared to affect the number of symptoms reported only when the mode of contact changed between two interviews. This suggests that the association results from a bias induced by changing modes and does not reflect a real underlying association between stress and health in this dataset. This is not an isolated result: similar regressions of symptoms on the two other measures of stress that varied with mode produced the same results.

Table 4. Linear Regressions Of The Number of Symptoms Reported At A Followup on Special Worries At That Contact and Symptoms At The Prior Contact, Among Women Who Did not Report Special Worries At The Prior Contact

	Followup		
Parameter	I-6	II-1	II-2
Intercept	$.8867^{**}$	1.7631^{***}	1.8893^{***}
Symptoms	$.6654^{***}$	$.6498^{***}$	$.5099^{***}$
Worries	.5392	1.2513^{**}	.6191

** $p\leq 0.01$
*** $p\leq 0.001$

DISCUSSION

In this paper, the effects of a change of survey mode on the responses in two longitudinal studies were examined. Altering the method of contact affected the responses to some important items in the study. The cross-sectional associations among variables were not affected but the associations between change in one variable and change in another were affected by the switch in survey mode.

The last result is particularly important because it indicates that under some circumstances the inferences that might be drawn from a longitudinal study, regarding the correlates of change in a dependent variable, could be affected by changes in the methods of contact used in the study. In this case, the change of method may have induced an association between change in one variable and change in another where no real association exists.

An important feature of this analysis is that both the independent and dependent variables were affected by the method of contact. Many analyses focus on the relation between change over time in a dependent variable and characteristics that are measured only once during a study, typically at baseline. In such a case, only the dependent variable would be subject to variation with survey mode. However, the effect of this variation on an analysis would still depend upon the relation between the tendency for responses to vary with mode and the independent variables in the regression. If response variation was unrelated to these independent variables, then mode-related response variation would constitute an extra source of variation in the dependent variable, which could reduce or, if strong enough, obscure the association between change in that variable and baseline characteristics of the subjects. If, however, the tendency for responses to vary with mode also varies with these same baseline characteristics (e.g. education), then altering the method of contact could again artificially strengthen the associations between the variables. In either case, it is important to carefully consider the effects of mode-related response variation on the results before drawing inferences from a study.

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PUBLIC HEALTH STATISTICS FOR ASIAN AND PACIFIC ISLANDER AMERICANS

Ninez Ponce, Asian American Health Forum, Inc.

Asian and Pacific Islander Americans present perhaps the most intriguing and complex methodological challenge among all racial and ethnic groups in public health statistics. Despite being the third largest and most heterogeneous minority in the United States, Asians and Pacific Islanders (API) are still lumped together as one monolithic entity, or worse, put in the "other" and "etcetera" categories in morbidity, ambulatory care, and vital statistics datasets.

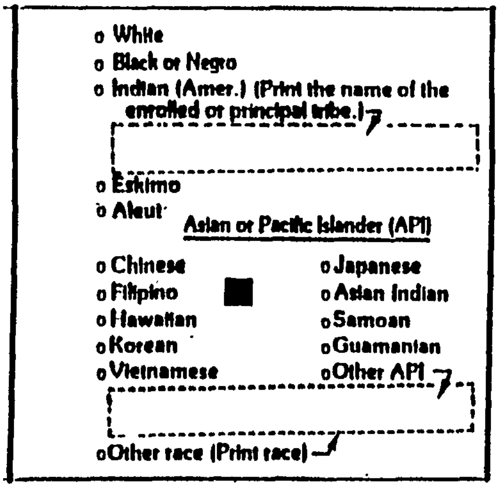
This paper asserts the importance of examining demographic characteristics in distinguishing the health needs of different API subgroups, and discusses the problems and solutions to current health surveillance methods at the local, state, and national levels.

A growing, diverse, and bimodal population

The 1980 Census enumerated 3.7 million Asians and Pacific Islanders in the United States. Extracting from the "other" category of a recent report, the Census Bureau estimates a 47.6% growth in the API population between 1980 and 1985.

1980 was the first time that the Census designated check-off boxes for six Asian and three Pacific Islander subgroups. (Exhibit A) Although the list seems long, it is far from being exhaustive. Because of the overwhelming number of additional API write-in entries in the 1980 Census, demographic information was also collected and cross-referenced for eight more API subgroups: Cambodian, Fijian, Hmong, Indonesian, Laotian, Pakistani, Thai, and Tongan. The race question format displayed in Exhibit A will be retained for the long and short form in the 1990 Census.

Exhibit A



○ White
○ Black or Negro
○ Indian (Amer.) (Print the name of the enrolled or principal tribe.)
○ Eskimo
○ Aleut

Asian or Pacific Islander (API)

○ Chinese
○ Filipino
○ Hawaiian
○ Korean
○ Vietnamese
○ Japanese
○ Asian Indian
○ Samoan
○ Guamanian
○ Other API

○ Other race (Print race)

Over seventy percent (70%) of API cluster in California, Hawaii, New York, Illinois, Texas, Washington, and New Jersey. API are more likely to live in urban rather than rural areas, building communities in coastal cities, notably in the thirteen standard metropolitan statistical areas (SMSAs) listed in Table 1.

Between 1970 and 1980, the API population grew by 141%, far outpacing the proportional growth of all other racial and ethnic groups. Most of this growth can be attributed to the steady stream of immigrants from the Philippines, Korea, and India,

Table 1

Where does each Asian Pacific Islander group cluster?

	Total A/PI	Chinese	Filipino	Japanese	Asian Indian	Korean	Viet-Namese	Laotian	Thai	Cam-Bodian	Hawaiian	Samoan	Tongan	Other
HONOLULU	463,117	52,301	96,421	190,218	637	16,566	3,251	1,284	706	58	82,868	13,975	1,398	3,434
LOS ANGELES	456,693	94,521	100,894	117,190	18,770	60,339	27,252	1,391	8,708	2,826	6,126	7,440	615	10,623
SAN FRANCISCO	335,689	143,551	97,154	40,390	12,782	11,452	10,250	1,635	887	800	5,307	3,502	1,265	6,714
NEW YORK	287,534	133,074	31,902	23,241	55,815	27,610	3,445	419	3,071	335	1,466	108	—	7,048
CHICAGO	152,011	24,980	41,511	16,042	33,541	21,336	4,411	1,924	2,654	473	788	62	—	4,289
SAN JOSE	101,922	22,745	28,229	22,262	5,187	6,237	11,156	420	376	240	1,437	890	52	2,691
SAN DIEGO	95,090	8,618	47,106	13,110	2,097	2,810	7,564	2,679	252	745	2,704	2,699	58	4,648
ANAHEIM	93,491	14,575	11,136	21,841	5,222	10,622	18,033	3,768	631	448	2,603	1,820	168	2,634
WASH.DC	87,037	18,250	12,810	6,318	15,698	17,734	9,910	654	1,099	607	774	121	19	3,043
SEATTLE	68,262	14,141	15,808	17,952	2,416	6,273	4,623	1,468	564	1,115	1,293	1,140	81	1,388
HOUSTON	55,147	13,956	5,801	3,275	11,805	3,542	12,946	528	728	424	413	9	—	1,720
SACRAMENTO	47,593	15,440	7,515	14,836	2,288	1,727	2,755	66	337	24	923	238	22	1,422
BOSTON	39,027	21,442	1,961	3,042	5,864	2,973	1,811	407	355	55	183	56	—	878
13 SMSA Totals	2,282,613	577,594	498,248	489,717	172,122	189,221	117,407	16,633	20,366	8,150	106,885	32,060	3,678	50,532
US Totals	3,726,440	812,178	781,894	716,331	387,223	357,393	245,025	47,683	45,279	16,044	172,346	39,520	6226	99,298

1980 CENSUS OF THE POPULATION FOR 13 SMSAs WITH HIGH A/PI CONCENTRATION Department of Commerce, Bureau of the Census §census\cluster.wk1§

Asian American Health Forum, Inc., San Francisco, CA, April 1989 augmented by the exodus of hundreds of thousands immigrants and refugees from the communist regimes of Vietnam, Laos, and Kampuchea.

In 1980, the top three API groups were the Chinese, the Filipinos, and the Japanese. By 1990, the top three groups are predicted to be the Filipinos, the Chinese, and the Vietnamese. By the year 2030, based on the current dynamics of the API populations, the Center for Migration Studies projections place Filipinos, Vietnamese, and Koreans well ahead of the other API groups. (Table 2)

Table 2

ASIAN AMERICAN HEALTH FORUM, INC.
Projections of the Asian Population in the United States, by Ethnicity: 1980–2030

Ethnicity	1980	1990	2000	2010	2020	2030
Chinese	812,178	1,259,038	1,683,537	2,084,509	2,457,043	2,779,127
Filipino	781,894	1,405,146	2,070,571	2,717,330	3,353,990	3,963,710
Indian	387,223	684,339	1,006,305	1,331,762	1,634,601	1,919,163
Japanese	716,331	804,535	856,619	893,135	929,914	945,534
Kampuchean	16,044	182,301	386,673	603,874	833,415	1,073,111
Korean	357,393	814,495	1,320,759	1,853,003	2,394,602	2,964,986
Laotian	52,887	259,674	502,599	762,398	1,035,273	1,317,353
Vietnamese	245,025	859,638	1,574,385	2,331,827	3,122,591	3,934,661
Other	95,873	261,442	448,919	645,656	849,434	1,055,168
Total	3,466,421	6,533,608	9,850,364	13,223,494	16,610,866	19,934,813

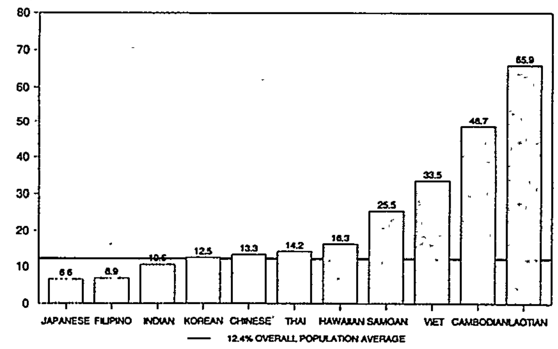
Source: *PACIFIC BRIDGES The New Immigration from Asia and the Pacific Islands, 1987*
East-West Population Institute and Center for Migration Studies $pacbridg.wk1$

The socio-economic profile of Asians and Pacific Islanders spans a wide and sometimes bimodal range, as exhibited in the 1980 Census. For instance, the percentage of individuals below the poverty level ranged from a low of 6% among Japanese, to a national high of 66% among Laotians, compared to 12.4% for the overall population. (Chart 1)

API are usually depicted as faring better than the national average because household rather than per capita income is analyzed, and because income is averaged over markedly diverse ethnic groups. Household-level analysis tends to inflate income reported by API because of the prevalence of extended and compound families, especially among immigrant and first generation API.

Chart 1

WHAT PERCENTAGE OF ASIANS AND PACIFIC ISLANDERS LIVE BELOW THE POVERTY LEVEL?



In 1980, 6.2% of the U.S. population was foreign born. For Asians, a low of 28.4% of Japanese, and a high of 94% of Cambodians were foreign born. For Pacific Islanders, 1.6% of Native Hawaiians and 74.7% of Tongans were foreign born. (Chart 2)

Except for Native Hawaiians, all API subgroups exceeded the US average (10.2%) of language other than English spoken at home. Less than 1% of Native Hawaiians and over 81% of Cambodians spoke a language other than English at home. (Chart 3)

The distinct demographic differences between API subgroups, particularly between the newly-arrived immigrants and the more assimilated larger Asian groups, conveys the relevance of API subgroup analyses in public health statistics.

Deficient API datasets

Unlike the Census, most government statistical gathering agencies neglect to collect, report, and analyze the health and associated socio-economic indicators on Asian and Pacific Islander ethnicities. In certain states, the public health statistics departments fail to even classify API as a separate race entity. Because of these oversights, the API health provider and research communities are unable to monitor and evaluate the health status, disease patterns, and risk factors which affect Asians and Pacific Islanders. By grouping API as "other", "etcetera", or as one broad "API" category, providers and researchers can not distinguish and address the

Chart 2

WHAT PERCENTAGE OF EACH ASIAN/PACIFIC ISLANDER GROUP IS FOREIGN BORN?

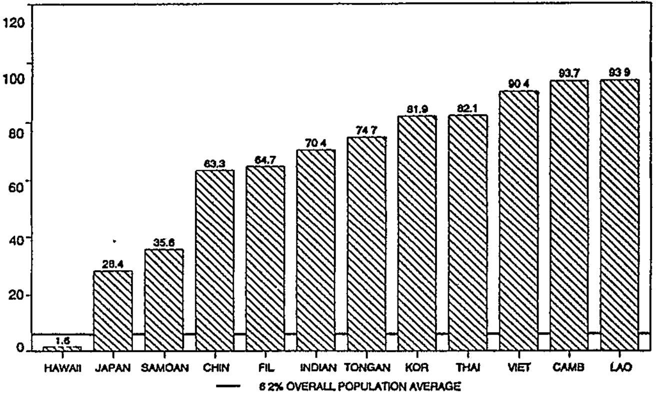
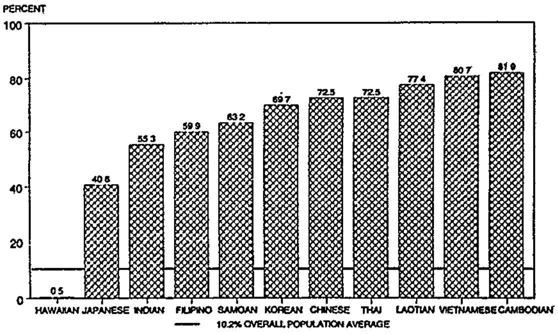


Chart 3

WHAT PERCENTAGE OF EACH ASIAN/PACIFIC ISLANDER GROUP SPEAKS A LANGUAGE OTHER THAN ENGLISH AT HOME?



the unique health promotion, disease prevention, and intervention needs of ethnic subgroups most at-risk.

Although there are available medical records and studies which point to the high incidences of smoking, hepatitis B, beta thalassemia, tuberculosis, cancer, hypertension, and suicide among segments of the API population, the numbers are meaningless to policy makers without a benchmark comparison to the rest of the US population.

Yet how are comparative prevalence rates derived if not enough API are sampled in population-based surveys? Furthermore, since most national, population-based surveys aggregate API, conclusions are likely to be wrong generalizations. In the aggregate, if survey respondents are overwhelmingly more assimilated American-born Asians, then their health profiles may significantly obscure the morbidity and behavioral risk-factor patterns of highland Hmongs and newly-arrived Samoans and Tongans.

Where are the gaps?

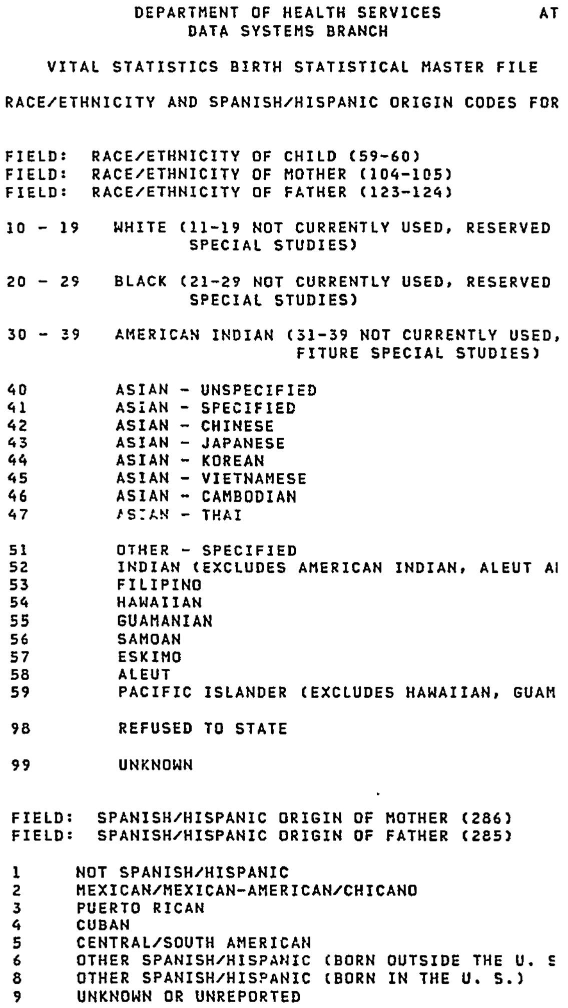
The 1980 Census included nine Asian and Pacific Islander ethnic groups as check-off entries and encoded seventeen API ethnicities. The State of California's race identification worksheet, used in conjunction with the birth, fetal death, and death certificates, designates check-off boxes for eleven API groups, and encodes fourteen API categories. (Exhibit B1 & B2) The National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results (SEER) database's current race definition was expanded to ten API categories in 1988.

The National Center for Health Statistics (NCHS), one of the leading Federal statistical agencies which collects datasets on the extent of illness in the United States and the determinants of health, excludes an identifier for Asians and Pacific Islanders in the race question for birth and death certificates. Revised in January 1989, the U.S. Standard for the birth and death certificates contains a race box which lists "American Indian, Black, White, etc." as examples for write-in entries. (Exhibit C1)

This format negates the significance of API as the third largest minority group, and reinforces the classification of Asians and Pacific Islanders as "etcetera".

Although the NCHS standard format is suggested and not mandated to be adopted by the states, the states where API cluster--Texas, New York, and Illinois have made no expansive modifications in the race question. California and Hawaii have been the most respon-

Exhibit B2



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              DEPARTMENT OF HEALTH SERVICES          AT
                   DATA SYSTEMS BRANCH

         VITAL STATISTICS BIRTH STATISTICAL MASTER FILE

     RACE/ETHNICITY AND SPANISH/HISPANIC ORIGIN CODES FOR


FIELD:   RACE/ETHNICITY OF CHILD (59-60)
FIELD:   RACE/ETHNICITY OF MOTHER (104-105)
FIELD:   RACE/ETHNICITY OF FATHER (123-124)

10 - 19    WHITE (11-19 NOT CURRENTLY USED, RESERVED
                  SPECIAL STUDIES)

20 - 29    BLACK (21-29 NOT CURRENTLY USED, RESERVED
                  SPECIAL STUDIES)

30 - 39    AMERICAN INDIAN (31-39 NOT CURRENTLY USED,
                           FITURE SPECIAL STUDIES)

40         ASIAN - UNSPECIFIED
41         ASIAN - SPECIFIED
42         ASIAN - CHINESE
43         ASIAN - JAPANESE
44         ASIAN - KOREAN
45         ASIAN - VIETNAMESE
46         ASIAN - CAMBODIAN
47         ASIAN - THAI

51         OTHER - SPECIFIED
52         INDIAN (EXCLUDES AMERICAN INDIAN, ALEUT AI
53         FILIPINO
54         HAWAIIAN
55         GUAMANIAN
56         SAMOAN
57         ESKIMO
58         ALEUT
59         PACIFIC ISLANDER (EXCLUDES HAWAIIAN, GUAM

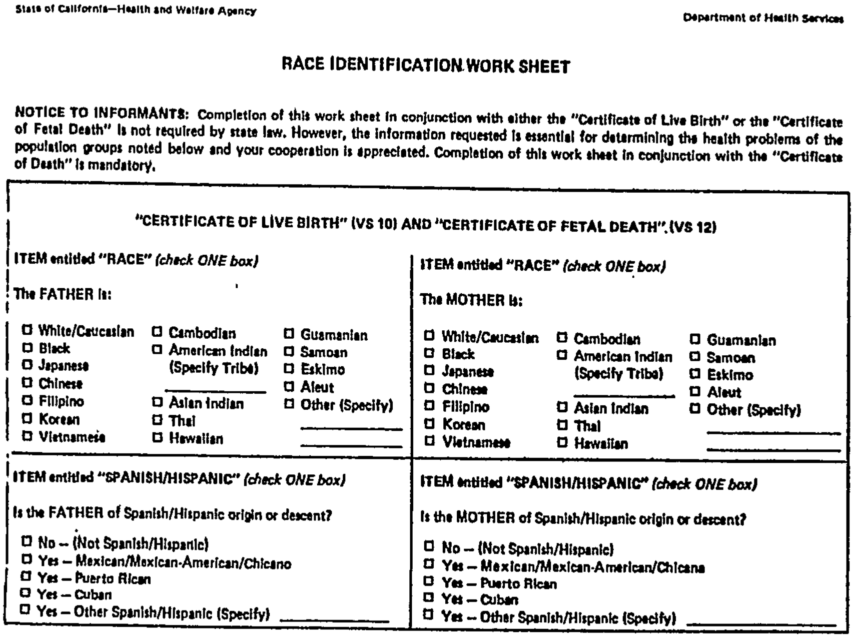
98         REFUSED TO STATE

99         UNKNOWN


 FIELD:  SPANISH/HISPANIC ORIGIN OF MOTHER (286)
 FIELD:  SPANISH/HISPANIC ORIGIN OF FATHER (285)

1       NOT SPANISH/HISPANIC
2       MEXICAN/MEXICAN-AMERICAN/CHICANO
3       PUERTO RICAN
4       CUBAN
5       CENTRAL/SOUTH AMERICAN
6       OTHER SPANISH/HISPANIC (BORN OUTSIDE THE U. S
8       OTHER SPANISH/HISPANIC (BORN IN THE U. S.)
9       UNKNOWN OR UNREPORTED
```

Exhibit B1



State of California—Health and Welfare Agency

Department of Health Services

RACE IDENTIFICATION WORK SHEET

NOTICE TO INFORMANTS: Completion of this work sheet in conjunction with either the "Certificate of Live Birth" or the "Certificate of Fetal Death" is not required by state law. However, the information requested is essential for determining the health problems of the population groups noted below and your cooperation is appreciated. Completion of this work sheet in conjunction with the "Certificate of Death" is mandatory.

"CERTIFICATE OF LIVE BIRTH" (VS 10) AND "CERTIFICATE OF FETAL DEATH" (VS 12)

ITEM entitled "RACE" *(check ONE box)*

The FATHER is:

☐ White/Caucasian
☐ Black
☐ Japanese
☐ Chinese
☐ Filipino
☐ Korean
☐ Vietnamese
☐ Cambodian
☐ American Indian (Specify Tribe) ____________
☐ Asian Indian
☐ Thai
☐ Hawaiian
☐ Guamanian
☐ Samoan
☐ Eskimo
☐ Aleut
☐ Other (Specify) ____________

ITEM entitled "RACE" *(check ONE box)*

The MOTHER is:

☐ White/Caucasian
☐ Black
☐ Japanese
☐ Chinese
☐ Filipino
☐ Korean
☐ Vietnamese
☐ Cambodian
☐ American Indian (Specify Tribe) ____________
☐ Asian Indian
☐ Thai
☐ Hawaiian
☐ Guamanian
☐ Samoan
☐ Eskimo
☐ Aleut
☐ Other (Specify) ____________

ITEM entitled "SPANISH/HISPANIC" *(check ONE box)*

Is the FATHER of Spanish/Hispanic origin or descent?

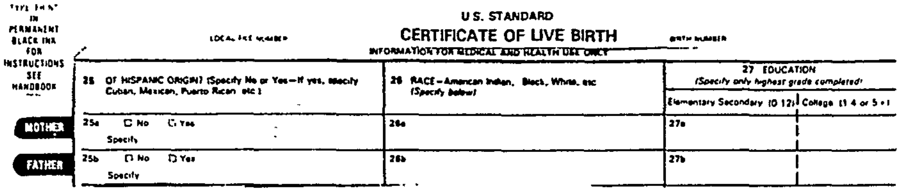
☐ No – (Not Spanish/Hispanic)
☐ Yes – Mexican/Mexican-American/Chicano
☐ Yes – Puerto Rican
☐ Yes – Cuban
☐ Yes – Other Spanish/Hispanic (Specify) ____________

ITEM entitled "SPANISH/HISPANIC" *(check ONE box)*

Is the MOTHER of Spanish/Hispanic origin or descent?

☐ No – (Not Spanish/Hispanic)
☐ Yes – Mexican/Mexican-American/Chicana
☐ Yes – Puerto Rican
☐ Yes – Cuban
☐ Yes – Other Spanish/Hispanic (Specify) ____________

Exhibit C1



TYPE PRINT IN PERMANENT BLACK INK FOR INSTRUCTIONS SEE HANDBOOK

LOCAL FILE NUMBER

U.S. STANDARD
CERTIFICATE OF LIVE BIRTH
INFORMATION FOR MEDICAL AND HEALTH USE ONLY

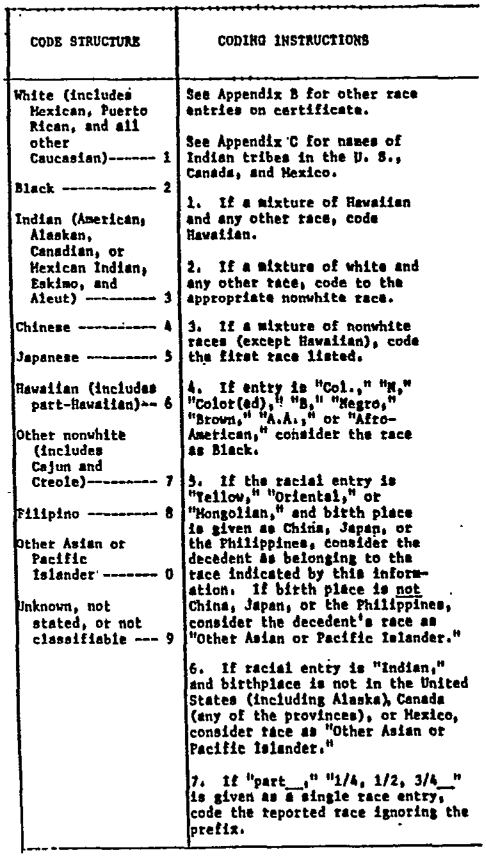
BIRTH NUMBER

	25 OF HISPANIC ORIGIN? (Specify No or Yes—If yes, specify Cuban, Mexican, Puerto Rican, etc.)	26 RACE—American Indian, Black, White, etc. (Specify below)	27 EDUCATION (Specify only highest grade completed) Elementary Secondary (0-12)	College (1-4 or 5+)
MOTHER	25a ☐ No ☐ Yes Specify	26a	27a	
FATHER	25b ☐ No ☐ Yes Specify	26b	27b	

sive to improving the morbidity and mortality surveillance of API.

NCHS contends that the race question in Exhibit C1 does not impede the entry of Asian or Pacific Islander or of different API ethnic identifiers. In their experience, NCHS has been able to collect and encode for Chinese, Japanese, Filipino, Hawaiian, and other API. (Exhibit C2).

Exhibit C2



CODE STRUCTURE	CODING INSTRUCTIONS
White (includes Mexican, Puerto Rican, and all other Caucasian)------ 1 Black ----------- 2 Indian (American, Alaskan, Canadian, or Mexican Indian, Eskimo, and Aleut) --------- 3 Chinese ---------- 4 Japanese --------- 5 Hawaiian (includes part-Hawaiian)-- 6 Other nonwhite (includes Cajun and Creole)--------- 7 Filipino --------- 8 Other Asian or Pacific Islander ------- 0 Unknown, not stated, or not classifiable --- 9	See Appendix B for other race entries on certificate. See Appendix C for names of Indian tribes in the U. S., Canada, and Mexico. 1. If a mixture of Hawaiian and any other race, code Hawaiian. 2. If a mixture of white and any other race, code to the appropriate nonwhite race. 3. If a mixture of nonwhite races (except Hawaiian), code the first race listed. 4. If entry is "Col.," "N," "Color(ed)," "B," "Negro," "Brown," "A.A.," or "Afro-American," consider the race as Black. 5. If the racial entry is "Yellow," "Oriental," or "Mongolian," and birth place is given as China, Japan, or the Philippines, consider the decedent as belonging to the race indicated by this information. If birth place is not China, Japan, or the Philippines, consider the decedent's race as "Other Asian or Pacific Islander." 6. If racial entry is "Indian," and birthplace is not in the United States (including Alaska), Canada (any of the provinces), or Mexico, consider race as "Other Asian or Pacific Islander." 7. If "part__," "1/4, 1/2, 3/4__" is given as a single race entry, code the reported race ignoring the prefix.

Since there is a sizable API response to this question, NCHS feels that there is no need to change the word "etc." to "Asian and Pacific Islander" in the race question. Pending the verification of this qualitative assessment, it is inherantly clear that absence of the prompt for Asian and Pacific Islander reponses results in misclassification and undercounting of API. NCHS lags behind the Census Bureau, NCI, and the State of California in advancing the analyses of the diverse health status and health care needs of Asian and Pacific Islander Americans.

Summary of problems of data on API

At the national level, specifically for the NCHS administered Health Interview Survey (HIS) and the Health and Nutrition Examination Survey (HANES), the major problems are:

1) Aggregation of API subgroups.
2) Small number of API sampled in surveys; about 1500 API are sampled out of 50,000 households in the HIS.
3) Lack of cultural sensitivity in survey design, data collection and analysis; Monolingual, non-English speaking API are excluded from most national surveys.
4) Near zero publication of results which highlight and crosstabulate API health status.

At the state level, the problems are:

1) Variability of ethnicity reporting for states.
2) Population denominator constraints; California's State Department of Finance collects inter Census population counts for "Asian and other", constraining the expansive API numerators collected by the State Department of Health.
3) Aggregation of data upstream when submitted to NCHS.

At the local level, recurrent problems for targetted local surveys are:

1) Surveys are not population-based; sample bias.
2) Lack of technical and fund support for building datasets which could have national or regional significance.

Recommendations to NCHS for improving API data

1) Disaggregate API to a minimum of the nine subgroups listed in the 1980 and 1990 Census race question. (Exhibit A) States can include emerging groups, particularly Thais, Cambodians, and Laotians.
2) Oversample for API in the HIS and HANES
3) Co-finance a California HIS
4) Include nativity and year of immigration in survey instruments
5) NCHS and Centers for Disease Control should increase grants for local surveys on morbidity and risk factors.

Given that the vital registration system provides a rich 100% count datasource, overriding all other recommendations is the inclusion of an identifier for Asians and Pacific Islanders in the US standard birth and death certificates.

PLANS AND PROSPECTS FOR STATE AND LOCAL ESTIMATES

Donald E. Starsinic, U.S. Bureau of the Census

I have been asked to report on the plans the Census Bureau has for the preparation of population estimates for subnational areas in the 1990s. Those of you who are familiar with our current estimates program have learned that the Bureau releases population estimates on a regular schedule for a wide variety of areas and that the coverage of our program has tended to expand over time in terms of additional geographic areas and additional characteristics. In the last few years we also have experimented with various options for releasing the estimates to the public to reduce the waiting time for access to data via formal publications. As we approach the 1990s there is considerable ferment within the Census Bureau to develop plans for modifying census-taking practices in future censuses. These plans can have a major impact on our estimates program as we get further into the 1990s. At this time, I'd like to review our current program with you and talk about the various ways the program will (or may) change after 1990.

CURRENT ESTIMATES PROGRAM

The Regular Estimates Program

In the 1980s the Census Bureau has published annual estimates of the resident population for states and counties. In addition, we publish biennial population estimates in five regional reports for counties and 36,000 subcounty political jurisdictions with active governments--all 19,000 incorporated places plus minor civil divisions (townships or towns) in the Northeast and Midwest.

For states, we also publish estimates of the components of change since 1980 (births, deaths, and residual net migration), as well as estimates by sex for 10-year age groups and for selected broad ages. We have the programming capability of generating these estimates for any age group requested by the user up to age 85 and over. Both the flexible age detail and the estimates by sex are new in the 1980's, developed in direct response to Federal agency needs for a variety of different age ranges and to the National Center for Health Statistics' need for sex detail. Another new state data set introduced in the 1980's is household estimates, developed experimentally by Campbell Gibson in 1985 and since then routinely incorporated into the state population estimates reports.

As a by-product of the county estimates, we also produce components of population change and estimates of the population 65 and over, which have been made available to users in unpublished form. The components of change will be incorporated into the county estimates publication beginning this year with the 1988 round of estimates. Rankings by population size and population increase are available upon request.

Population estimates for metropolitan statistical areas (MSAs) are derived from the county estimates by summarizing the county data to obtain MSA totals. In New England, further estimating is neccessary to separate the county estimates into the parts in different MSAs and a nonmetropolitan balance. MSA estimates are released each year in Census Bureau press releases. Periodically during the decade, analytical reports are published on metropolitan area population trends, focusing on metropolitan-nonmetropolitan patterns of change by region and division. Components of population change for each metropolitan area and its component counties are made available in unpublished form annually, and they are being published this month for the 1980-87 period.

For subcounty areas, the only population detail available is the published totals, which appear for even-numbered years together with estimates of each area's per capita income (PCI) developed from data reported for the previous year (e.g., PCI for 1985 is shown with the 1986 population estimates). Data are published by county within state in five regional reports, with the Midwest split into two divisions. Within each county all incorporated places are presented in one alphabetical cycle, followed by an alphabetical presentation by township or town where appropriate. The estimates universe consists of those jurisdictions which have active functioning governments. This program was developed in the 1970s to provide data for the Federal General Revenue Sharing Program. Since the demise of that program in 1987, demand for continued availability of population and PCI estimates for these areas by other Federal government programs has overridden the Census Bureau's inclination to limit estimates to areas with populations above 2,500 because of the relatively high estimation error for smaller areas.

General Methodologies

The estimates for each of these area levels are developed using one or more methodologies, all of which use the 1980 census as a base and utilize current data series to estimate the current population. The most universally used method is the Administrative Records method, which estimates the components of change since the previous estimate and adds (or subtracts) them to obtain a current population total. Births and deaths are estimated for states and counties using reported vital statistics; for subcounty areas they are estimated using 1980 birth or death rates and adjusting to county totals. The net internal migration component for all areas is derived by matching reported Federal individual income tax returns for successive 1- or 2-year periods to measure the number of persons moving into and out of a jurisdiction, converting this into a net migration rate, and applying the rate to the population at risk for the jurisdiction.[1] An allowance for net immigration from abroad for the migration period is added.

The second commonly used methodology is the Ratio-Correlation method, which measures the change in each subarea's share of the parent area's population (the dependent variable) by relating it to change in shares of other data series (the independent variables). For example, the parent area is a state and the subareas are the counties within the state. The operations are done in two steps: (1) Develop a base equation for a prior period (1970-80), establishing the interrelationships between change in the population share and changes in the shares of the independent variables. This base equation provides a set of predictive weights; and (2) Apply the weights to the change in each independent variable's share of the parent area's total during the 1980s to predict the change in the population share for the current period.[2]

A third less commonly used methodology is Component Method II, in which the migration component is derived by (1) relating changes in school enrollment since 1980 to changes in the school-age cohort (those who would be of school age on any given estimate date), (2) reducing this to a net migration rate, (3) adjusting this school-age rate to a migration rate for the broader population, and (4) applying the adjusted migration rate to the population at risk.[2] Component Method II also is used in preparing the state age estimates. Other methods may be used for a few states in developing the county estimates totals.

When these methods are used to estimate the total population for subcounty areas, they apply to the total population. At the state and county level they are used only to estimate the population under 65 years of age, with the older population estimated using change in reported Medicare enrollments since 1980 applied to the 1980 census population 65 and older.

Publication Format

The formal publication vehicle for the Census Bureau's population estimates is Current Population Reports, Series P-25 (states and metropolitan areas, as well as U.S. estimates and all population projections) and Series P-26 (counties and subcounty areas). Because of the increasing delays in publication of the estimates and the intense demands by the public for early access to the numbers, we have developed several publication alternatives. State estimates totals, which must be published by December 31 of the estimate year, first appear in a Census Bureau press release. This year, state age estimates also have had early release in this format. The annual MSA estimates also have used the press release format as their publication vehicle.

The estimates in the regular program are selectively placed on CENDATA at the earliest possible opportunity to make them available to microcomputer users on CompuServe and DIALOG. This form of electronic publication has been accomplished weeks or months prior to the release of the estimates in the Series P-25 and P-26 printed reports. It triggers the release of the data on IBM diskette, 9-track tape, and paper copy to users at cost prior to the formal publication. Special summaries are generated, such as rankings of counties, MSAs, and cities by population size or percent change since 1980. These are made available on paper, diskette, or tape. See figure 1 for the availability of estimates series in the various publication formats.

Experimental Estimates

The Census Bureau has maintained two experimental population estimates series in the 1980s. The first is a set of annual county estimates by 5-year age group by sex and race (White, Black, and other races). Richard Irwin developed this series in the mid-1970s using a cohort-component projection technique but using current estimates data as rim controls--total county population, national age, race, and sex estimates, plus estimated county births and deaths, as available.[3] This series, prepared annually for use by the National Cancer Institute (NCI) in developing rates of cancer incidence, is not fully integrated with the current state data by age and sex, and there are very few race estimates available for use as rim controls. It is running several years behind the regular estimates in processing--1985 estimates were only released this spring. The 5-year series is available on 9-track computer tape or on printouts, one page per county (see figure 2).

The second experimental series produces current population estimates for about 500 discrete areas by race (White, Black, and other races) and Hispanic origin. Within each state the areas are each MSA (or MSA part within the state) and the state's nonmetropolitan balance. There are also estimates for about 100 selected counties with large Black, other races, or Hispanic populations. These estimates are developed by a variation of the Administrative Records method, where a 20-percent sample of the Federal income tax returns was matched with Social Security records to estimate net migration by race and Hispanic origin. Estimates for the years 1980 to 1985 were published in June.[4] There are no plans for publishing later years in the decade, but we will do the estimates for these later years to test the procedure. This series has not been integrated with the independent state and county estimates published by the Census Bureau.

ESTIMATES AND PROGRAM MODIFICATIONS FOR THE 1990s

Tests of Methods/Intercensal Series

The 1990 census results will provide a benchmark for evaluating the population estimates for all areas. We plan to test each of the estimating methods for its accuracy in estimating the 1990 population. Variations of each method, combinations of methods, and new methods will be tested to improve the accuracy of the estimates product. New methodologies for the 1990 decade will be selected as a result of the test. Selection of methods at the county level will be made jointly by the Census Bureau and the state agency represented in the Federal-State Cooperative Program for Population Estimates (FSCPE). For states and subcounty areas the selection decision will be the Bureau's, although the FSCPE agencies will be consulted.

The availability of 1990 census counts also will permit a reworking of 1980-90 annual estimates time series to make them consistent with the 1990 benchmark. Revised estimates for the 1980s for states, counties, and metropolitan areas will be published in the early 1990s, but subcounty estimates probably will not be revised because of the cost and time required.

Possible Estimates Program Changes for the 1990s

The Census Bureau expects to continue into the 1990s the various regular estimates programs now in place. We hope to have the funding to incorporate the experimental race-Hispanic estimates into our regular program and also to extend the match of Internal Revenue Service and Social Security records from 20 percent to the entire file. This would permit making estimates by race and Hispanic origin for smaller geographic areas. It also would vastly improve the race estimates used in the experimental NCI county age-sex-race estimates, which also could be incorporated into our regular estimates. The race/Hispanic estimates also potentially could provide age detail that would improve upon those generated by the projection methodology used in the NCI estimates and possibly replace this series.

We are also considering the possibility of using new methodologies. As part of our internal review of the 1990 census counts for reasonableness, we expect to develop the capability of generating population estimates by the Housing Unit method using the Census Bureau's files on building permit and demolition activity for 17,000 subcounty areas. For the 1990s we expect to use these as alternative estimates to the Administrative Records method, which to this point has been the only methodology available to us for use in our subcounty estimates. We are also investigating other data and methods.

Population totals and the voting-age population for Congressional districts, which were estimated during the 1970s, are the only estimates program cut back in the 1980s, when the funding for this series was deleted from the Census Bureau's budget. It is possible that this series will be restored for the 1990s if there is sufficient demand.

Perhaps the most intriguing changes in the estimates program which could occur in the 1990s will be in response to the Census Bureau's search for improved ways to take future censuses. The Bureau has become increasingly concerned about its ability to maintain a trained field staff large enough to take the decennial census in its present configuration. Costs have skyrocketed and staffing demands are becoming impossible to accommodate for the temporary field work required in the years ending in 9 and 0. As a result, the Census Bureau is considering several options which would make future censuses more limited in scope and field operations but would still provide the demographic detail expected by users.

One option would supplement a limited population and housing census with several surveys. There could be a large mid-decade national survey that would provide long-form census data down to the census tract level. There also could be a monthly sample survey that would produce annual data for population groups of 100,000 or more, for example.

The impact of such an expanded set of surveys on the current population estimates program is obvious. Greatly expanded estimates would be required as controls for the surveys in terms of areas covered and demographic detail provided. We would be expected to provide some age-race-sex detail down to the place level. We would also be challenged to find ways of developing comparable detail for census tracts, for which the Census Bureau has not prepared population estimates in the past.

The demands of the surveys also would force us to develop techniques for producing estimates with less of a time lag than we currently have (6 months for states, 12 months for counties/MSAs, and 15 months for subcounty areas).

Such a challenge would require a greatly expanded estimates staff and an integration of computer operations beyond our current operating levels. I believe that major changes in census taking procedures will take place, and that it will greatly increase the demand for population estimates during the 1990s. I look forward to the challenges that this demand will prompt.

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[1] Current Population Reports, Series P-25, No. 699, "Population and Per Capita Money Income Estimates for Local Areas: Detailed Methodology and Evaluation," June 1980.

[2] Current Population Reports, Series P-25, No. 957, "Estimates of the Population of States: 1970 to 1983," October 1984 (all ages), and No. 1010, "State Population and Household Estimates, With Age, Sex and Components of Change: 1981-86," September 1987 (age-sex and households).

[3] Current Population Reports, Series P-23, No. 158, "Methodology for Experimental County Population Estimates for the 1980's," September 1988, and No. 103, same title for July 1, 1975, May 1980.

[4] Current Population Reports, Series P-25, No. 1040-RD-1, "Population Estimates by Race and Hispanic Origin for States, Metropolitan Areas, and Selected Counties: 1980 to 1985," by David L. Word, May 1989.

Figure 1. BUREAU OF THE CENSUS' SUBNATIONAL POPULATION ESTIMATES PROGRAM, 1980s

Population estimates series	Frequency[1]	Latest date released	Publication format				Methodology
			Advance press release	CEN-DATA	P-25, P-26	Tape/diskette[2]	
State estimates	A	7/1/88	x	x	P-25	D	Composite CM II Ratio-Cor. Admin. Records
State age-sex estimates[3]	A	7/1/88	-	x			
Metropolitan area estimates	A	7/1/87	x	x	-	D	Based on county ests.
Metropolitan trends	I	7/1/87	x	-	P-25	D	
County estimates	A	7/1/88	x	x	P-26	T/D	Admin. Records Ratio-Correlation Component Method II Other
County age-sex-race estimates	A	7/1/85	-	-	-	T	Cohort Component
Subcounty estimates[4]	B	7/1/86	-	x	P-26	T/D	Admin. Records
Race/Hispanic estimates	I	7/1/85	-	x	P-25		Extended Admin. Rec.
Congressional district estimates	I	7/1/86	x	x	-	-	Based on subcounty est.

[1] A annual; B biennial; I irregular. [2] T tape; D diskette. Note that any data available on tape or diskette can be obtained on paper copy at cost. [3] Also state household estimates. [4] Also per capita income for the previous year.

Figure 2. DISPLAY OF EXPERIMENTAL AGE-SEX-RACE ESTIMATES FOR PRINCE GEORGE'S COUNTY, MD

(Note: Actual county display shows annual data from 1980 to 1985)

	July 1, 1980						July 1, 1981					
	Total		White		Black		Total		White		Black	
AGE	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female
0-4	23820	22856	11814	11092	11105	10927	24321	23343	11660	10972	11678	11454
5-9	25111	23722	12079	11315	12139	11571	24141	23027	10947	10498	12258	11652
10-14	29966	28955	15411	14628	13641	13498	29097	28246	14385	13781	13736	13582
15-19	34427	34432	20829	20211	12718	13387	32878	32946	19377	18813	12586	13276
20-24	35852	38054	24133	23249	10889	13833	36328	38687	24156	23258	11267	14381
25-29	32514	35183	19421	18274	12132	15783	34136	36366	19558	18123	13491	17014
30-34	29787	32749	16238	15686	12559	15899	30424	33072	15786	15044	13555	16790
35-39	23765	25788	12967	13465	9956	11392	24220	26135	12729	13063	10574	12050
40-44	19921	20187	11569	11689	7632	7782	20050	20284	11147	11213	8114	8280
45-49	17007	16714	11022	10910	5487	5243	16987	16741	10665	10618	5771	5515
50-54	15302	15350	11189	11295	3724	3668	15376	15279	10976	10951	3971	3900
55-59	12981	14650	10196	11579	2538	2812	12810	14506	9895	11291	2652	2931
60-64	9737	10834	7942	8800	1624	1830	9831	10985	7902	8859	1739	1903
65-69	6216	8009	5055	6492	1024	1360	6549	8291	5270	6635	1123	1476
70-74	3742	5802	3056	4840	599	874	3860	6010	3126	4941	638	966
75-79	2219	4053	1778	3395	391	613	2335	4281	1856	3562	423	667
80-84	1077	2708	897	2385	154	308	1104	2737	909	2372	167	348
85+	749	2096	623	1802	114	281	783	2219	637	1895	132	310
All Ages	324193	342142	196219	201107	118426	131061	325230	343155	190981	195889	123875	136495

For information on availability on paper copy, call (301) 763-5072. Tape available through Data Users Services Division, (301) 763-4100.

EXAMPLES OF RECENT POPULATION ESTIMATES AND PROJECTION REPORTS
AND FILES RELEASED BY THE BUREAU OF THE CENSUS
(Published in Current Population Reports, Series P-25 unless otherwise indicated)

National Estimates and Projections Reports

1. No. 1041.--"Estimates of the Population of the United States to April 1, 1989," May 1989. (Monthly)
2. No. 1023.--"United States Population Estimates and Components of Change: 1970 to 1987," September 1988. (Annual)
3. No. 1022.--"United States Population Estimates, by Age, Sex, and Race: 1980 to 1987," March 1988. (Annual)
4. No. 995.--"Projections of the Hispanic Population: 1983 to 2080," November 1986.
5. No. 1018.--"Projections of the Population of the United States, by Age, Sex, and Race: 1988 to 2080," January 1989.
6. No. 986.--"Projections of the Number of Households and Families: 1986 to 2000," May 1986.

State and Outlying Areas Estimates and Projections Reports

1. No. 1019.--"Projections of the Population of Voting Age for States: November 1988," January 1988. (Biennial)
2. No. 1024--"State Population and Household Estimates to 1987, with Age, Sex and Components of Change," May 1988. (Annual) Advance population totals for 1988 appeared in a Census Bureau Press Release CB89-47, March 1989. See also No. 957 and 1010 for detailed methodology and accuracy of methods.
3. No. 1017.--"Projections of the Population of States, by Age, Sex, and Race: 1990 to 2010," October 1988.
4. No. 1030.--"Estimates of the Population of Puerto Rico and the Outlying Areas: 1980 to 1987," August 1988. (Annual)

Race/Hispanic Estimate Reports

1. No. 1040-RD-1.--"Population Estimates by Race and Hispanic Origin for States, Metropolitan Areas, and Selected Counties: 1980 to 1985," May 1989. Experimental estimates show "black," "other races," and "Hispanic" detail.

Metropolitan Area, County, Place, and MCD Estimates Reports

1. Series P-26, No. 87-A.--"County Population Estimates: July 1, 1987 and 1986," September 1988. (Annual). Press Release CB 88-157 summarizes the estimates for metropolitan statistical areas. Report No. 88-A in preparation.
2. Series P-23, No. 156.--"Estimates of Households, for Counties: July 1, 1985," March 1988.
3. No. 1039.--"Patterns of Metropolitan Area and County Population Growth: 1980 to 1987," June 1989. Shows 1987 estimates for individual metropolitan areas, component counties and central cities, and summary data by metropolitan-nonmetropolitan for regions, divisions, and States. Based on P-26, No. 87-A.
4. Series P-26, No. 85-AL-C to 85-WY-C.--Individual State reports prepared jointly by the Bureau of the Census and designated State agencies under the Federal-State Cooperative Program for Population Estimates. Covers counties and MSA's as of July 1, 1981 through 1985. Consistent with Series P-26, No. 86-A.
5. Series P-26, No. 86-(region)-SC.--Regional reports (Northeast, East North Central, West North Central, South, West) presenting 1986 population estimates for counties, incorporated places, and minor civil divisions for the States in the region; March 1988. (Biennial) Also shows 1985 per capita income for these areas. Update to 1988 (pop.) and 1987 (PCI) to be available late 1989.
6. 1980 Census Supplementary Report, PC80-S1-17, "Gross Migration for Counties: 1975 to 1980," March 1984.--Shows in- and out-migration to each county by sex, race, and age as derived from the 1980 census question "Where did you live in 1975?"

Experimental County Age Estimates

1. Tape file on experimental county estimates by age, sex, and race (white, black, other races) for the years 1980 through 1985. Available through Data User Services Division, 301/763-4100.
2. Series P-23, No. 158.--"Methodology for Experimental County Population Estimates for the 1980's," September 1988.

Survey of Agencies Report

1. No. 723.--"Inventory of State and Local Agencies Preparing Population Estimates and Projections: Survey of 1975-76," May 1978. New survey is being conducted in 1989.

Tests of Methods Reports

1. No. 933.--"Evaluation of Population Estimation Procedures for States, 1980: An Interim Report," June 1983. See also No. 957 for completion of test.
2. No. 963.--"Evaluation of 1980 Subcounty Population Estimates," February 1985.
3. No. 984.--"Evaluation of County Population Estimation Procedures," October 1986.

Session D

Small Area Techniques

PHCRS

A REVIEW OF STATISTICAL METHODS FOR SMALL AREA ESTIMATION

Joseph Sedransk, Ph.D.
National Center for Health Statistics

(Not available for publication)

MULTIPLE-REGRESSION ESTIMATES OF POVERY RATES FOR SMALL AREAS IN TEXAS

John Hugg, M.A.
Texas Department of Health

(Not available for publication)

VARIATIONS IN MEDICAL PRACTICE:
A FRAMEWORK FOR PROVIDER AND PUBLIC EDUCATION

Kirk Phillips, Iowa Foundation for Medical Care

Introduction

Extreme differences have been found in per capita rates of hospitalization across Iowa communities for certain medical and surgical conditions. We have discovered an eleven-fold difference in hospital admission rates across Iowa communities for back and neck operations among Medicare patients hospitalized during 1984[1]. There was a ten-fold difference across Iowa communities in the hospital admission rate for adult diabetes among Medicaid patients hospitalized during 1985[2]. Pneumonia, psychoses, and carpal tunnel release procedures exhibited similarly wide variations in rates of hospitalization in related studies of Iowans aged under 65.

Wide differences in hospital admission rates for these conditions offer a striking contrast to far less variation in hospitalization rates for other conditions such as repair of broken hips, inguinal hernia repair and other causes. These findings naturally focus attention upon conditions with wide variability. Critical questions have been raised in the literature, including -- What causes variability?[3] Should there be more consistency in the hospitalization of these patients?[4] Which rate is right?[5]

Upon discovering medical and surgical conditions which exhibit wide statistical variability then, we have attempted to characterize the notion of clinical variability, or qualitative factors which contribute to differences in hospitalization rates. This paper quickly moves from the quantitative methods of developing per capita use rates of hospitalization, to more qualitative concerns of: (A) validating findings of variability, (B) understanding causes of variability, and (C) designing strategies to influence those rates of hospitalization. These are three critical components of our frame work for provider and public education, and more generally, for our contribution to health policy in Iowa.

The Iowa Foundation for Medical Care is an organization performing medical review services for Medicare, the Iowa Medicaid program, and numerous private insurers in Iowa and other states. The clinical orientation of our staff, including physicians, nurses, and allied health professionals, supports credible decisions about the medical necessity of certain hospital and non-hospital treatments. Similarly, our application of variations studies have both contributed to Iowans' understanding of clinical variability, and have supported an improved product design of medical review services.

Data Sources and Methodology

This framework for provider and public education is based upon research conducted for three parties: The Health Care Financing Administration, Robert Wood Johnson Foundation, and the Iowa Medicaid Program. Three data bases have been constructed for each respective party, describing populations of: Iowans over age 65 (1980-1984), Iowans under age 65 (1984-1987), and Iowa Medicaid eligibles (1980-1987).

Each of the three data bases noted above were constructed with use of inpatient hospital claims supplied by respective payers. Conveniently, Iowa State Legislation enacted six years ago, requires all hospitals to report uniform data elements (UB-82) which are available to certain parties through public and private insurers. The Medicare and Medicaid claims paid during the years noted above were used with their direct authority. Claims for Iowans under age 65 were gathered for approximately 85% of insured Iowans, by the Iowa Health Data Commission, a public information organization created under the same legislation. Special factors were used to estimate the shortfall of claims, as well as account for the flow of Iowans attending non-Iowa hospitals for care.

All claims and corresponding population estimates were processed by the Codman Research Group in Hanover, NH. Per capita admission rates, day rates, and costs are readily displayed in tabular and graphic form with use of special personal computer display software provided by the Codman Research Group.

Standard epidemiologic methods of calculating these rates were applied. This includes age/sex standardization of rates, as well as calculation of coefficients of variation and significance testing. Detailed notes regarding these calculations are available from the author upon request.

Validation

Table 1 offers several causes of hospitalization and associated statistics, rank ordered by variability. A standard coefficient of variation (SCV) is used, along with ratio of highest community rate to lowest community rate (ratio H/L) for each cause of admission. Figures of this kind have been used in a dialogue with clinicians to validate statistical variability with their explanations of clinical variability. With two mechanisms, we have asked them to explain variability from their perspective, and perceived causes of variability such as physician discretion, uncertainties in diagnosing certain disorders, unknown efficacy of alternative treatments, and other reasons. The two mechanisms are presentations to specialty society meetings where these matters can be discussed in detail, and use of written surveys.

For example, two presentations were made at meetings of the Iowa Urological Society. Wide variations were cited in admission rates for transurethral resections and consequently, certain practitioners initiated studies to more closely examine causes of variability. A ten year retrospective study of tumors by Boatman[6] found steady increases in the incidence of cancer. Contrary to current literature, a higher incidence of bladder and prostate cancer was found in rural areas than metropolitan areas within his community which had been characterized in our variation study. Boatman concludes that the higher incidence of bladder cancer in these rural communities is influenced by the quality of drinking water and a higher proportion of Czechoslovakian residents.

Stemming from similar presentations to the same specialty society, Paul Rohlf, M.D. chose to influence insurance underwriting in Iowa. Rohlf suggested that residents of communities with lower rates of hospital admission were subsidizing the cost of care for residents with higher rates, where they were charged equally in insurance plans such as the State Medicaid Program. Rohlf authored a series of articles appearing in his local and state wide newspapers as well as presented to the Board of Blue Cross of Iowa[7]. Accordingly, he has increased the sensitivity of consumers who may opt out of insurance plans electing to set their premiums in equal amounts on an area wide basis.

A second form of dialogue with clinicians has been through written surveys distributed to physicians in Iowa. Again, more detailed information has been gathered regarding to the causes of variability, as well as their recommendations for intervention strategies. In table 2, several medical and surgical causes of admission are shown which were judged to be discretionary. That is, responding physicians believed that physicians have a wide latitude of choice between use of inpatient hospital services or other remedies in treating these cases.

Table 1. Measures of Variation within Iowa Communities for Sample Causes of Hospitalization (Medicare, 1986)

			-- Outliers --		Ratio
Cause of Hospitalization	Cases	Count	Pct	SCV	H/L
Hypertension	377	1	0.8%	525.7	6.7
Atherosclerosis	369	2	1.5	507.7	4.3
Craniotomy	400	1	0.8	494.5	9.7
Acute Adjustment Reaction	229	1	0.8	484.7	1.0
Lens Operations	575	8	6.2	460.6	15.3
Deep Vein Thrombophlebitis	428	4	3.1	434.7	8.3
Poisioning & Toxic Effects of Drugs	474	4	3.1	379.5	8.6
Skin Ulcers	209	0	0.0	378.3	1.0
Cardiothoracic Procedure	340	1	0.8	297.1	5.8
Chronic Obstructive Pulmonary disease	1,407	22	16.9	284.0	9.5

Strategies For Influencing Rates

Wennberg has offered that physician education alone will exert an influence on these rates of hospitalization, generally reducing variability. Physicians rarely see their practice or the practice of other physicians in these terms. Upon viewing their practice relative to others, Wennberg suggests that they may voluntarily develop more consensus with other physicians in the practice of certain medical treatments.

Certainly, discussions within specialty society groups, such as those conducted in Maine[8] have yielded changes in hospital rates of treatment. In addition to providing information to individual physicians, these sessions have produced new clinical guidelines for treating disorders, again in an effort to develop more consensus in the practice of medicine.

As a third strategy, medical review services such as those offered by the Iowa Foundation for Medical Care are continually focused upon variable conditions, particularly those which are treated with higher levels of physician discretion. During the years 1984-1986, the IFMC reduced Medicare hospital admission rates for adult pneumonia by more than 20% through focusing resources in this manner.

The supply or availability of hospital and non-hospital services may also influence higher or lower rates of hospitalization. In a clinical discussion with the Iowa Psychiatric Society, we found that fewer community services for psychiatric care may have exerted a higher rate of inpatient treatment for psychoses.

Finally, the reimbursement of certain services through capitated payments, preferred provider choices, or even selective applications of coinsurance and deductibles can be used to influence these rates. Deere and Company, a self insured Iowa based manufacturer discovered a higher rate of inpatient treatment of psychiatric patients in 1984. Through careful discussions with local physicians, and the addition of a DRG reimbursement plan, their inpatient rates of treatment have fallen off significantly.

Conclusion

The science of monitoring health care delivery, and designing intervention strategies has blossomed during the last decade, due to an increasing demand for information from payers, employers and the general public and also due to an inspiring response of the scientific community, notably John Wennberg, M.D.. Our continuing challenge is to construct valid and understandable models of measurement, and translate their findings into the realities of health care management systems.

Table 2. Selected Causes of Hospitalization Judged to be Discretionary by 27 Physicians in Iowa (Medicare, 1986)

Cause of Hospitalization	Pct. of Physicians Judging as Discretionary
Medical Back Problems	100%
Adult Gastro-Enteritis	100%
Respitory Signs & Symptoms	100%
Other Nervous System Disorders	100%
Seizures & Headaches	94%
Chron Obs Pulmonary Disease	94%
Substance Abuse	93%
Adult Otitis Media & URI	93%
Depressive Neurosis	93%
Pediatric Gastro-Enteritis	93%
Foot Procedures	93%
Pedaitric Otitis Media & URI	92%
Other Ear, Nose, Throat Dx	92%

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Session E

Setting Year 2000 Objectives

PHCRS

OVERVIEW: SETTING NATIONAL HEALTH OBJECTIVES

Ashley Files, Office of Disease Prevention and Health Promotion

Origin of the Health Objectives

In 1979, the Surgeon General published the first Surgeon General's report on health promotion and disease prevention, titled Healthy People. The report reviewed what had been — and what could be — accomplished through prevention, if resources were targeted and specific efforts made to change peoples' behavior and the environmental structures that contribute to ill health.

Healthy People laid out five age specific, national goals that were to be met in 10 years time. Goals were set to:

1. Reduce infant mortality.
2. Reduce mortality among children.
3. Reduce mortality among young adults.
4. Reduce mortality among adults.
5. Reduce disability among the elderly.

Healthy People was quickly followed by Preventing Disease/Promoting Health: Objectives for the Nation. The so called "1990 Objectives" are a set of specific, measurable, national targets, that if met, should lead to accomplishment of the five national goals laid out in Healthy People.

The 1990 Objectives were organized under 15 priority areas and into three broad categories:

1. Preventive Health Services: includes the priority areas High Blood Pressure; Family Planning; Pregnancy and Infant Health; Immunization; and Sexually Transmitted Diseases.
2. Health Protection for Population Groups: includes the priority areas Toxic Agent and Radiation Control; Occupational Health; Accident Prevention; Dental Health; and Infectious Diseases.
3. Health Promotion for Population Groups: includes the priority areas Smoking; Alcohol and Drugs; Nutrition; Physical Fitness; and Stress and Violent Behavior.

The 1990 objectives were developed very quickly, with limited public and professional input. The first draft was hammered out at a three day conference in Atlanta, involving 167 subject-area experts. Approximately 2,000 individuals and groups were sent a draft of the objectives; 600 comments were received. This process, started and finished within a single year, resulted in 226 specific objectives.

Limited public input had a cost. Nearly no one in public health knew what the objectives were, why they mattered, and how they could be used. As a result, the Federal Public Health Service (PHS) had to spend the first 5 years of the 1980s "selling" the 1990 objectives within PHS, to the States, to local health departments, schools, employers, cities, etc.

By mid-decade, the selling efforts began to pay off. In 1985, only a third of the States had set their own State objectives based on the national set. By 1988 — just a couple of years later — 90 percent had done so and only a single State had no plans to set State objectives.

Also at mid-decade the Public Health Service conducted a thorough review of the 1990 objectives. The review, published as The 1990 Health Objectives for the Nation: A Midcourse Review, examined each of the 226 objectives, showed how far we had come, and projected where we might be by 1990.

At mid-decade we had made substantial progress:

- 13 percent of the objectives had already been achieved and
- 34.5 were on track to be achieved.

Of course, there were failures too. It was clear that the nation would not meet 26.5 percent of the objectives and perhaps worse still, there was not have enough data to evaluate progress toward a full 26 percent. This problem — data sufficient to track progress — remains a nagging issue as we move toward setting new objectives for the Year 2000.

Drafting Objectives for the Year 2000

Almost as soon as the Midcourse Review was published, the Public Health Service turned its attention to drafting a new set of objectives for the up-coming decade. In drafting the new set, PHS had several advantages over the first group that sat down to draft the 1990 objectives:

- First, many, many people and organizations already knew about the objectives and wanted to help draft the new objectives.
- Second, the nation as a whole is currently very interested in health promotion and improving their health practices.

Development of the national health objectives is nicely represented by a pyramid. At every stage of development, we have added more and more voices, opinions, and suggestions. Initial planning, the top of the pyramid, began in 1987 with formation of the PHS Steering Committee — representatives of the 7 PHS agencies plus representatives of the PHS staff offices. This small group of about 20 people has been intimately involved in development of the objectives, setting overall policy for the objectives development process. From early work by the Steering Committee, the pyramid of input was broadened through seven regional public hearings, held in cooperation with the Institute of Medicine of the National Academy of Sciences. The seven hearing sites were selected to reflect geographic diversity, accessibility, and potential for minority population involvement. Public and professional input was further expanded through 18 "mini-hearings" — targeted sessions held as part of national membership organizations' annual meetings.

These public hearings were conducted to solicit testimony from a broad range of individuals and community organizations about appropriate and attainable national health promotion and disease prevention objectives for the year 2000. The hearings were held as a forum for groups and individuals to propose precise quantitative objectives for maintaining health and reducing death, disease, and disability; interventions to meet these objectives; and surveillance programs to assess prevention needs and efforts. The hearings were also intended to clarify the local perspective on health care needs, opportunities, and problems, and to describe ways of applying the lessons learned with the 1990 national health objectives. PHS also hoped that the hearings would provide detailed information about the special needs of local, racial, ethnic, and other special groups, as well as information about successful State and local prevention programs.

PHS and the Institute of Medicine also solicited testimony in professional journals and other publications. In all, PHS/IOM received 761 pieces of written and oral testimony. The Institute of Medicine compiled all the testimony into a data base, which can be used to sort the testimony by subject. On the basis of the testimony, 21 priority areas were designated by the PHS Steering Committee; IOM distributed relevant testimony to each of the 21 work groups that were formed to draft the year 2000 objectives.

The 21 priority areas fall into four broad categories:

HEALTH PROMOTION PRIORITIES

Nutrition
Physical Activity and Fitness
Tobacco
Alcohol and Other Drugs
Sexual Behavior
Violent and Abusive Behavior
Vitality and Independence of Older People

HEALTH PROTECTION PRIORITIES

Environmental Health
Occupational Safety and Health
Unintentional Injuries

PREVENTIVE SERVICES PRIORITIES

Maternal and Infant Health
Immunization and Infectious Diseases
HIV Infection
Sexually Transmitted Diseases
High Blood Cholesterol and High Blood Pressure
Cancer
Other Chronic Disorders
Oral Health
Mental and Behavioral Disorders

SYSTEM IMPROVEMENT PRIORITIES

Health Education and Preventive Services
Surveillance and Data Systems

These groupings are illustrative and are not intended to be exclusive. There is often considerable overlap among the objectives of the various priority areas.

In August 1988, the Assistant Secretary for Health assigned responsibility for drafting objectives for each of the 21 priority areas to a Public Health Service agency or agencies. These "lead agencies" were responsible for putting together a primarily Federal work group of subject area experts to prepare the first draft of the objectives. The 21 work groups began their work in September 1988, using the public testimony and their own expertise to produce first drafts; these draft were completed in January 1989. At this point, the pyramid was broaden further through review of the first drafts by non-Federal subject-area experts. Nearly 2,000 non-Federal experts reviewed and commented upon the drafts. Once expert review panel comments were incorporated, second drafts were submitted to the Office of Disease Prevention and Health Promotion for editing and internal PHS review. The draft will be available for public review and comment in mid-September.

By this point — preparation of the public review draft — nearly 7,700 individuals and group representatives have participated in the year 2000 project — either by attending a public hearing, submitting testimony, participating on a work group, or serving on an expert review panel.

Focusing on the Needs of Special Populations

So far, I have described two important ways in which the year 2000 national objectives differ from those set for 1990: the vast expansion of public and professional input into the year 2000 project compared to the 1990 objectives and the addition of several new priority areas, including HIV Infection, Cancers, and Vitality and Independence of Older People. A third, and perhaps more important difference, is the new emphasis on the needs of special populations.

Unlike the 1990 objectives, the year 2000 objectives will include "special population targets." These targets parallel general population objectives, and in fact are part of the general population objectives, but are specific targets for populations that experience greater risk, higher rates of disease, or lower rates of knowledge. For example, the Nutrition priority area contains a special population target to reduce anemia among low income black women and Unintentional Injuries contains a special population target to reduce residential fire deaths among children age four and younger.

The special population targets are intended to focus resources and attention on the groups who suffer most from particular health problems.

The draft year 2000 objectives include special population targets for Asian Americans, blacks, Hispanics, American Indians/Alaska Natives, children, adolescents, older people, people with disabilities, and people with low incomes and/or education levels. Special targets have also been set for particular settings, where actions in the settings could have a sizable affect on American health status. For example, the draft includes targets for worksites/employers, primary and secondary schools, and clinical settings/health care providers.

We believe including special targets in the revised objectives will help focus national attention on the needs of the underserved. However, we do not intend to leave action on improvements for special populations to "hope" and chance. The Office of Disease Prevention and Health Promotion (ODPHP) is promoting achievement of the special population targets by engaging relevant national organizations in the development of implementation plans that are tailored to the particular needs of the special populations themselves. ODPHP has awarded three-year cooperative agreements to groups representing Hispanics, Asian Americans, children in schools, adolescents, older people, people with disabilities, and clinical settings. We hope to award two additional cooperative agreements before the end of September to groups representing blacks and native Americans. ODPHP will work with these groups to develop national plans to pursue achievement of the objectives.

The draft we have been working on for nearly three years will be available for public comment in mid-September, 1989. Availability of the draft will be announced in the Federal Register and the public will have until November 15 to submit comments. We anticipate sending the draft to around 10,000 individuals and groups. The objectives will be officially released at a national conference to be held in Washington July 9 and 10, 1990.

We sincerely hope that everyone with an interest in the national objectives will review the draft and let us know how we can modify it to better meet their needs. If the objectives are to fulfill their potential as a genuine national plan — not just a Federal blueprint -- then the people, governments, and organizations who will be affected by progress toward the year 2000 objectives must help formulate the plan.

STATISTICAL ISSUES IN FORMULATING HEALTH OBJECTIVES FOR THE YEAR 2000

Michael A. Stoto, Institute of Medicine

Experience with implementing and tracking the 1990 Health Objectives for the Nation has shown that the form of quantitative expression can sometimes lead to confusion in using the objectives and difficulties in finding appropriate data.[1] In order to achieve more meaningful objectives for the year 2000 that are easier to implement, the Institute of Medicine organized a one-day workshop to consider statistical issues relevant to the formulation of national and subnational objectives.

The workshop covered three general topics: 1) the statistical format for national objectives; 2) using statistical models to help set objectives; and 3) facilitating the development of state and local objectives. The focus of the workshop was on how to use available data, not on data needs.

The workshop participants included members of the PHS steering committee on the Year 2000 Health Objectives, staff of the National Center for Health Statistics and the Office of Disease Prevention and Health Promotion, members of work groups developing specific objectives, members and staff of the IOM Committee on Health Objectives for the Year 2000, staff of state and local health departments that have used the 1990 objectives, members of the Model Standards Committee, and other biostatisticians, epidemiologists, and technical experts.

The workshop was held on September 1988 under the auspices of an ongoing cooperative agreement with the PHS Office of Disease Prevention and Health Promotion. This report summarizes the discussions at the workshop with a focus on available options and their strengths and weaknesses. Although all of the participants had an opportunity to comment on a preliminary draft, this report does not necessarily represent the opinions of all of the participants or the recommendations of the Institute of Medicine or the National Academy of Sciences. One section of this paper, on using statistical models to help set the objectives, has been expanded by the author since the workshop, and the views expressed are necessarily his own.

General conclusions

While there are general statistical principles that could be brought to bear on the problem of setting objectives, it would be inappropriate to develop hard and fast rules about the formulation of objectives in quantitative terms. Good statistical practice requires careful consideration of the intended use of the objectives. All objectives will require tracking. In addition, objectives will be used for resource allocation, program design, advocacy, and other purposes. Each purpose could require a different format. It would be desirable to track down actual examples of uses of the numerical objectives in order to help make future objectives more relevant and useful. Furthermore, the choice of measures must reflect the subject matter of the individual objectives and data availability, and therefore must be left to the work groups formulating the objectives. This summary, however, lists some general principles that may be helpful to the work groups in formulating the objectives.

The national objectives form the basis for objectives for many subnational populations, including states, smaller geographic areas, racial and ethnic groups, and others. A major consideration in the development of the quantitative measure used in a national objective should be the ease of translating this objective to subnational populations. This is discussed in more detail below.

Objectives should be presented in terms of a specific, absolute target, such as an infant mortality rate of 9 per thousand. Such a presentation removes all ambiguity about what the objective is, and whether it has been met. The statistical methods for deriving appropriate objective levels, however, can be more complex, and requires a combination of the statistical techniques discussed below and subject matter expertise.

Presenting the objectives in absolute terms increases the need for clear documentation of the means used for assessing the baseline and subsequent values and the way in which the target was derived. Such documentation is needed for monitoring the progress toward the objectives, for making revisions as necessary if new data or scientific knowledge becomes available, and most importantly for translating the objectives to subnational populations. While detailed documentation does not need to be in the report which will go to the public and decision makers, it does need to be readily accessible to others involved in setting the national objectives, to others who want to set state and local objectives and to scholars, students, and others using the objectives for scientific and educational purposes. To accomplish this, a separate volume could be planned.

Finally, because health agencies and health professionals at all levels throughout the country have made great investments in the 1990 objectives, continuity with them should have high priority. Although continuity goes beyond statistical issues to the subject and content of the objectives, significant changes in their statistical formulation could detract from the credibility of the objectives.

Formulation of the objectives

Each objective should be accompanied by documentation of the data sources used in its formulation. If no data currently exist, a suitable mechanism for obtaining them should be identified. Proxy measures may be appropriate where data are not available, but their implicit logic should be clearly documented.

In general, objectives should be formulated in terms of rates, proportions, or averages (means or medians) rather than counts. The meaning of these measures does not depend on the size of the population, so the relevant objectives can be translated directly to subnational populations and to the national population in the year 2000, despite anticipated population growth.

The number of states is one possible exception. Some participants suggested that counts could be appropriate where denominator data on the population at risk are not available. For instance, trends in the distribution of bleach may be the only way to monitor whether IV drug users are using clean needles to prevent the spread of HIV. In these cases, consideration should be given to whether a gross denominator such as the population in a particular age group is better than none at all. Counts could also be appropriate for serious but infrequent events that signal a breakdown of preventive measures, such as cases of measles associated with encephalitis (that demonstrate the need for vigilance in immunization), or for instances of rare but serious threats to large groups, such as toxic spills on highways or nuclear reactor safety violations. See, also, the discussion of sentinel events below.

Objectives should be stated in terms of absolute levels rather than percentage reductions, rates of change, or differences between two groups. Absolute measures are unambiguous, easier to track, and generally have a bigger impact on decision makers. Percentage reductions and similar measures should play a role in deciding what the numerical target for the objective should be, as discussed below. Because the national objectives will often be translated to subnational populations by assuming the same percentage reduction applied to a different baseline, the assumptions and calculations used to determine the target level should be explicitly stated. Baseline values should also be clearly stated.

Rates, proportions, and averages should be disaggregated by demographic, racial, ethnic, and socioeconomic categories when possible and especially when there are important differences. Such disaggregation has two advantages. First, it targets those groups in which a problem is particularly important or for which an intervention would make a large difference. Second, disaggregation facilitates the transfer of national objectives to subnational areas that have different demographic, racial, and ethnic compositions.

Targets for racial and ethnic minority goals should be stated in absolute terms rather than in terms of the differences from a reference group. Measures of differential mortality and morbidity (such as the measures of excess mortality used by the Secretary's Task Force on Black and Minority Health[2] or Darity's Differential Deficit Ratio[3]), however, are useful in determining levels for these groups. Target groups should be identified clearly, not left unspecified as "all racial and ethnic groups."

In order to facilitate the translation of national targets to subnational groups, measures could be standardized by demographic, racial, and ethnic characteristics. Socioeconomic measures should not be used for standardization because it is not appropriate to set a less ambitious goal just because a population is poorer or less educated. Standard populations age breakdowns should be documented. Lifetable-based measures such as life expectancies and cumulative rates that do not require a standard population are other alternatives.

Incidence measures are preferable for prevention activities that seek to avoid new occurrences of a health problem or acquisition of a risk behavior. Prevalence measures are preferable for objectives that seek to make changes in risk factors, behaviors, public and professional awareness, access to services, and so on. The measures used should reflect the nature of the objectives to which they refer. For instance, an incidence measure is appropriate for an objective of preventing smoking in adolescents; a prevalence measure is appropriate for an objective to reduce smoking in adults. Because they measure different things, both might be used. In general, prevalence measures are slower to show the effects of interventions because they measure cumulative changes over long periods of time.

In practice, the choice between incidence and prevalence often depends on the kinds of data that are available. Prevalence measures can sometimes serve as proxies for incidence. For example, smoking prevalence among 20 to 24 year olds might be used as a proxy for teenage incidence. When using proxies, the logic must be clearly documented, and "incidence" and "prevalence" should not be used loosely.

Means and proportions are alternative ways of specifying population distributions. For instance, an objective on serum cholesterol could be phrased, as it was in the 1990 objectives, as

> "By 1990, the mean serum cholesterol level in the adult population aged 18-74 years of age should be at or below 200 mg/dl."[1]

or as

> "By 1990, the proportion of adults aged 18-74 with a serum cholesterol level of greater than 200 mg/dl should be below X percent."[1]

These measures represent different aspects of the distribution of serum cholesterol in the population. The first measure addresses the whole population, with the implicit assumption that a change in the mean reflects a shift in the entire distribution. The second measure addresses the part of the distribution with the highest risk of cardiovascular disease. The choice between them depends more on subject matter than on statistical criteria. Because the shape and spread of the population distribution can change independently of the mean, it could be useful to have both kinds of measures. For example, between 1973 and 1983, the mean birth weight of Black infants in the United States increased at the same time that the proportion of newborns weighing less than 1500 grams rose.[4]

Using proportions and averages requires the choice of a unit of analysis. Objectives can be phrased in terms of the population:

> "By 2000, at least 75 percent of adults should be aware of ..."

in terms of states, local areas, or other units:

> "By 2000, at least 75 percent of cities with a population of over 10,000 should have the capability for ..."

> "By 2000, at least 50 percent of all firms with more than 500 employees should have ..."

or calculated by other units, but population weighted:

> "By 2000, firms offering ... should employ at least 30 percent of all workers."

From an outcome standpoint, the relevant criteria should be the proportion of the population covered, the population average, and so on. However, phrasing the objective in terms of the actor responsible for achieving it ("communities," "firms," "schools," and so on) may have greater policy impact. Population weighting, as in the final example above, has the advantage of addressing the population outcome as well as the appropriate actors, but may be difficult to state in nontechnical terms.

Measures of quality of life, activities of daily living, quality adjusted life years, years of productive life, and related measures were not commonly used in the 1990 objectives. There has been substantial progress in the development of such methods in the last decade, however, and they might be used more frequently in the year 2000 objectives. Although some of these measures have serious methodological problems, they are frequently used in clinical trials for cancer treatment and heart disease prevention and in other applications. The National Center for Health Statistics maintains a clearinghouse on quality of life measures that could assist working groups interested in their use.

The specific formulation of measures of public and professional awareness and of access to services should be determined primarily by subject matter rather than by statistical considerations. With regard to awareness, consideration should be given to measures of attitudes, beliefs, and skills in addition to simple knowledge. These may be equally or more related to health behaviors, risks, and outcomes. With regard to access, its components--availability and utilization--could also be measured. The choice of access measures should depend on the nature of the intended intervention programs and how they are delivered.

Using statistical models to help set objectives

There are a number of statistical methods that can help the working groups set meaningful numerical objectives. None of these can be used on a strictly mechanical basis and all require significant subject matter judgment. These methods can, however, give some idea of what is likely to happen in the absence of further interventions or indicate the likely impact of interventions on outcomes. Thus, models can help to set or to fine tune the objectives.

The most straightforward statistical model is simple trend analysis and projection. Such models can predict the level of various objective measures--assuming that current trends continue--as well as provide statistical confidence intervals. The implication is that objectives should usually be somewhat more favorable than what the trend analysis suggests will happen anyway. For example, the year 2000 objective for adult smoking prevalence was set by looking at the trend in smoking prevalence from 1974 to the present, and setting a more ambitious target, as shown in Figure 1.

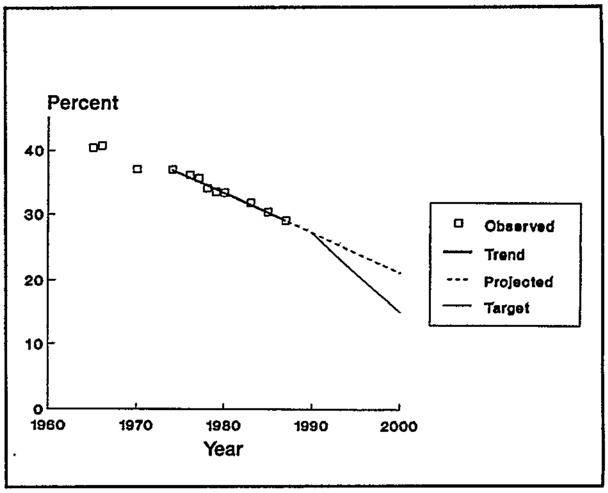

Figure 1. Prevalence of cigarette smoking among people aged 20 and older (in percent), with trend line fitted to data from 1974-1987 and projected to 2000, and proposed target for 2000.

This type of model offers three advantages. First, it can help the working groups select meaningful and feasible objectives. Second, the graphs it produces provide a simple and compelling way to communicate with decision makers on how the objective was set and what progress is being made. Third, the model can help to identify inconsistencies within the set of objectives. For example, as an analysis by Joel Kleinman of the National Center for Health Statistics illustrated, the 1990 infant mortality goals of 9 per thousand overall and 12 per thousand for Blacks together imply a 1990 rate of 8.5 per thousand for Whites. Even if there was no acceleration in the rate of decline for Whites, the White infant mortality rate could have been 6.8 per thousand in 1990. Thus, the overall goal could have been set to 7.5 per thousand rather than 9 (which assumes acceleration in the rate of decline for Blacks and none for Whites), or lower.

There are, however, a number of problems with this approach. First, one must decide how far back to go in fitting the regression lines. Figure 2 illustrates that for the same smoking data, fitting the line to all available data yields a different projected value. Figure 3 shows a more extreme example, per capita alcohol consumption. In one sense, this more extreme case is easier, to deal with because a marked behavioral change is plausible, and fitting a regression line to only the later data points is justified.

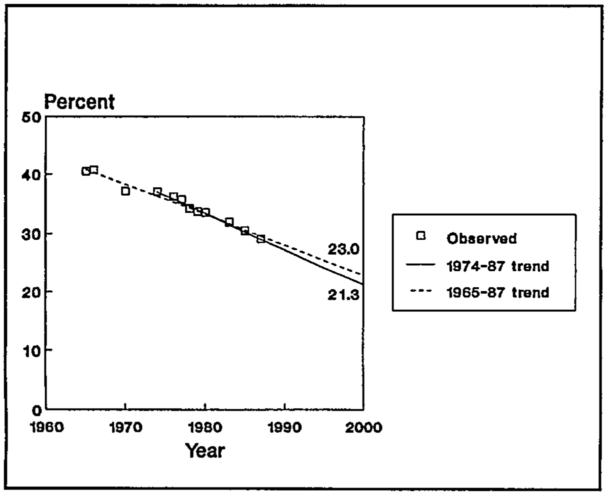

Figure 2. Prevalence of cigarette smoking among people aged 20 and older (in percent), with trend lines fitted to data from 1974-1987 and 1965-1987.

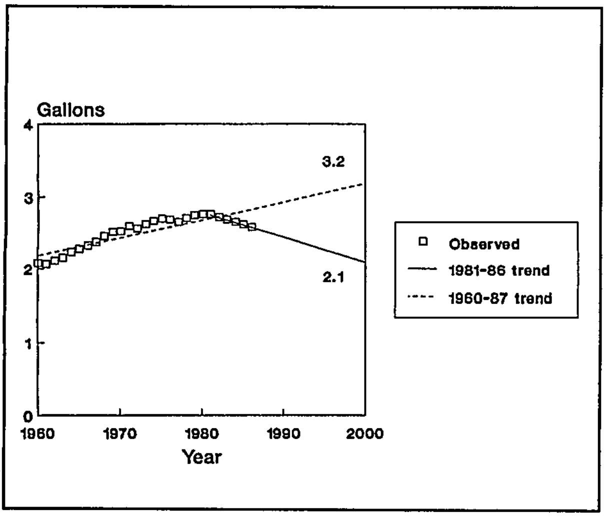

Figure 3. Alcohol consumption per person aged 14 and older (in gallons per person), with trend lines fitted to data from 1981-1986 and 1960-1986.

Another problem occurs when there are too few points or too much variability. For instance, Figure 4 plots the per capita motor vehicle fatality rate over time. Depending on how many data points are used in the regression equation, radically different projected values obtain. In this example the message is the variability, and the futility of determining trends, at least in the short run. One approach for dealing with cases like these is to show the data and the target only, let readers fit rough lines by eye to see is they think the target is reasonable. It is important to show enough data, however, so that the roughness in the data is clear.

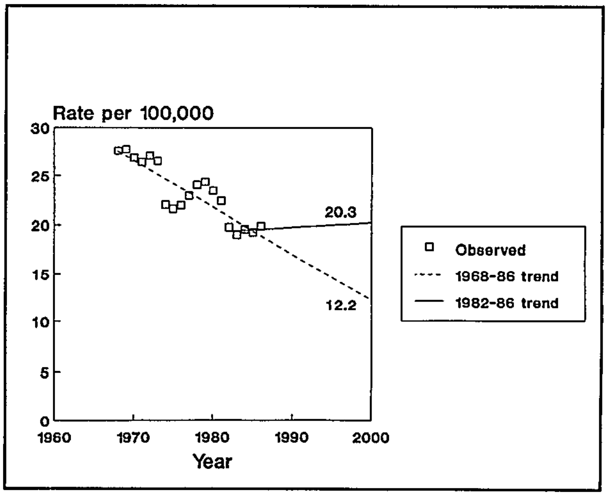

Figure 4. Motor vehicle fatality rate per 100,000 population, with trend lines fitted to data from 1982-1986 and 1968-1986.

The third problem is the choice of scale: linear, logarithmic, or perhaps something else. Figure 5 shows how the projected cervical cancer mortality rate depends on whether the projection is done in the original linear scale, or whether the data are transformed to a log scale before the projection is done. Note also that even in the log scale, the starting point matters for the projected value. This suggests that another transformation might be appropriate, but choosing a more complex transformation may be overreaching the ability of a small amount of data to distinguish between the alternatives.

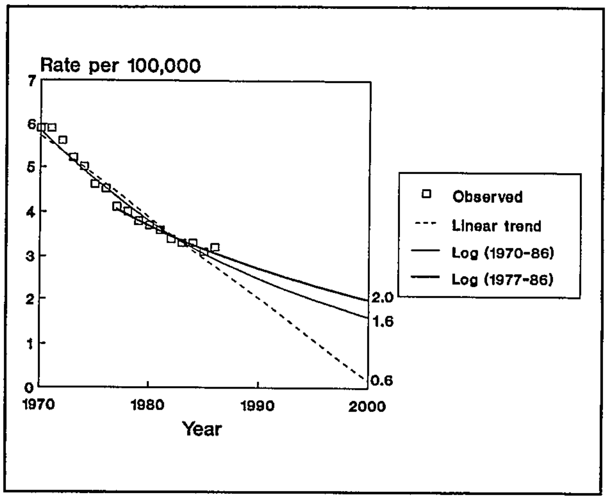

Figure 5. Cervical cancer mortality rate per 100,000 population, with linear trend fitted to data from 1973-1986 and logarithmic trends fitted to data from 1970-1986 and 1977-1986.

The implication is that the groups setting the objectives should not blindly accept projections as target values for the year 2000. Rather, the projected value should be a base to work from, and the level of the objective adjusted up or down from there. Working groups drafting objectives should consider: (1) the likely impact of new knowledge or prevention activities, (2) whether demographic or policy changes will make current trends hard to maintain, and (3) whether a more ambitious objective could be justified.

There are also deeper questions that must be addressed concerning the relationship between trends and intervention efforts. For example, declining smoking prevalence rates reflect a level of quitting among adults that is low enough to offset smoking initiation by teenagers. Demographic changes also contribute, because high smoking cohorts are reaching the age where many of them quit or die. In this context, an added effort means raising the adult quit rate or lowering the teenage initiation rate.

Trends in the motor vehicle fatality rate, however, are more complex. At one level of analysis, just maintaining the status quo seems to be a struggle, anything below current level might be an appropriate goal for the nation. Another way of looking at motor vehicle mortality, however, is in terms of vehicle miles traveled. In one sense, this is a more realistic predictor, because it removes the uncertainty about how many miles people will drive. But is it acceptable to have an increasing number of deaths (on a per capita basis) just because people drive more?

Models that identify the lowest possible morbidity and mortality rates that have been observed in specific groups could also be useful in setting objectives. The specific groups could be other countries or geographic, racial, ethnic, or socioeconomic subpopulations of the United States. Woolsey,[5] for instance, has proposed a version of this which determines an achievable low mortality rate by calculating a low point in the geographic frequency distribution of 9 census regions for each of 21 causes of death in each of 20 age-sex groups. These minimum rates are then combined to derive an overall estimate of how much mortality could be reduced if the "achievable" rates applied to the population of the United States, a particular state, or a large local area. The Carter Center's Closing the Gap[6] offers another approach to identifying achievable mortality rates. Although these methods do not address how much reduction is feasible by the year 2000, they can help to identify long-range goals.

Working groups should consider using mathematical models that relate health outcomes to specific interventions for many specific diseases and health behaviors. These models, many of which have already been developed, could provide insight into achievable health outcome levels and the relationship between the process and outcome objectives. For instance, the National Cancer Institute has developed a model to project cancer incidence and mortality under various cancer control programs such as prevention programs, screening, and treatment.[7] Such models require more data than simple extrapolations, and take time to develop and verify. In addition, there can be substantial uncertainties in modeling the interventions and interactions among them. The modeling process itself, however, helps to focus discussion and thinking, and leads to a range of plausible objectives. Similar models have been, or are being, developed for cardiovascular disease, AIDS, and other diseases.

The simple extrapolation model and process models such as the cancer model form two extremes of a spectrum. Extrapolation models that take into account age-period-cohort effects, projected demographic changes, and other factors[8,9] fall between the two and offer some promise. Modeling is really an effort to use data better. In this sense, the specific model chosen is less important than the attempt to be careful and consistent in setting objectives.

Facilitating the development of state and local objectives

The main problems that state and local health departments face in developing their own objectives are the unavailability of data and the quality of data that are available. They also must face problems of infrequent events, differences in demographic and ethnic backgrounds and current levels of outcome and process variables, and data comparability. While the workshop could not address all of these problems in detail, participants did have a number of useful suggestions.

Although none of the problems in using the objectives at the state and local level can be totally alleviated by the way that the national objectives are stated, some forms of national objectives are easier to translate to the state and local level than others. The planned integration of the national objectives and the Model Standards[10] will be an opportunity to provide guidance to state and local officials on interpreting the national objectives in the context of their own communities and ascertaining whether they are doing their share to help achieve the national goal.

At the national level for instance, rates of infant or maternal mortality, are stable enough to justify a quantitative objective, but at the local level there may be simply too few cases to set meaningful objectives. One possible solution to this problem is to aggregate three or five years of numerator data into one calculated rate. Calculating rates over a running series of three or five years is another approach. Such measures are slower to show the impact of interventions because they include data from past years, but they may be stable enough to show meaningful trends. Standards need to be developed to judge whether the variability of rates and measures is sufficiently small for tracking purposes.

Rare but serious outcomes can be treated as "sentinel events"[11] at the local level even though rates were used at the national level. For instance, if the expected number of events at the local level (based on the national objective rates) is less than 1 or 2 per year, the local objective should be zero occurrences, and even a single occurrence should be a cause for concern. Where small numbers of events are involved, indirect standardization should be used to calculate the number of expected events.

Another alternative is to use measures that are more stable at the local level as proxies for the measure used in the national objective. For instance, rather than measure infant mortality rates when only a few cases would be expected, a local health department may phrase its objective in terms of the proportion of low birth weight babies born.

These measures have the advantage of being more stable because more infants are born with low birth weight than die. They do not, however, measure precisely the same thing as the national objective.

As mentioned above, disaggregation and standardization provide means for accounting for different population breakdowns in local areas. In order for state and local health departments to do this, however, they need as much detail as possible on demographic breakdowns. Even if the national objectives refer to the entire population, disaggregated baseline data could help state and local officials translate the national objectives for their own use. Similarly, good documentation on the assumptions used to set the national objectives would enable state and local officials to calculate appropriate objectives for their own areas, especially if they are starting at different levels.

Questions of data availability and comparability go beyond the scope of the workshop, but there are steps that federal, state, and local officials can take to improve the situation. The objective process itself tends to improve data availability and comparability. By focusing attention on data needs, the 1990 objectives have helped to stimulate some data collection efforts where they were needed, especially in the area of consumer health knowledge and practices. New data have also become available at the state level. If the data sources employed to formulate and track the year 2000 health objectives at the national level are well documented, the process itself may encourage the adoption of consistent definitions across states.

To further aid states and local areas, steps can be taken to develop surveys that are consistent across states--such as the Centers for Disease Control's Behavioral Risk Factor Surveys[12]--and possibly to increase the sample sizes of national surveys to allow for better use of state and local data. National objectives could be written so that they can be monitored through telephone surveys, which are easier to implement on a state basis than surveys which require home visits. More states could link vital records with records gathered for program purposes, as is already being done in Missouri and other states. Standard definitions and population groups could be developed through cooperation of federal and local officials. Finally, the federal government and schools of public health could offer technical assistance to state and local officials in terms of adapting national data to local conditions, and in developing better channels for states and local areas to share their expertise.

The workshop participants were Norman Breslow, University of Washington, (Chairman); Lynn Artz, Office of Disease Prevention and Health Promotion; Edgar Adams, National Institute on Drug Abuse; Susan Addiss, Quinnipiack Valley Health District; Steve Corbin, National Institutes of Health; Tony D'Angelo, Indian Health Service; Jack Elinson, Rutgers University; Ashley Files, Office of Disease Prevention and Health Promotion; MaryAnne Freedman, Vermont Department of Health; Mitchell Gail, National Institutes of Health; Axel Goetz, General Health, Inc.; Pat Golden, National Center for Health Statistics; William Harlan, National Institutes of Health; Gary Hogelin, Centers for Disease Control; Samuel Kessel, Health Resources and Services Administration; Dushanka Kleinman, National Institutes of Health; Joel Kleinman, National Center for Health Statistics; Garland Land, Missouri Department of Health; Joel Nitzkin, Monroe County Department of Health; John Pierce, Office on Smoking and Health; Richard Remington, University of Iowa; Katharine Bauer Sommers, Institute of Medicine; Andrew Sorensen, Johns Hopkins School of Public Health; Michael Stoto, Institute of Medicine; Nancy Watkins, Centers for Disease Control; Linda Webster, Centers for Disease Control; Doug Williams, National Center for Health Statistics; David Williamson, Centers for Disease Control; Ronald Wilson, National Center for Health Statistics; Theodore Woolsey, Consultant.

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OREGON'S HEALTH 2000 PROJECT

Donna L. Clark, Oregon Health Division

INTRODUCTION

In 1987, the Oregon Health Division appointed a Project Team to develop health objectives for Oregonians for the year 2000.

The approach used to develop these objectives was framed by the following guiding principles:

1) Health Objectives for the Year 2000 must be prepared in a timely manner in order to guide statewide health policy making and planning for a full decade.

2) The state public health agency would have a leadership role. This included organizing, convening, participating in and providing technical assistance to and publishing the final report of the Project Team.

3) Health Objectives for the Year 2000 would be "owned" by the Project Team collectively. A broad-base of support and commitment to the objectives was essential.

4) The Project Team would include representation from various groups, organizations and citizens.

5) The state public health agency would select a methodology for the Project Team that anticipated future trends and realities that would shape the health of Oregonians between now and the year 2000.

6) Health Objectives for the Year 2000 must describe measurable health outcomes unique to Oregon.

This approach to health objective development allowed the state public health agency to:

- Emphasize the importance of health data in setting health policy directions.
- Educate a broad group of representatives, normally outside the traditional public health arena, about public health problems.
- Promote the development of commitment and linkages to other organizations or groups who could assist in mobilizing resources to address these important public health concerns.

Overall, this model for health planning was exciting. While it was not without risk, it generated creative ideas, new strategies for addressing problems, and a "community" spirit of commitment to Oregon's public health issues.

PLANNING PROCESS

Oregon's Health Division Administrator appointed and convened a nineteen member Project Team in the summer of 1987. Team members included people who represented various state agencies, minority groups, health providers and advocate groups, public health organizations, associations and citizens. The mix of perspectives stimulated group discussions and strengthened overall results of their work.

The Project Team was convened in an all day meeting once a month for six months to complete their assignment. To identify the key health objectives for Oregon for the year 2000 was a somewhat overwhelming task, but the group was eager to pursue this challenge. All members were encouraged to share this project's progress with their organizations or groups they represented. Draft objectives were available for review and comment from the Team member's organizations. The objectives needed to be realistic and have credibility with a variety of audiences.

Two private consultants experienced in strategic planning provided the Project Team with a structure for leading to the identification of 13 objective areas.

The strategic planning process required the Team to follow a format which required them to:

- identify goals for the project
- develop value statements
- identify future trends by reviewing and then interpreting health data and various health status indicators
- evaluate specific factors that would influence future health issues (e.g. target populations, constituency groups, and program strategies)
- develop future scenarios by blending health trend data with other trend influences
- develop strategic directions to shape the major health issues for Oregon
- finalize and prioritize Oregon's Health Objectives for the Year 2000.

A short discussion regarding the futures research portion of the project will serve to highlight the importance of data and trend analysis.

It's difficult to project years into the future. But, the futures research concept provided the framework for the Team to pursue this challenge. They reviewed 30-40 publications or documents which characterized the future health problems or issues for the United States and Oregon. They followed with the identification of trend factors that would be influencing the health status of Oregonians. These trend factors included issues about environment, technology, demographics, social behaviors and attitudes, economics, and politics. With these pieces of information they wove together future scenarios which would eventually lead to the development of the strategic health directions.

The Team then proceeded to develop measurable health outcomes and recommendations for actions which would help achieve these goals.

THE HEALTH OBJECTIVE REPORT

The Project Team had several goals in mind in relationship to a project report. They believed that the report must have credibility and be used to promote changes in health policy. They expected the document to be used by policy makers, as well as private and public organizations interested in health issues. The document needed to describe attainable goals and recommendations for action plans which would be carried out by key players.

The report included thirteen Oregon Health Objectives areas for the Year 2000. They are:

- HEALTHY BABIES
  Increase the proportion of babies born in Oregon who are healthy.
- PHYSICALLY FIT CHILDREN
  Increase the proportion of all children who meet health-related fitness standards, and the proportion who participate regularly in a physical education and fitness program which can be carried into adulthood.
- UNINTENTIONAL INJURIES
  Reduce the rate of deaths and years of potential life lost due to unintentional injuries.
- INTENTIONAL INJURIES
  Reduce the incidence of injuries and deaths due to violence and severe depression.

- DRUG AND ALCOHOL ABUSE
  Reduce the incidence of death due to drug and alcohol use.
- SEXUALLY TRANSMITTED DISEASES
  Reduce the incidence of sexually transmitted disease by 50%.
- HUMAN IMMUNODEFICIENCY VIRUS (HIV) INFECTIONS
  Limit the prevalence of HIV infections among gay males, intravenous drug users, and heterosexuals with more than one partner.
- CARDIOVASCULAR DISEASE
  Reduce the rate of premature death due to cardiovascular disease.
- TOBACCO CAUSED DISEASES
  Reduce the rate of death caused by tobacco use.
- CANCER
  Reduce the statewide rate of death and disability due to cancer.
- IMMUNIZABLE AND CHEMOPROPHYLAXABLE DISEASES
  Reduce the incidence of infectious diseases which are preventable by immunization or chemoprophylaxis.
- ENVIRONMENTAL CAUSED DISEASES
  Reduce the incidence of diseases and death due to unintended exposure to environmental agents.
- INDEPENDENT LIVING AMONG DEPENDENT POPULATIONS
  Increase independent living skills of dependent populations: the elderly with physical impairment, the mentally ill, and the developmentally disabled.

This list provides only an overview of the thirteen objective areas. In addition, each objective area in the report included:

- Health Objectives for the Year 2000 with measurable health status indicators
- Current status and trends in Oregon
- Health implications of the problem
- Recommendations and key organizations who would be called on for implementation
- Data needs for the future

An example of portions of the Objective Area for "HEALTHY BABIES" is shown in Table 1.

Other graphics provided the reader with a view of the current problem compared with Oregon's target objective. For example, Graph 1 describes Oregon's Low Birthweight problem over time without any new action, compared to a target objective for this health status indicator.

Overall, the report has drawn attention to the health problems for Oregon in the year 2000. It is presented in a format which appeals to both the public health community as well as non-health people, hence achieving its goal of a credible, user friendly report.

IMPLEMENTATION

Keeping visibility for Oregon's Health 2000 Objectives over the next ten years will be a challenge. This document alone will not be enough to sustain the momentum of this project. The goal of maintaining awareness around these 13 Objectives will require a continued commitment from the state public health agency.

Plans have been made to assure that commitment and visibility continues. These plans include:

- Convening coalitions meetings around each objective area over the next year and one-half.

Table 1.

HEALTHY BABIES

HEALTH OBJECTIVE FOR THE YEAR 2000

Increase the proportion of babies born in Oregon who are healthy

Indicator	Statewide Rate 1986	2000 Projection (No New Action)	Year 2000 Objective
Low birth weight infants among live births (%)[1]	5.1[2]	5.6[3]	4.5
Perinatal deaths: ratio to 1,000 live births[4]	11.6[2]	11.6	7.0
Infants with congenital anomalies reported at birth among live births (%)	1.2[2]	1.4[3]	0.8
Oregon mothers who receive inadequate prenatal care (%)[5]	8.3[6]	12.2[3]	5.0
Teenage pregnancies: births and abortions per 1,000 females age 15-19	72.0	60.0	45.0

[1] Low birth weight defined as <2,500 g

[2] Source: Center for Health Statistics, Oregon Health Division

[3] Estimate based on linear regression for 1980-86 data

[4] Perinatal deaths defined as fetal deaths plus neonatal deaths (death during first 27 days of life)

[5] Inadequate prenatal care defined as no care, care that began in the third trimester of pregnancy, or care consisting of <5 visits

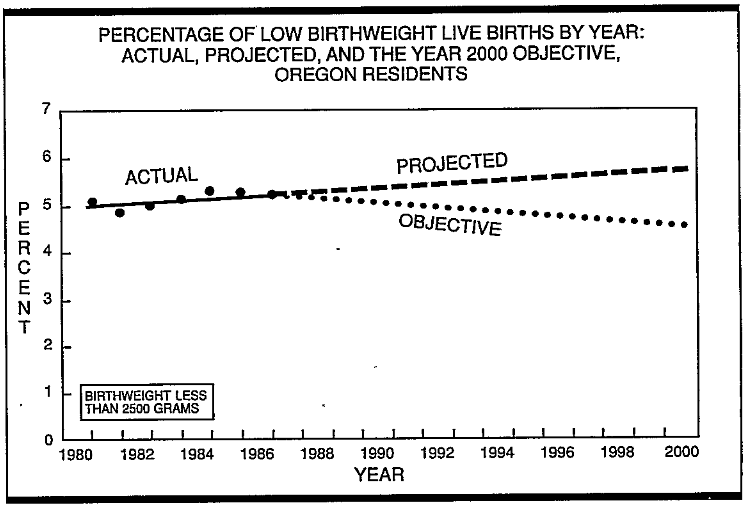
[6] Source: Maternal and Child Health Program, Oregon Health Division

- Assigning a full-time project coordinator to organize and plan follow-up activities.
- Assigning oversight of the project to the state agencies' Governor - appointed advisory board.
- Developing a quarterly newsletter to inform people of Oregon's progress and projects for Health 2000.
- Preparing a mid-point publication, evaluating data/trends and progress toward the Objectives.
- Sharing the document statewide; currently there have been 9,000 copies distributed.

Progress in achieving Oregon's Health Objectives for the Year 2000 will not really be visible for several years. However, the document and project model of strategic planning has been a combination of scientific analysis and discussion blended with the art of politics and marketing.

The Project Team and the state public health agency believe that this document will ultimately result in stimulating public health policy and mobilizing more resources to help make Oregonians healthier by the year 2000.

Graph 1.



Session F

Infant Mortality

PHCRS

APPLICATION OF VITAL RECORDS DATA TO THE EVALUATION OF A COMMUNITY HEALTH PROJECT FOR THE PREVENTION OF INFANT MORTALITY

Cheryl A. Lee, Kansas City Health Department

The purpose of this presentation is to share experiences at the Kansas City, Missouri Health Department in using vital records data in the evaluation of a community health project for the prevention of infant mortality. Some of the problems surrounding the collection of good program data at the local level will be discussed.

INTRODUCTION

Inadequate prenatal care and unhealthy lifestyles of pregnant women are frequently associated with the delivery of low birthweight infants who are at increased risk for mortality and morbidity. Numerous risk factors are associated with low birthweight infants, defined as weighing less than 2,500 grams (or 5.5 pounds) at birth. These infants are many times more likely to die within the first month of life and, if they survive, are at increased risk for many health problems. Unhealthy maternal lifestyles which contribute to the risk of delivering a low birthweight infant include poor nutrition, cigarette smoking, and alcohol and drug abuse. Other known risk factors for poor birth outcomes include preterm birth, very young maternal age, minority racial group, low level of maternal education, and the mother being unmarried.[1]

PROJECT DESCRIPTION

In 1985 in Kansas City, Missouri, a community health project, funded by the county legislature, was created to focus on reducing infant mortality and low birthweight among the high-risk, indigent portions of the population in the city. The on-going project is coordinated through a neighborhood health center and cooperates with other neighborhood health centers, hospitals, public health clinics and school-based clinics in the city.

The primary goals of the community health project are (1) to reduce the incidence of low birthweight and infant mortality, (2) to enable pregnant women to receive early and consistent prenatal care, and (3) to work with the community to increase awareness of the medical and economic consequences of the problems of low birthweight and infant mortality.

At this time the project team includes a nurse, who is the project coordinator, a social worker, a nutritionist, 2 van drivers, a secretary and a consulting physician. They presently work with approximately 700 teenage and other high-risk women who are either pregnant or who have infants under 1 year of age. The services that are provided to these women by the project include the following:

1. case finding,
2. appointment follow-up,
3. van transportation to and from prenatal care services and infant health clinics,
4. nutrition counseling,
5. smoking cessation classes,
6. "Healthy Lifestyle" presentations on topics including stress management, human development and baby care,
7. home visitation,
8. counseling for pregnant teenagers and their families,
9. encouragement for teenagers to enroll in the school district's school for pregnant teenagers or to return to their own schools to continue their education,
10. infant follow-up for 1 year,
11. social services assistance, and
12. referral to other community services.

The project team works with participating agencies, social service organizations, schools and churches to contact pregnant women who have not entered prenatal care programs. The goals are to ensure a minimum of 9 prenatal visits for a full term pregnancy and to follow up with women who fail to schedule or return for prenatal care appointments.

Two of the main reasons frequently given for failure to seek and sustain prenatal health care, as documented by a recent Missouri study on barriers to prenatal care, are lack of money and lack of transportation.[2] Since encouraging prenatal care without providing easy access to it is not likely to be effective in improving pregnancy outcomes, the community health project has established a system to provide free van transportation between the high-risk client's home or school and the area prenatal and infant health care clinics of their choice.

In addition to these other services, all participants in the project are followed, whenever possible, until the infant's first birthday.

EVALUATION

After the community health project had been in existence for approximately 2 years it was suggested by the project's advisory board that an evaluation of the project would be appropriate. The Kansas City Health Department undertook an outcome evaluation to try to determine if pregnant women who participated in the project had pregnancy outcomes which were different than they would have been had they not participated in the program.

Methodology

The evaluation was done through analysis of information obtained from birth and death certification records. A nonequivalent control group design was used in which 2 other groups were studied as "comparison," rather than as "control," groups.[3]

An attempt was made to locate birth certificate information on each client served by the project who delivered an infant during 1986 or 1987. All data collected for the 2-year period was combined for analysis. Birth and death information was obtained from vital records data tapes provided by the Missouri Center for Health Statistics. Computer facilities were available through the City of Kansas City's IBM mainframe computer system, and SPSS^x software was used in data analysis.

Figure 1: The map in Figure 1 shows the city of Kansas City divided by zip code zones. The central, cross-hatched area shows the inner-city zip zones from which approximately 85 percent of the community health project's clients are drawn. This area consists of 10 zip zones which are generally considered to be the high-risk areas of the city in terms of health status indicators.

Data was compared on all 1986 and 1987 live births for 3 population groups: (1) 780 community health project clients, (2) 7,346 residents of the 10 central city zip zones from which 85 percent of the project's clients were drawn, and (3) 15,681 residents of the whole of Kansas City. 46.8 percent of the births to Kansas City residents occurred to residents of the 10 high-risk central zip zones. About 5 percent of the births to city residents during 1986 and 1987 were to women who participated in the community health project. It was deduced that about 10 percent of pregnant women in the 10 central zip zones participated in the project.

Birth certificate data was successfully obtained for 780 project clients. No birth certificate could be located for 88 clients for whom pregnancy outcomes were unknown. The analyses included data on selected known risk factors for low birthweight and on pregnancy outcome measures which could be readily obtained from the birth certification record.

Risk factor analyses

Figure 2: Young maternal age is frequently considered to be a risk factor for low birthweight and infant mortality.[4] This factor was compared by examining the percentage of births to teenagers, defined here as women less than 20 years of age, in each of the 3 comparison populations. Figure 2 shows that, citywide, 16.1 percent of all live births were to teenage mothers, compared with 22.9 percent in the central zip zones and 45.1 percent among the project clients. This indicates that the project has been successful in reaching their target high-risk population of pregnant teenagers.

Figure 3: This figure shows that for the low birthweight risk factor of minority racial group, 38.6 percent of live births citywide and 75.4 percent of live births in the central zip zones were to minorities (primarily black women), and that 78.1 percent of live births to project clients were to minority women.

Figure 4: The level of maternal education was compared among the 3 groups by determination of the percentages of women having live births who had not completed high school. Figure 4 shows that 22.5 percent of citywide mothers had completed less than 12 years of education, with figures of 32.9 percent for the central zip zones and 51.2 percent for project clients.

Figure 5: Prenatal care has a strong association with pregnancy outcome, especially among poor and minority populations. Second only to socioeconomic status, the prenatal care a woman receives is thought to be the most important determinant of birth outcome.[5] The percentages of women who began prenatal care during the first trimester of their pregnancy are shown in Figure 5. 75.2 percent of the citywide women began prenatal care within the first 3 months of the pregnancy, compared with 65.8 percent of women in the central zip zones and only 61.8 percent of the project clients.

Figure 6: Maternal smoking during pregnancy is a well-established risk factor for low birthweight and infant mortality.[6] This factor is compared in Figure 6 for the 3 population groups. 27.4 percent of the citywide group of women identified themselves as smokers during their pregnancies, compared with 29.8 percent of women in the central zip zone group and 31.5 percent of project clients.

Figure 7: The data in Figure 7 show that, citywide, 38.2 percent of live births were to women who were not married. This figure for unmarried mothers compares with 61.3 percent in the central zip zone group and 80 percent of the community health project participants.

For all of these risk factors for low birthweight (young maternal age, minority racial group, maternal education of less than 12 years, no prenatal care in the first trimester, maternal smoking during pregnancy and unmarried status of the mother), the community health project clients clearly were the population group at greatest risk for delivery of a low birthweight infant.

Outcome analyses

Pregnancy outcomes for the 3 groups of women with live births during 1986 and 1987 were compared by analysis of low birthweight percentages, preterm birth percentages, Apgar scores and infant mortality rates.

Figure 8: The results of an analysis of the incidence of low birthweight for all 3 population groups, seen in Figure 8, showed that 9.5 percent of all live births citywide were less than 2,500 grams. This figure compared with 12.0 percent low birthweight for the central zip zone residents and 11.0 percent for the project participants. The incidence of low birthweight was significantly less in the citywide group than in the other 2 groups; however, the difference in percentage of low birthweight infants between the central zip zone group and the project clients was not statistically significant. When incidence of very low birthweight of less than 1,500 grams was compared for the same 3 groups of women, the numbers were 2.0 percent citywide, 2.7 percent in the central zip zones and 1.7 percent for the project clients.

Figure 9. Examination of the percentages of preterm births with gestational age of less than 37 weeks, illustrated in Figure 9, showed that the percentages of preterm births were 10.4 percent in the citywide group, 13.7 percent for the central zip zone residents and 11.0 percent for the project clients. There was no statistically significant difference in percentages of preterm births between the 2 groups of citywide residents and project participants. However, there was a significant difference in preterm birth percentages between these 2 groups and the central zip zone residents.

Figure 10: Many physicians consider the Apgar score to be a significant indicator of infant health status at birth, with a score of 7 to 10 indicating that the infant is in good condition.[7] An analysis of the Apgar scores recorded at 5 minutes after birth was included in the evaluation. Figure 10 shows that there was no real difference among the 3 population groups for percentages of infants with scores of 7 or greater. 97.3 percent of the project clients had live births for which the score was 7 or more.

Figure 11: Infant mortality rate was the final factor examined in this evaluation. The community health project participants were the population group with the lowest infant mortality rate for the years of 1986 and 1987. Figure 11 shows that the infant mortality rates (defined as the number of infant deaths occurring before 1 year of age per 1,000 live births during the same period of time) were 15.7 citywide, 18.5 for the central zip zone group and 15.4 for the project clients. There was no statistically significant difference between the infant mortality rates for the project clients and for the city as a whole. However, the infant mortality rate was significantly higher for the central zip zone group when compared with the other 2 groups.

OBSERVATIONS AND CONCLUSIONS

The conclusion from the foregoing data was that birth outcomes for participants in the community health project are better than would be expected, based on the prevalence of the project clients' risk factors for low birthweight and infant mortality. It appears that the project is having a positive impact upon the community population group that it serves. Evaluation of this project has shown that the project team has made real progress toward their goal of bringing the health status of a high-risk group of pregnant women and newborn infants up to the levels shown for the population of the city as a whole. As support for future requests for program funding and expansion, it has been important to provide documentation of impact of the program upon the community. This impact must be viewed not only in terms of saving of infant lives and prevention of future developmental difficulties, but in economic terms of saving the community many dollars in the costs of newborn intensive care and longterm follow-up support.

DISCUSSION

Numerous difficulties were encountered in attempting to perform this type of project evaluation. A few of the major problems will be discussed for the potential benefit to others who may decide to undertake a similar task.

No data collection or evaluation component was built into the project at the time of its inception, and it was difficult to institute one at a later time.

The project agency was unable to give an accurate accounting of the number of clients they served each year, the number that were lost to follow-up or dropped out of the program, the number who moved away from the area or delivered their infants outside of Kansas City, or the number who had therapeutic abortions or miscarriages.

Analyses were based on data on all clients for whom the community health project could provide a name and for whom a birth certification record could be located in the Kansas City system. No information was obtained for approximately 10 percent of the project participants.

Birth certificate records were often impossible to locate because the name of the infant was frequently unknown or not provided. In these cases, it was necessary to try to locate the record by a computer system search for the mother's name or the residence address at the time of the birth. The mother's maiden name is the one which is placed on the infant's birth certificate. Difficulties in locating records increased when the mother gave only her married name to the project staff, when she gave them some other name that she was using, or when the name was misspelled. Spellings were often incorrect, which made names very difficult to locate.

The women who participate in the project tend to be part of an unstable population who change their addresses frequently. Many of them move often or live with a variety of relatives and friends for short periods of time. It is often difficult to do follow-up with them or to get complete and accurate information from them.

There is concern that it is so difficult to get reliable and useful data from community programs such as the one evaluated in this presentation. The objective should be to provide the project with an adequate data collection and maintenance system. Such small community programs frequently work with paper-only filing systems with no access to personal computers for record-keeping purposes. In this community health project reports are currently compiled through a process of reviewing all client files and completing a hand tally on the factor of interest. The situation of having an exceedingly limited number of staff members available does not permit good reporting. It is strongly recommended that a funding source be found to provide a personal computer system and technical assistance for establishment of a simple client database, as well as for an administrative assistant to carry out the data entry and paperwork tasks so that the remainder of the project staff can be free to do what they do best - work with their clients! It is essential for local level programs such as this community health project to begin developing an awareness of the need for adequate data collection for documentation of programming needs, client outcomes, and community impact of their programs.

ACKNOWLEDGEMENTS

The following persons are to be acknowledged for helping to make possible this presentation: Information on women participating in the community health project, description of the program goals and services, input to the project's advisory board, and encouragement for completion of this evaluation were provided by Ivy A. Ganaway, Project Coordinator. Technical assistance, suggestions and support were also provided by Drs. Mark A. Mitchell and Quintin B. Welch of the Kansas City Health Department, Margo Quiriconi of Adolescent Resources Corporation, and Dr. Patricia DeMarinis of Truman Medical Center.

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FIGURE 1.

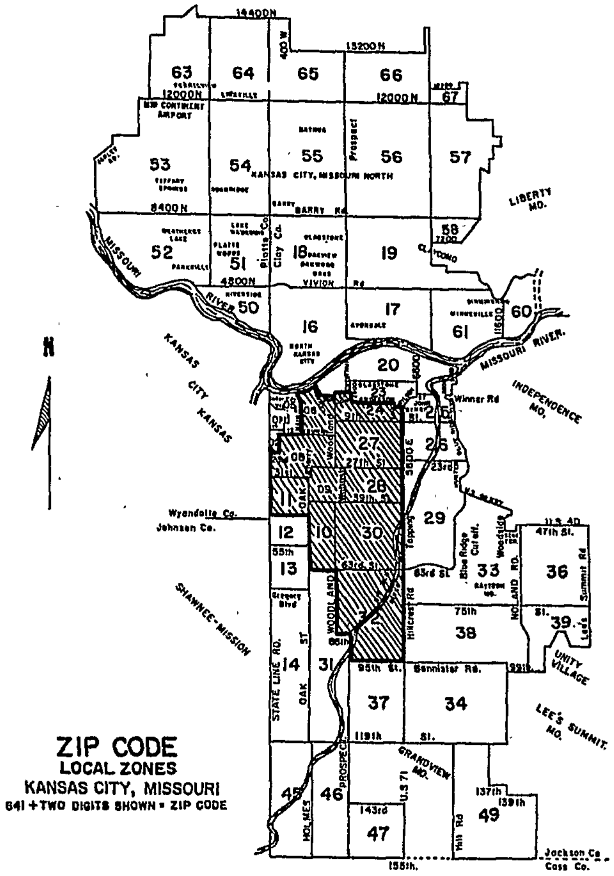


FIGURE 2.

BIRTHS TO TEENAGERS
Kansas City, Missouri, 1986-87

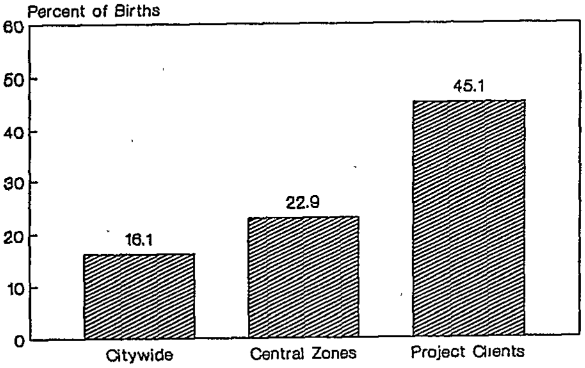


FIGURE 3.

BIRTHS TO MINORITY RACES
Kansas City, Missouri, 1986-87

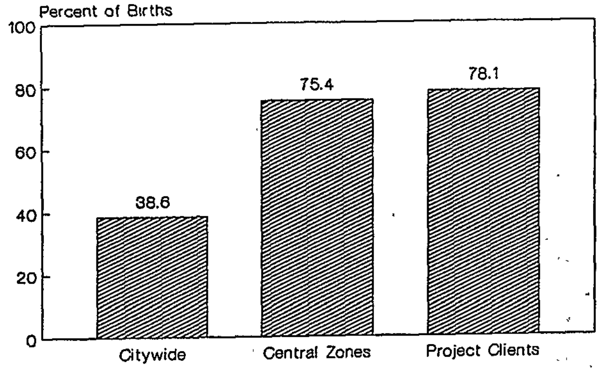


FIGURE 4.

MOTHERS' EDUCATION UNDER 12 YEARS
Kansas City, Missouri, 1986-87

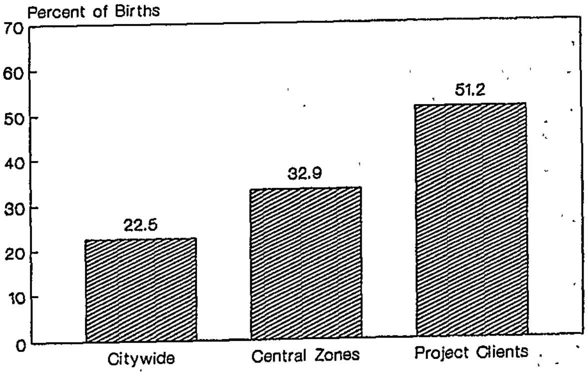


FIGURE 5.

PRENATAL CARE IN 1ST TRIMESTER
Kansas City, Missouri, 1986-87

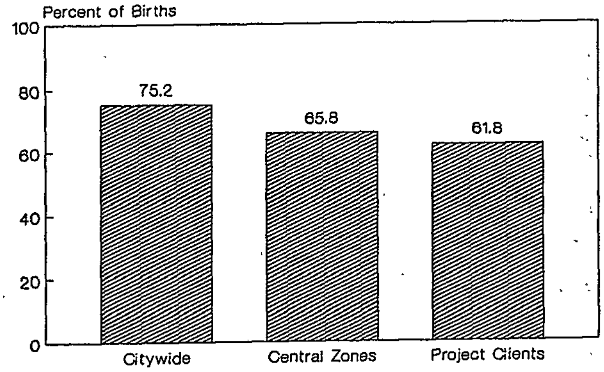


FIGURE 6.

MATERNAL SMOKING DURING PREGNANCY
Kansas City, Missouri, 1986-87

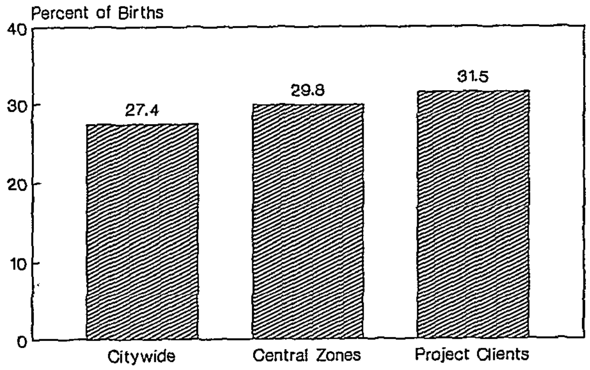


FIGURE 7.

MOTHER NOT MARRIED
Kansas City, Missouri, 1986-87

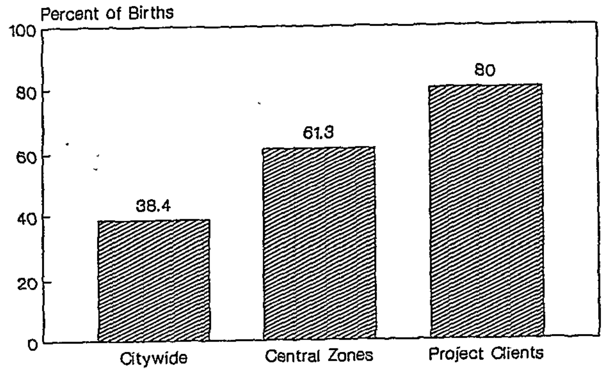


FIGURE 8.

LOW BIRTH WEIGHT
Kansas City, Missouri, 1986-87

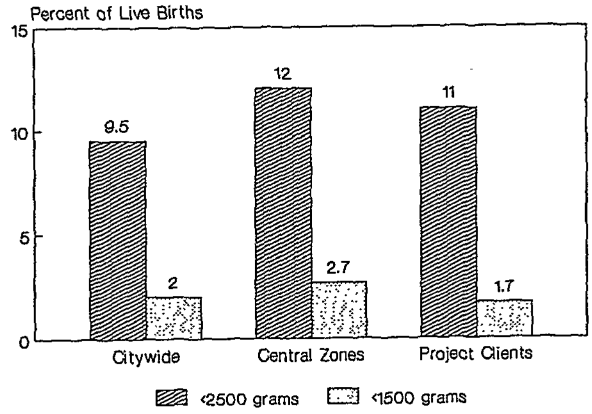


FIGURE 9.

GESTATION UNDER 37 WEEKS
Kansas City, Missouri, 1986-87

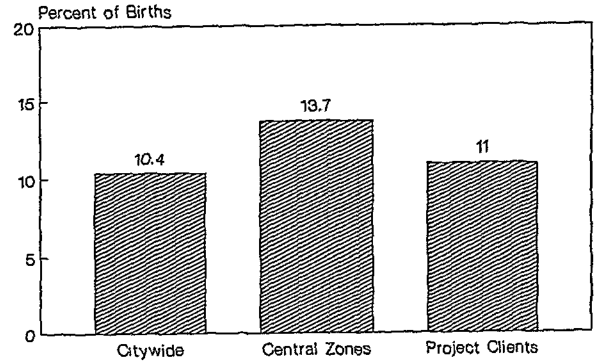


FIGURE 10.

5 MINUTE APGAR SCORE OF 7 OR GREATER
Kansas City, Missouri, 1986-87

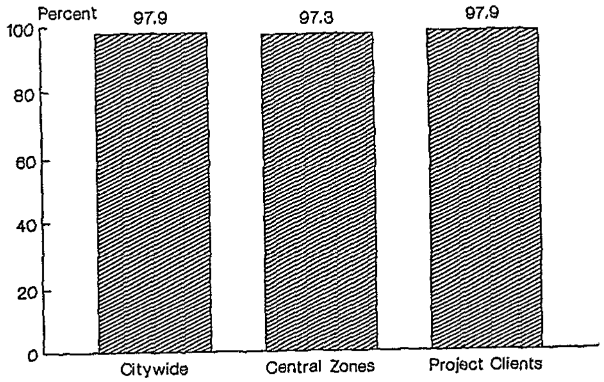
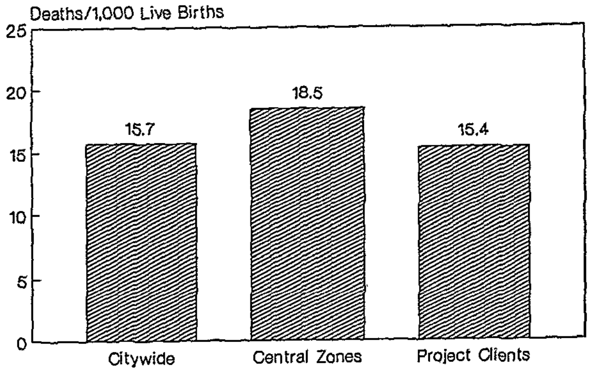


FIGURE 11.

INFANT MORTALITY RATE
Kansas City, Missouri, 1986-87



INCREASING CESAREAN SECTION RATES IN VERY LOW BIRTH WEIGHT INFANTS: EFFECT ON OUTCOME

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Introduction:

The rate of cesarean deliveries in the United States has increased remarkably over the last two decades. From a rate of 4.5 percent of all deliveries in 1965 the rate increased to 24.1 percent in 1986. Whether or not this trend has occurred across all birth weights is not clear. Also uncertain and controversial is whether or not there is justification for the increase in cesarean sections. Does the use of cesarean section provide survival advantages for specific groups of infants? This is a particularly important question to answer for the less than 1500 gram infant, because these infants comprise the majority of our national infant mortality experience. Cesarean section of the less than 1500 gram infant in the breech position has been associated with decreased mortality. However, the benefit of cesarean section of the less than 1500 gram infant that presents in the vertex position is more controversial.

In order to address these questions my colleagues, George Rhoads at NICHD and Wayne Schramm and Garland Land at the Missouri Department of Health report an analysis of linked birth and death certificate information from Missouri for the years 1980 to 1984. Missouri is representative of the national experience in cesarean sections and the national incidence of low birth weight infants. In 1980 14.7% of the births in Missouri were by cesarean section and 0.84% of the live-born infants weighed less than 1500 grams. These percentages are only slightly lower than the national cesarean section rate in 1980 of 16.4% and the national very low birth weight rate of 1.15%.

Methods:

Our specific objectives in this population-based study were to describe the trend in cesarean section rates by birth weight specific categories and to determine within the very low birth weight category whether cesarean delivery was associated with a reduced risk of adverse birth outcome.

We chose to use deaths occurring in the first day of life as our outcome measure with the view that deaths in the first 23 hours of life might be closely related to causes associated with trauma or asphyxia that in turn might be related to the method of delivery.

The data used in this analysis were obtained from linked birth and death certificate data from Missouri for the years 1980 to 1984. For this analysis we used only singleton pregnancies and births weighing 500 grams or more. Records without the method of delivery were excluded from the analyses. 3.7% of 3214 live births weighing 500-1499 grams were missing the method of delivery; as were 2.4% of 18,132 live births weighing 1500-2499 grams; and 1.9% of 354,348 live births weighing more than 2499 grams.

Variables obtained from the birth certificate included the mother's race, age and parity, number of births from this pregnancy, the method of delivery, complications of pregnancy and labor, and the level of care provided at the place of birth. Complications of pregnancy and labor were recorded on the birth certificate as a fill-in-the-blank question. Also on the birth certificate was a question asking for an indication for cesarean section. From the death certificate we obtained the age and cause of death.

Tests for trends of rates over time were done using a stratum adjusted Cochran-Mantel-Haenszel statistic. For analyses combining all 5 years worth of data tests for general associations of discrete variables were accomplished using a chi square statistic. Tests for continuous variables were carried out by unpaired t-tests. Logistic regression models were developed to determine the independent association between the age of death and the method of delivery.

Results:

Cesarean section rates varied widely for the different birth weight groups. In each group the rate increased significantly over the 5 year period ($p<0.0001$). For infants weighing 500-1499 grams the rate of cesarean section increased 1.8 times from 25.2% in 1980 to 44.1% in 1984. Of interest is the observation that the greatest rate of increase was in the 500-799 gram group. The rate in this group increased from 9% in 1980 to 27% in 1984. These increases were not associated with any change in the incidence of births of 500-1499 gram infants which remained near 0.8% throughout the study period. For the larger infants the cesarean section rates increased 1.2 times between 1980 and 1984 to 26.0% for infants weighing 1500-2499 grams and to 18.7% for infants weighing more than 2500 grams. The 5 year average cesarean section rate was 36% for the 500-1499 gram infants, 24% for the 1500-2499 gram infants and 16% for infants weighing more than 2500 grams.

Cesarean section rates for the combined 5 year period differed considerably at different birth weights under 1500 grams. The rate was 19% for infants weighing 500-799 grams, 35% for the 750-999 gram infants, and 41-42% for those over 1000 grams.

The rates for our primary outcome variable, day 1 deaths, also varied considerably amongst these infants. Of the 559 births that weighed 500-749 grams, 304 or 54% of them died in the first day of life. This represents 70% of all the deaths that occurred in the 500-749 gram infants over the first year of life. The day 1 death rates were much lower for the larger infants. For the 725 infants weighing 750-999 grams 21% died in the first day. There were 800 infants weighing 1000-1249 grams of which 8% died in the first day. While only 4.6% of the 1250-1499 gram infants died in the first day.

Thirty-three percent of the 500-749 gram infants delivered by cesarean section died in the first day of life compared to 59% delivered vaginally ($p<0.0001$). The larger infants delivered by cesarean section also had slightly lower day 1 death rates than those infants delivered vaginally but there was no statistically significant association between the method of delivery and day 1 death. We therefore, focused our analysis on the 500-749 gram infants.

We considered a number of demographic and obstetric characteristics of the mothers of infants weighing 500-749 grams, and will review those characteristics that demonstrated a strong relationship with cesarean section or first day deaths. Males are noted to have a higher incidence of first day deaths than females (61 vs 47%) and women less than 18 years are noted to have a low incidence of cesarean section (6%) compared to older women.

There was a low incidence of cesarean section in level 1 hospitals; a low incidence of sections in women with premature labor (13%); and women with a diagnosis of hypertension had a very high incidence of sections (86%) and a low incidence of first day death (20%).

Women with malpositioned fetuses had a high incidence of section (55%) and a low incidence of first day death (37%); women with fetal distress were sectioned frequently (51%) and the incidence of first day deaths was low (24%); the incidence of cesarean section in infants with a diagnosis of asphyxia was low (12%), but the first day death rate was high for asphyxiated infants (73%); and the incidence of section in infants resuscitated was high (37%) and first day death rates were low (29%) compared to infants not resuscitated.

The mean gestational age of infants delivered by cesarean section was 27.3 weeks and did differ from the mean gestational age of 25.1 weeks for infants delivered vaginally. The mean birth weight of infants delivered by cesarean section in this smallest group of infants was 642.7 grams and did not differ from the mean birth weight of 629.4 grams for infants delivered vaginally.

The demographic and obstetric characteristics of the pregnancies that produced infants weighing 500-749 grams along with the first order interactions with the method of delivery were entered into a stepwise logistic regression procedure. The final model included the gestational age, the sex of the infant, a variable developed to describe whether or not a successful resuscitation occurred at birth and the labor complication variable for fetal distress. The adjusted odds ratio for day 1 death, that is, death between 0-23 hours, was 0.48 with a 95% confidence interval of 0.29 to 0.78. This protective effect, however, was confined to the first 23 hours. Infants delivered by cesarean section had a higher odds of dying between 1 and 6 days of life than did infants delivered vaginally. The odds ratio for this group was 2.09 with a 95% CI of 1.06 to 4.10. When the two periods were combined no significant relationship between the method of delivery and death in the first week was noted. The odds ratio was 0.85 with 95% CI of 0.52 to 1.39.

The odds ratios of time of death by method of delivery for the neonatal periods inclusive and exclusive of the first week of life, as well as the odds ratios for the entire first year of life inclusive and exclusive of the neonatal period. There were no significant associations between the method of delivery and death for any of these time periods.

Comments:

Other studies have examined the association between the method of delivery and neonatal death and in most instances have found no protective effect of cesarean section. In those studies that reported a lower neonatal mortality rate for very low birth weight infants after adjusting for perinatal risk factors the significant univariate protective relationships between cesarean section and neonatal mortality disappeared. Our analysis has differed from previous ones in focusing on first day deaths when the benefits, if any, of cesarean section on fetal survival might be most clearly seen. A potential benefit was noted for deaths in the first 23 hours in the smallest infants weighing 500-749 grams, but excess deaths in the cesarean group in the succeeding 6 days suggested that death was being briefly postposed rather than prevented.

The mechanism by which cesarean section is related to a lower death rate in the first 23 hours after birth is not clear, although prevention of asphyxia is an obvious possibility. Asphyxia was listed as the primary cause of first day death in the 500-749 gram infants in only 5% of cases. Diagnosis of prematurity, respiratory failure, respiratory failure, and respiratory distress syndrome were much more common. However, low five minute Apgar scores, which are commonly held to be an indicator of asphyxia and of poor prognosis, were frequent. Apgar scores below four occurred in 66% of vaginal deliveries compared with 39% of cesarean deliveries. We found evidence that effective resuscitation, defined as an increase in Apgar score of four or more between one and five minutes, occurred in 20% of the cesarean born infants compared to a 9% occurrence rate in vaginally born infants. Perhaps this reflects the usual practice of having a resuscitation team present at the time of a preterm cesarean section.

In a vital statistics analysis of obstetric outcomes one is concerned that complications of pregnancy may not be reliably recorded. In particular, it is possible that such complications are more likely to be noted for cesarean than for vaginal deliveries since the Missouri birth certificate requests an indication when a cesarean section is reported. Under-reporting of complications on the birth certificates of the vaginally delivered infants, if it occurred, might help to explain the higher death rate in that group. However, in multivariate analysis these complications did not appear to be important confounders and, except for fetal distress, did not contribute significantly to the model. Perhaps this was because all of these very small infants were at such high risk. For example, those delivered preterm for a specific reason, such as maternal hypertension, may not have had a worse prognosis than those delivered as result of idiopathic preterm labor.

It is reasonable to suppose that obstetricians would not usually have performed a cesarean section unless they believed that the fetus had a substantial chance of surviving. Moreover, some women delivering vaginally presumably arrived at the obstetric unit too late to receive optimal care. These unmeasured biases, which could be of considerable importance, would be expected to lead to worse results after vaginal than after cesarean birth. Nevertheless, after adjusting for differences in gestational age, sex of the infant, and other measured factors, there was no statistically significant advantage of cesarean section beyond the first day. It is possible that the failure to find such an advantage, despite the unmeasured biases, could reflect a harmful effect of cesarean section.

In summary, we conclude the following: In Missouri, the cesarean section rate has increased more rapidly among very low birth weight infants than among heavier infants. Those infants weighing 500-749 grams delivered by cesarean section do have a lower risk of day 1 deaths.

However, the deaths of these infants delivered by cesarean section appear to be delayed into the first week of life. We suggest that the apparent early protective effect of cesarean section is related to a number of biases in the selection of women for this procedure. Women selected for cesarean section are more likely to carry more mature fetuses; to not be in labor; and to have their infants selected for resuscitation. Finally, because of the lack of survival advantage associated with cesarean sections independent of maternal or fetal compromise there appears to be little justification for the rapidly increasing cesarean section rate in these small infants.

HOW LOW CAN IT GO? ESTIMATES OF PERINATAL MORTALITY REDUCTIONS THROUGH MATERNAL/FETAL TRANSFER OF THE HIGH RISK PREGNANCY

Russell S. Kirby, Arkansas Center for Health Statistics
Susan K. Patton, Arkansas Department of Health

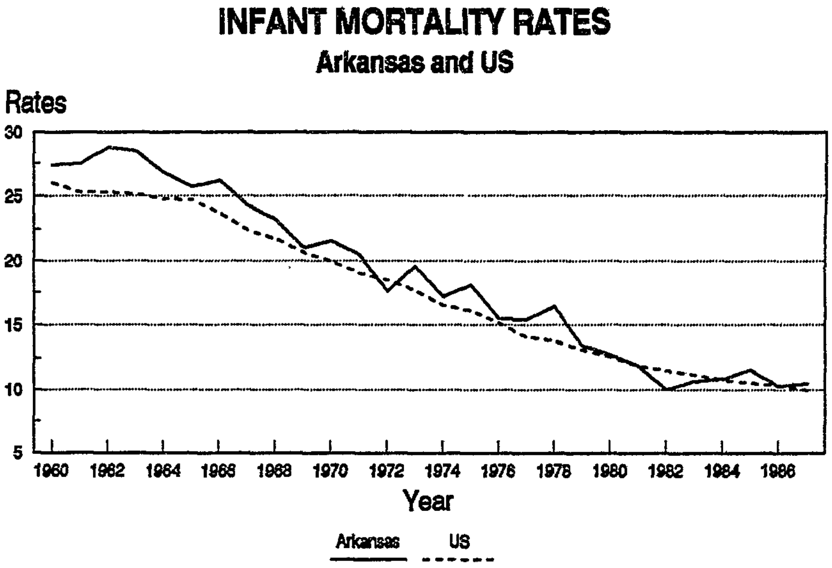
One measure of health status, infant mortality, has been improving in the United States (US) and Arkansas for over two decades. (Figure 1) However, infant mortality rates experienced in some social groups and geographic areas are still remarkably high. From 1976 through 1980, ten percent of all counties, mostly rural, in the US had infant mortality rates above 20 per 1,000 live births. This level of mortality is comparable to that reported for Costa Rica (20.2), Cuba (19.6), and Poland (21.3). (1) One explanation for persistently high infant mortality rates in rural areas is the poor, uninsured, isolated populations with low levels of education and inadequate housing. While it is critical to recognize the environmental and social contributions to the production of health, it is important to recognize that deficiencies in the medical care system and variations in the quality of care may also be factors.

The concept of regionalizing perinatal care in order to improve quality of care received national attention in the mid-1970's with the 1976 report of the Committee on Perinatal Health, <u>Toward Improving Pregnancy Outcome</u>. Regionalization calls for a system of care to be developed within a geographic area for a defined population base. The system should be designed so that each region can provide complex and specialized care. It should encourage the best use of expensive, scarce technology and personnel.

Hospital facilities are defined as Level I, II, or III depending upon the complexity of services each is capable of providing. The American Academy of Pediatrics and the American College of Obstetricians and Gynecologists define the care that is expected at each level in their book, <u>Guidelines for Perinatal Care</u>. Level I units provide services primarily for uncomplicated maternity and newborn patients. Level II units provide a full range of maternal and neonatal services for uncomplicated patients and for a majority of complicated obstetrical problems and certain neonatal illnesses. Level III units may provide services for normal patients as well as serious maternal-fetal and neonatal illnesses and abnormalities. They should serve regions with 8,000 to 12,000 annual deliveries. (2)

Population based data shows improvements in neonatal outcomes in high risk neonates transported to hospitals with intensive care units as compared with similar nontransported populations. (3) Data on pregnancy outcomes demonstrates that a high risk maternal transport system developed subsequent to a well established newborn transportation and intensive care system further reduces perinatal mortality and morbidity in the region it serves and a dose response gradient of mortality associated with the intensiveness of the care. (4,5,6,7) The very low birth weight (VLBW) infant benefits most from in-utero transport and birth in a

Figure 1.



rates are per 1,000 live births
US 1987 rate is provisional

perinatal center rather than birth in an outlying hospital and transport as a newborn to a regional center. (8,9,10)

Neonatal mortality can be viewed as determined by two factors: the distribution of birth weights and the birth weight specific mortality. The VLBW rate is the major contributor to the neonatal mortality rate. (11) According to The National Commission to Prevent Infant Mortality, the risk of neonatal death is 200 times greater for VLBW than for normal birthweight infants . A neonatal mortality rate from which the major contributor to variance is removed will likely be a better indicator of quality perinatal care than the crude neonatal rate.

When the crude neonatal mortality rate is divided by the rate of delivery of VLBW babies, an index of outcome standardized for population risk is obtained. (Table 1) Arkansas' crude neonatal mortality rate decreased by 26 percent in the years considered (1980-1987). The VLBW rate increased by 18 percent, coinciding with a 33 percent decrease in the index.

Advances in reducing neonatal deaths have come from the increasing ability to save smaller babies. (12) With this information, we can better understand why the decline in infant mortality occurred, how we can make better medical care resource allocations, and determine priorities for research which are likely to achieve further reductions in mortality.

Although VLBW infants benefit from being born in a Level III perinatal center and fetal death rates decrease as intensiveness of care increases, the benefits of advances in medical technology are not provided equitably to all. In 1985-1987, 18.4 percent of fetal deaths and 45 percent of Arkansas' VLBW births occurred at the centers providing such care. Further regionalization of perinatal services for maternal/fetal pairs at risk should lead to a further reduction in perinatal mortality.

All live birth and fetal and neonatal death certificates of Arkansas residents for 1985 through 1987 filed with the Division of Vital Statistics of the Arkansas Department of Health were reviewed. Perinatal and neonatal mortality rates were calculated within 500 gram weight categories according to level of hospital of birth. Deaths were assigned to hospital of birth regardless of whether infants were transferred elsewhere. Therefore, the analysis indicates the availability of intensive care at birth (or before) and not the complete absence or presence of intensive care services.

For this study, we chose not to use standard Level I, II, III designations as they have never been officially applied in Arkansas. Level III hospital determinations are based upon the availability of maternal/fetal medicine and/or neonatal specialists and presence of a newborn intensive care unit. Separate designations are made for obstetrical and neonatal facilities.

The location of births of VLBW infants and of fetal deaths provides a measure of the extent of perinatal regionalization. (13, 14, 15) During the study period, 20 percent of VLBW infants were born at level 1 hospitals, 34 percent were born at level 2 hospitals, and 45 percent were born at level 3 hospitals, although only 11 percent of the total births occurred at level 3 centers. (Figure 2, Tables 2 and 3) Approximately 45 percent of fetal deaths occurred at level 1 hospitals, 33 percent occurred at level 2 hospitals, and 18.4 percent occurred at level 3 centers. (Figure 3)

For live births, mortality rates were lower at Level III centers for infants weighing less than 1500 grams at birth. By applying the level III mortality rates at day 1 to all very low birth weight infants, the difference

Table 1.

Arkansas Neonatal Mortality Rates

adjusted to birthweight distribution

	Births	Neonatal Mortality*	Incidence very low birthweight births*	Index
1980	37,278	7.6	10.97	0.69
1981	35,807	6.7	11.87	0.56
1982	35,380	5.6	11.31	0.50
1983	34,996	6.2	13.57	0.46
1984	34,840	7.0	12.54	0.56
1985	35,221	7.1	15.27	0.46
1986	34,393	5.6	11.19	0.50
1987	34,574	6.0	12.92	0.46

*per 1000 live births

Figure 2.

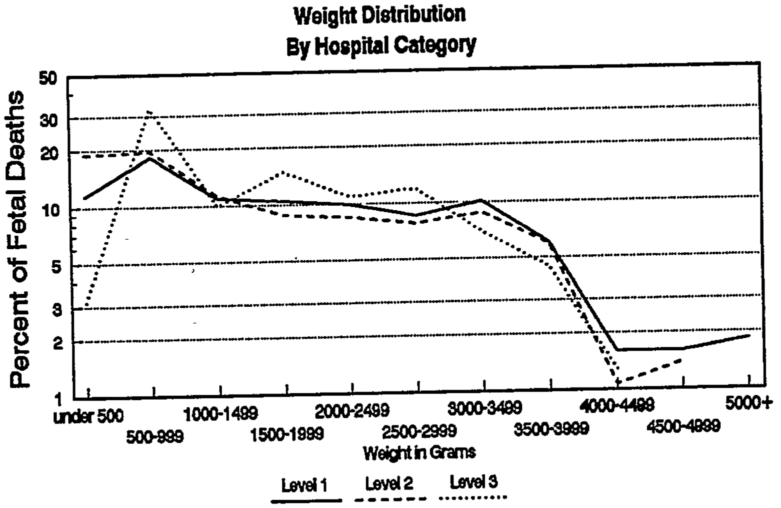

Weight Distribution
By Hospital Category

Table 2.
DISTRIBUTION OF LIVE BIRTHS BY BIRTHWEIGHT AS A RATIO TO THE PERCENTAGE OF BIRTHS IN HOSPITAL CATEGORY

	Out of Hospital	Level 1	Level 2	Level 3
< 1500 gms	1.08	0.41	0.86	4.08
1500-2499 gms	0.75	0.83	0.95	1.95
2500+ gms	1.02	1.02	1.01	0.89

Table 3.
DISTRIBUTION OF LIVE BIRTHS BY GESTATIONAL AGE AS A RATIO TO THE PERCENTAGE OF BIRTHS IN HOSPITAL CATEGORY

	Out of Hospital	Level 1	Level 2	Level 3
< 28 wks	0.97	0.68	0.83	3.44
28-31 wks	1.27	0.74	0.82	3.12
32-36 wks	0.78	0.90	0.98	1.68
37-41 wks	1.06	1.02	1.02	0.83
42+ wks	1.07	1.02	0.96	1.03

Figure 3.

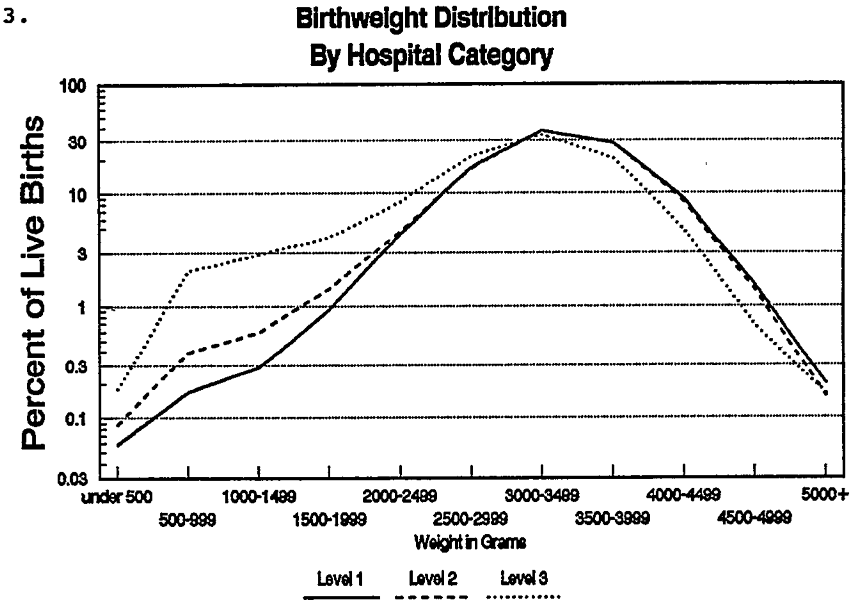

Birthweight Distribution
By Hospital Category

Table 4.

HOW LOW CAN IT GO?

	less deaths	old rate	new rate
fetal	186.00	8.0	6.30
neonatal: 1 day	37.75	3.2	2.85
neonatal: 1 month	23.39	6.3	6.10
perinatal	115.00	14.3	13.00

Table 5.

STANDARDIZED FETAL MORTALITY RATIOS

	OOH	Level 1	level 2
under 1500 grams	3.50	3.00	2.00
1500-2499 grams	0.70	1.20	0.77
2500+ grams	1.53	0.63	0.49

between actual deaths and expected deaths is 37.25. The overall mortality rate would decrease from 3.2 to 2.85 per 1,000 live births. Differentials did persist throughout the neonatal period, although they were attenuated. By applying the level III mortality rates at the end of the first month of life to all very low birth weight infants, the difference between actual deaths and expected deaths is 23.39. The overall neonatal mortality rate would have decreased from 6.3 to 6.1 per 1,000 live births. For the 55 percent of Arkansas very low birth weight babies born outside level III centers, the excess neonatal mortality was 10 percent.

By applying level III fetal mortality rates to all VLBW births, the difference between actual and expected deaths is 186. The fetal mortality rate would decrease from 8.0 to 6.0 per 1,000 live births and fetal deaths.

Under 1500 gram birth weight specific perinatal death rates were lower at level III centers, the largest component in the perinatal difference was fetal mortality. By applying level III perinatal mortality rates to all VLBW births, the difference between actual and expected deaths is 115. The perinatal mortality rate would decrease from 14.1 to 13.0 per 1,000 live births and fetal deaths. (Table 4)

Relative risk ratios for weight-specific fetal and neonatal death were calculated for out of hospital births and levels 1 and 2 with level 3 used as the reference group and its relative risk ratio set to 1. (Tables 5, 6, 7)

The risk was lower for level 3 centers than level 2 and for level 2 than level 1 for the very low birth weight babies and higher for level 3 centers than levels 1 or 2 for normal birth weight births. This would indicate that the referral process is truly selective and those at greatest risk are referred to tertiary centers. Mothers who were referred to the tertiary perinatal center before delivery are more likely to have one or more high risk conditions. (16,17,18,19) Studies of outcome based on delivery site need to account for the variation in infant selection resulting from antenatal referral.

Although further reduction in infant mortality rates can be expected through improvement and wider application of regionalization in Arkansas, long term maintenance of the downward trend in mortality for the population and major reductions in the

Table 6.

STANDARDIZED NEONATAL MORTALITY RATIOS: 1 DAY

	OOH	Level 1	Level 2
under 1500 grams	1.24	1.48	1.21
1500-2499 grams	5.88	0.80	1.38
2500+ grams	2.40	0.30	0.45

Table 7.

STANDARDIZED NEONATAL MORTALITY RATIOS: 1 MONTH

	OOH	Level 1	Level 2
under 1500 grams	0.79	1.18	1.09
1500-2499 grams	4.54	0.72	0.59
2500+ grams	1.54	0.48	0.47

excess mortality among economically disadvantaged groups and in rural areas will depend much more on reducing the incidence of low birth weight.

Consolidation of the impressive gains of perinatal intensive care of the past two decades will require more intensive screening of mothers of high risk infants for place of delivery.[20] Such maternal transfers cannot take place unless pregnant women are enrolled in a system of prenatal care that includes identifying high risk pregnancies and preventing premature labor.

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Session G

Chronic Diseases

PHCRS

CANCER SURVEILLANCE USING MULTIPLE DATA SOURCES

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For over a century, we have applied concepts of surveillance to problems of disease control. This application has played an integral part in controlling, and at times, eliminating a variety of infectious diseases. Surveillance principles, however, have yet to be fully employed in chronic disease control. For cancer, in particular, surveillance has followed the traditional approaches used for acute infectious diseases by focusing principally on trends in case incidence and mortality. Only recently has interest begun to move towards surveillance of risk experiences and prevention behaviors. This movement is important. The long-lasting nature of cancer makes current trends in case occurrence a poor measure of current prevention efforts. Only by tracking present patterns of risk exposure and present prevention practices, can we adequately gauge the success of existing control programs. In so doing, we will be using the full potential of surveillance as a practical public health tool. The thesis of this presentation is that a balanced program of cancer surveillance must serve multiple purposes, and hence use multiple sources of data, by following not only eventual trends in disease occurrence, but also current trends in causation, early diagnosis and care.

Background

To understand the role of surveillance in disease prevention, it is useful to review its history. The concept of surveillance, like so many other features of epidemiology, has French roots.[1] The word comes from the French verb "to watch over", and it probably first came into use during the French Revolution, and later in the Napoleonic era, when people were watched closely for their political loyalties. In this original context, the term conjures up sinister images of Madame Defarge and her ever-present knitting in Charles Dickens' The Tale of Two Cities. Madame Defarge may have been the world's first surveillance specialist, keeping records in her knitting of people destined for the guillotine. In discussing this special occupation, Dickens recognized an enduring epidemiologic concern: confidentiality and accessibility of patient records. The question is asked "Are you sure no embarrassment can arise from our manner of keeping the register?" and then answered "without doubt it is safe, for no one beyond ourselves can decipher it."

From these partly fictional beginnings, surveillance has been adapted for public health work in two rather different ways.[2] The first continues the tradition of watching and tracing individuals, although for health rather than political reasons. This is largely a strategy used in some aspects of infectious disease control whereby the contacts of persons with contagious diseases are kept under watch so that any spread of disease can be contained.

The other use of surveillance, and the one which concerns us here in the context of chronic disease, involves watching communities or populations as a whole. The great pioneer in population-based surveillance was William Farr who used mortality records and other sources of health-related data for investigating and controlling diseases prevalent in 19th century England and Wales.[3,4] Most celebrated was his collaboration with John Snow in efforts to understand and prevent cholera. From Farr's work have evolved our present-day concepts of public health surveillance.

Definition

In applying surveillance concepts to cancer, we must first be clear what we mean by the term. It is not, for instance, just the maintenance of a cancer case registry or the performance of a survey or research study regarding smoking practices or cancer knowledge in a community. Instead, as defined through long application in infectious disease fields, surveillance has three essential parts.[5] First, data regarding disease occurrence or risk patterns are collected on a regular continuing basis in a defined population area. Second, those data are promptly analyzed, and third, those analyses are made available in a timely fashion to whatever persons and organizations are responsible for programs aimed at controlling the disease in question.

Timeliness and continuous operation are critical ingredients in all three steps - data collection, data analysis and data application - so that the entire process can have maximal impact on the development and guidance of current disease control and prevention activities in communities. In this way, surveillance provides an up-to-date road map by which public health programs can keep their bearing.

Latency

Application of these principles to classical infectious disease control is a considerably simpler task than their application to cancer because such infectious diseases are acute, short-latency problems. In a short-latency setting, surveillance can comfortably focus on disease occurrence (incidence or mortality), and can be assured that such events will closely reflect causal events since the interlude between cause and illness is usually only a few days or weeks. Not all infections are that simple, of course, witness tuberculosis, AIDS and various latent virus problems, but for most traditional infectious diseases, those for which surveillance practices have evolved, this generalization is appropriate. For cancer, where the interval between causation and disease occurrence is often a matter of years or decades, merely watching disease trends has little direct impact on controlling the causes of those trends since such trends arise from events long past. Counting lung cancer cases today only relates to smoking habits as they existed 20 or more years ago, and at best gives us the indirect predictive value of delayed trends over time.

For surveillance best to serve present control efforts, we must give greater attention to present-day patterns in risk behaviors and to the impact of current community programs aimed at reducing carcinogenic exposures. Surveillance of eventual disease trends is essential, of course, since it is the ultimate measure of success in cancer prevention programs, but its relative value in terms of day-by-day surveillance applications must be kept in perspective.

Arenas for Surveillance

Given the fact of long latency, the process of cancer control can be perceived as involving three separate arenas in which surveillance can measure effects of prevention activities. The first of these is the stage at which cancer prevention and control programs change attitudes or improve knowledge in individuals and communities regarding the origins, diagnosis and treatment of cancer. The second is when those changes in perceptions and knowledge then lead to cancer prevention actions on the part of individuals and communities (mammography, reduced sun exposure, smoking reduction, smoke-free ordinances). The third stage comes when eventually, as a result of these actions, cancer incidence rates fall, mortality decreases, or survival lengthens.

In each of these three areas, surveillance can distinguish not only among the three major phases of prevention (primary, secondary and tertiary), but also between changes which arise from collective community actions and those which reflect the attitudes and behavior of individuals. Primary prevention implies activities which reduce risk factor exposure (smoking, radiation, etc.) prior to any cancer initiation, while secondary prevention means activities which improve the early diagnosis of cancers after their initiation, whether or not symptoms have developed. Tertiary prevention means improved therapies, rehabilitative services and support care, whereby survival is improved and undue medical complications are averted. For each of these three basic areas of prevention one can identify various kinds of data around which useful surveillance activities can be built. The accompanying table provides a framework for considering such data, both in relation to the three phases of prevention and to the three arenas in which surveillance activities should occur.

Table. Sources of Data for Cancer Surveillance

	Arenas for Surveillance		
Prevention	Attitudes and Knowledge	Personal Behavior and Action	Incidence, Mortality and Survival
Primary:			
Reduction of carcinogenic risk.	A	A, B, C	D, E
Secondary:			
Early diagnosis or screening.	A	A, B, C	D, E
Tertiary:			
Treatment, supportive care.	A	A, B, C	D, E

A = Community Surveys
B = Clinic and Hospital Records
C = Community Resource Inventories
D = Vital Records
E = Cancer Registries

Attitudes and Knowledge

In traditional surveillance of disease trends, existing sources of data (medical records, official documents) form the basis for information to be analyzed. In the phase of cancer surveillance concerned with attitudes and knowledge, however, no such pre-existing data sources are usually available, and hence, the development de novo of systems for data collection is especially critical. The Behavioral Risk Factor Surveillance System (BRFSS), created and fostered over the past decade at the Centers for Disease Control, provides a model by which such data collection can proceed.[6,7] The BRFSS operates as a computer-assisted telephone interview system with careful attention given to sample selection, questionnaire design and practical utility in terms of applicability in multiple simultaneous locations through state and local health department programs. Data are centrally pooled and analyzed, and results are then returned to local sources for local application with minimal delay. Although surveillance topics necessarily cover the full gamut of disease prevention and health promotion, they include some questions in particular areas relevant to cancer, either in the BRFSS core questionnaire or in optional question modules (especially regarding smoking, breast cancer detection and cervical cancer detection).

Emphasis in BRFSS questions tends to be more on prevention behavior than on underlying attitudes and knowledge. A second source of surveillance data in which attitudes and knowledge questions have been more directly addressed is the Cancer Control Supplement to the National Health Interview Survey (NHIS) conducted in 1987 by the National Center for Health Statistics. Although less amenable than BRFSS to rapid analysis and feedback, that particular NHIS data source, if repeated at regular intervals as planned in the future, will fill a critical need for cancer prevention surveillance data at the overall national level.

The further area of knowledge and attitudes regarding cancer treatment as a basis for full utilization of adequate and timely therapy (tertiary prevention), is not at present addressed by any ongoing surveillance system, although it is certainly the object of much continuing interest and occasional studies. For full surveillance of cancer prevention progress, however, systematic tracking of data in this area deserves attention through recurring collection of survey data.[8]

Individual Behavior and Community Action

The second arena for cancer surveillance has two components. One involves assessing the extent to which individuals, through evolving knowledge and attitude, actually modify their cancer prevention behavior: smoking cessation, diet modification, use of mammography and cervical PAP testing. As indicated, the BRFSS addresses such questions in some of its components, as does the NHIS Cancer Control Supplement. The second component, however, concerns actions which communities take as collective maneuvers aimed at cancer control or risk reduction. Here, although no systematic, ongoing uniform system yet exists for tracking such actions nationally, information is readily available, and it is often widely publicized as communities act to reduce smoking in public areas, to promote or facilitate access to mammography or PAP testing, to eliminate unnecessary medical x-ray exposures, to encourage dietary changes, etc.

Inventories of existing community programs and services could provide one approach to developing such data. A full cancer surveillance program should encompass such data in a form by which comparisons can be made over time and among geographic jurisdictions.

For measuring action and behavior regarding tertiary prevention (availability and utilization of healthcare resources by cancer patients), existing hospital and clinic records and inventories of community programs and healthcare facilities should over time provide usable sources of surveillance information. Examination of such data from the viewpoint of social class and income variables will be of particular importance since access to adequate treatment and prompt diagnosis is a particular problem for poor people.

Incidence, Mortality and Survival

Of the three cancer surveillance arenas, the one in which data sources and analytic capacities are most fully developed is obviously that of disease occurrence and progression.[9] Mortality registration continues to be the fundamental national data resource for measuring levels of disease occurrence. About the same time that national death registration became complete in 1933, the first population-based cancer incidence registry was begun (Connecticut). Such incidence registries, in one form or another, now exist in a majority of states. For estimation of national case incidence trends, however, we depend on the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) registry system which covers about ten percent of the U.S. population.

The SEER registry operates through a network of geographically-defined registries in selected parts of the country, and it utilizes a uniform system for collecting case incidence and survival data. In recent years, efforts have been made to stimulate greater uniformity of data-collecting procedures among non-SEER population-based registries so that more meaningful assessments of cancer incidence data and comparisons among regions of the country can be performed.

Measurements of progress in cancer case survival (tertiary prevention) depend also at present largely on the SEER system[10], although increasing numbers of non-SEER registries have incorporated survival follow-up into their surveillance operations. In recent years, as a combined measure of effectiveness in all three phases of prevention, the concept of years of productive life lost (YPLL) has been introduced.[11] This concept expands on the fundamental measure of mortality by allowing consideration of age at death (age 65 has arbitrarily been used as an upper limit for "productive life") as well as the relative frequency of particular causes of death. The use of YPLL numbers and rates in cancer surveillance work adds a useful dimension for measuring relative progress in cancer control.

Summary

Public health surveillance of chronic diseases is a more complex process than surveillance of acute infectious diseases because of the long and variable latencies which exist between disease initiation and diagnosis. To be of practical service for programs in prevention, chronic disease surveillance must focus not only on case occurrence data but on current prevention beliefs and practices.

Cancer surveillance must therefore involve not merely observations regarding incidence, mortality and survival, but also the tracking of patterns of risk factor exposures, early detection practices and attitudes and knowledge regarding cancer and its control. Such information addresses all three phases of cancer prevention and control: 1) prevention of cancer initiation, 2) early detection of tumors and 3) improved therapeutic outcome. It also concerns both individual and community levels of knowledge, attitudes and action regarding cancer risks.

Data regarding these several aspects of cancer control can be acquired through a variety of information sources. Mortality records and cancer registries provide established approaches for surveillance of case occurrence patterns. Ongoing or recurring surveys of various kinds (BRFSS, NHIS), as well as continuous access to inventories of community and professional resources and services, can be used for data regarding knowledge, attitudes and prevention actions. Taken together, such information can be used to build practical population-based surveillance programs by which cancer control efforts can be guided and appraised on a continuing basis.

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Projections of the End-Stage Renal Disease Population to the Year 2000

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Medicare coverage of patients with end-stage renal disease (ESRD) began on July 1, 1973. Projections of the growth of Medicare's ESRD program have always exceeded expectations (Eggers, 1984). The earliest projection, based on an assumption of 10,000 newly treated patients each year, was that the program would grow to 35,000 within 5 years of implementation (Klar, 1972). In three years, the Department of Health, Education and Welfare had revised the estimates up to 50,000 to 60,000 (Van Hoek, 1975). By 1980, estimates were that the program would level off at about 90,000 persons (Rettig and Marks, 1981; Iglehart, 1980; and Kolata, 1982).

A more recent projection shows that the Medicare ESRD population is unlikely to level off in the near future (Eggers, 1984). Based on Census estimates of the aging of the U.S. population and increasing percentages of nonwhite populations, who are at much higher risk of renal failure, this study estimated program enrollment to grow to 94,400 by 1990, 117,200 by 2000, and 162,100 by 2030. This projection also has underestimated program growth. By 1987, total Medicare ESRD enrollment had increased to more than 123,000 (Eggers, 1989). The primary reason that the 1984 estimate (and the earlier ones as well) were too low was the unanticipated increases in rates of initiation of treatment for ESRD. During the 1980s, ESRD program incidence increased very rapidly (HCFA, 1986, 1987, 1988).

This study updates previous projections of the Medicare ESRD population by incorporating updated information on trends in incidence and mortality among persons with ESRD. In addition, the model defines both dialysis and functioning graft components of the ESRD population. Finally, the proposed model incorporates ranges of estimates for incidence, mortality on dialysis, increases in numbers of transplants, and improved transplant graft survival rates.

Data/Methods

Data for this study were obtained from the end-stage renal disease Program Management and Medical Information System (ESRD-PMMIS) maintained by the Bureau of Data Management and Strategy (BDMS) at HCFA. The ESRD-PMMIS is a longitudinal file of ESRD patients entitled to Medicare. The ESRD-PMMIS is based on Medicare's entitlement and claims records and is supplemented with data collected through specific ESRD data forms. These include the Chronic Renal Disease Medical Evidence Report (HCFA 2728-U4),the Transplant Information form (HCFA 2745-U3), the transplant followup form, and the ESRD Death Notification form (HCFA-2746). As of January, 1989 the ESRD-PMMIS contained historical information on over 300,000 ESRD Medicare beneficiaries and over 56,000 kidney transplants.

The basic projection model consists of a set of empirically defined probabilities associated with transition from initiation of treatment, to dialysis, to transplant, to graft failure or success, and to death. Beginning in each year, the total Medicare ESRD population is divided into persons on dialysis and those with a functioning graft. One of a number of events can occur to members of the dialysis group; (1) they can stay on dialysis for the entire year, (2) they can receive a transplant, either from a living related or a cadaver donor, or (3) they can die. Persons with a functioning graft can (1) retain the graft for the entire year, (2) experience a graft failure and return to dialysis, (3) die, or (4) exit Medicare due to termination of benefits. About one-half of persons with a functioning graft exit Medicare at the end of three years following the transplant (Eggers, 1988). During the next year a new cohort of incident cases is added to the the population. Members of the new incident cohort can also experience a number of events; (a) enter the diaysis group, (b) receive a transplant, or (c) die.

Those persons receiving a transplant in each year also have a number of possible outcomes including (a) graft failure and return to dialysis, (b) successful graft and entry into the functioning graft cohort, or (c) death. This basic model is replicated for each of 8 different age groups ranging from persons less than 14 years old to persons 75 years and older. Also included in the model is the transition of a percentage of each dialysis and functioning graft cohort into the next older age group. The transitional probabilities associated with each possible outcome were determined empirically from the most recent experience of the Medicare ESRD program.

The most important factor influencing Medicare ESRD program is the number of patients initiating treatment each year, or program incidence. Table 1 summarizes the trend in program incidence over the decade 1978 through 1987. During this time, total program incidence rose from about 15,100 to nearly 33,600, an increase of 121 percent. This greatly exceeded increases in the U.S. population, as shown when incidence is expressed as rates per million population. Program incidence in 1978 was 68 per million U.S. population. By 1987, this had more than doubled to 138 per million. Further, the increases were not uniform across age groups. For the four age groups under age 45, the net increase in ESRD program incidence per million from 1978 to 1987 was in the range of 25 percent to 33 percent. Increases were much larger in the older age groups. For persons aged 55 to 64, program incidence rates more than doubled, from 159 per million in 1978 to 347 per million in 1987. The increase was 150 percent for persons aged 65 to 74. However, for persons aged 75 and over the increase during this decade was 339 percent, from 85 per million persons to 373 per million persons.

The projection model used in this study assumes a continuing increase in the rate of treated renal failure. However, it is unlikely that increases will continue at the same rate as in the past decade. In fact, the rate of increase has slowed in recent years across all age groups and is fairly stable in the youngest age groups (HCFA, 1988). Complicating the estimates of newly treated patients are changes within each population age group. For instance, between 1987 and 2000, there will be a 50 percent increase in the U.S. population between the ages of 45 and 54 (the "baby boom"). There will be little change in the age group 65 to 74 but a large increase in persons aged 75 and over (Spencer, 1987).

Table 2 shows ranges of estimated increases in program incidence per year used in this model. Each range includes the same underlying U.S. population change predicted by the U.S. Census. The middle range projection assumes that current increases in program incidence rates will gradually decline until a steady state is reached by the year 2000, at which time increases will be due solely to population increases. The low estimate assumes that the "steady state" will be reached more rapidly (half the distance to 2000, i.e. 1993). The high incidence projection assumes that the rate of increase in program incidence per million population will only decline to one-half of the current rate. For instance, program incidence per million persons has been increasing at 11.0 percent for persons aged 75 and over. The low estimate assumes this will decline to zero by 1993 and remain there; the middle estimate assumes this will decline to zero by 2000; the high estimate assumes that the rate will only decline to 5.5 percent by 2000.

The annual rates of increase in incidence shown in table 2 are the net product of population changes and assumed incidence rate changes described above. For the age groups less than 35 years, incidence projections range from annual declines of 1.0 percent to increases of 2.3 percent. This is due to relatively stable incident rates in the past few years combined with relatively little change in population over the next decade or so. The increases of 5.4 percent to 7.9 percent for persons aged 45 to 54 is largely driven by population increases. Increases of 6.5 percent to 11.6 percent among persons 75 and over are the combined effect of population changes and high recent increases in treated incidence.

Also shown in table 2 are estimated mortality rates among dialysis patients. Annual mortality on dialysis ranges from 5.1 percent among persons aged 15 to 24 to 35.7 percent among persons aged 75 and over. In the past few years, dialysis mortality has remained relatively constant (Eggers, 1989). The middle range assumption, reflecting this stability, is that these rates will remain unchanged through the year 2000. A plausible argument could be made either for decreasing or increasing mortality. Decreasing mortality could result if dialysis therapy improves in the next few years or if other therapy such as use of erythropoeitin improves dialysis patient prognosis. On the other hand, the increased incidence of treated renal failure has resulted in a more fragile ESRD population. Perhaps the expansion of dialysis to a "sicker" patient population will worsen the overall prognosis of ESRD patients.

Both of these options are incorported into the model, a relative decrease or increase in mortality of 10 percent within each age group. The changed mortality rates are assumed to occur gradually over the entire time span between 1987 and 2000.

Graft survival rates used in the projections are also shown in table/2. The middle projection rates are the age specific graft survival rates observed in Medicare kidney transplants which occurred in 1986. Overall, one year graft survival rates were about 75 percent for cadaver grafts and about 88 percent for living related donor (LRD) grafts. The middle projection assumes no change in these rates through the year 2000. This represents a fairly conservative assumption because historically, graft survival rates have been improving (Eggers, 1988; Eggers, 1989). Therefore alternative projections were made based on improving graft survival, up to 80 percent for cadaver grafts and up to 92 percent for living donor grafts by the year 2000.

Mortality rates following transplantation are fairly low, about 8 percent for patients receiving cadaver grafts and 3 percent for patients receiving living donor grafts. These were assumed to be unchanged. Also, because both graft failure and patient mortality rates for subsequent years have not markedly changed in recent years, these were also kept at a constant rate, about 6 percent annual graft failure and 3 percent annual patient mortality.

Results

Table 3 shows the summary results of the midline projection for the years 1990, 1995, and 2000 (the numbers for 1980 and 1985 are actual counts of Medicare beneficiaries). The model estimates program incidence to grow to 61,700, a 113 percent increase over 1985. The number of transplants occurring in 2000 are estimated at 14,700, an increase of 110 percent over 1985. Given these trends in numbers of new patients and transplants, and assuming no changes in mortality or graft survival rates, the total Medicare ESRD population will be about 245,000, a 134 percent increase over 1985. However, the shift in patient therapy from dialysis to transplant (Eggers, 1988) will continue. The dialysis patient population is projected to increase by 118 percent (to 187,300), but the functioning graft population is projected to increase by 210 percent (to 57,700). Thus, while the functioning graft population accounted for 17.8 percent of the total Medicare ESRD population in 1985, it will grow to 23.6 percent by the year 2000, given the assumptions of the model. It is important to note that the counts in the table are for Medicare covered patients only. A considerable number of persons with functioning grafts leave the program each year due to the three year post transplant coverage rule. The model estimates that nearly 35,000 persons will exit Medicare with a functioning graft between 1985 and 2000.

As stated above, the model allows for the manipulation of a number of parameters which affect program population growth. The model was run under 9 variations of the basic projection model. Table 4 summarizes these projections. Under the assumption of higher incidence rates, there will be 78,100 patients initiating ESRD treatment in the Medicare program in the year 2000. This represents a 27 percent higher estimate than under the midline projection model. This would result in 14 percent more patients on dialysis (213,900) and 11 percent more total patients (271,600). The lower incidence projection would result in 16 percent fewer dialysis patients (167,000) and 12 percent fewer total patients (215,100).

A 10 percent rate of growth (high projection) in number of transplants would result in 25,300 transplant procedures in the year 2000, 72 percent more than the midline model. This would result in 40 percent more patients with a functioning graft, but only 11 percent fewer patients on dialysis. The total Medicare ESRD patient population would remain largely unchanged because the larger numbers of persons leaving the program would be offset by higher survival rates under transplantation, rather than dialysis. The low transplant model results in 7 percent more dialysis patients and 27 percent fewer functioning graft patients than the midline model, and a similar total population. The major effect of higher or lower increases in transplants is in the patient mix. Under the high rate, almost one-third of the Medicare ESRD population will have a functioning graft by the year 2000. Under the low rate, only 17 percent will have a functioning graft, somwhat under the rate in 1985.

A gradual increase in dialysis patient mortality by 10 percent will lower the dialysis patient estimate for the year 2000 by 6 percent. A decrease of that amount will result in 7 percent more dialysis patients.

The increased transplant survival rates postulated in this model will have little effect on the patient population, reducing the dialysis patient population by only 1 percent and increasing the number of functioning graft patients by only 4 percent. If cadaver graft survival rates increased to 90 percent and living donor graft survival rates increased to 95 percent (not shown), it would increase the functioning graft population by 11 percent. However, it would have only a small effect on the dialysis patient population (a 3 percent decrease).

Combined effects of these assumptions would have much greater effects on the Medicare ESRD program. The lowest dialysis population would occur under a scenario of (a) lower incidence, (2) more transplants, (3) improved transplant outcomes, and (4) increasing dialysis mortality rates. The dialysis population would increase to only 124,200 (34 percent below the midline) and the functioning graft population would increase to 84,200 (46 percent higher than under the midline assumptions). Functioning graft patients would account for 40 percent of the 208,400 total Medicare ESRD population.

The highest dialysis patient population would occur with (1) higher incidence, (2) fewer transplants, (3) unchanged transplant outcomes, and (4) decreasing dialysis mortality. This would result in 242,800 dialysis patients (30 percent higher than the midline projections) and 41,900 functioning graft patients (27 percent lower than the midline projections). Less than 15 percent of the Medicare ESRD patient population would have a functioning graft.

Summary

The history of Medicare's ESRD program has been one of continued growth beyond initial expectations. This study presents a model of program population growth which incorporates Census Bureau projections of the U.S. population, continued increases in the rates of treated renal failure, growth in numbers of kidney transplants, and expectations of dialysis mortality and kidney transplant graft survival rates.

Medicare's ESRD program is very likely to continue growing during the next decade. The midline projection suggests that the ESRD population will more than double between 1985 and 2000. However, there will be a continuation of the shift of the patient population from dialysis to functioning graft.

The model is sensitive to basic growth assumptions, particularly changes in the underlying program incidence rates. The projection associated with higher rates of incidence could result in almost 55,000 more ESRD patients than the projection associated with more modest increases in program incidence rates. Changes in the number of transplants performed will not have much impact on the total patient population but will effect the distribution of patients by therapy type. Failure to increase transplants over the current levels will result in a reversal of the current trend toward increasing percentages of patients with functioning grafts.

It is unlikely that the projections from this model will be exceptionally accurate predictions of the future of Medicare ESRD enrollment. Nevertheless, the model is consistent within the limitations of the underlying assumptions and give a fairly realistic portrayal of future enrollment should current treatment trends and treatment outcomes persist. In addition, the model can be updated and expanded as we increase our understanding of the basic processes affecting the treatment of end-stage renal disease.

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Table 1
Medicare end stage renal disease program incidence
by age, 1978 and 1987

	Number of Persons			Rate Per Million Population		
	1978	1987	Percent Increase	1978	1987	Percent Increase
All Persons	15,168	33,587	121	68	138	103
0-14	328	424	29	6	8	26
15-24	1,104	1,239	12	25	32	28
25-34	1,760	2,788	58	49	64	31
35-44	2,038	3,914	92	86	114	33
45-54	2,840	4,786	69	126	206	64
55-64	3,454	7,632	121	159	347	118
65-74	2,837	8,276	192	188	468	150
75+	807	4,528	456	85	373	339

SOURCE: Health Care Financing Administration, Bureau of Data Management and Strategy: Data from the Program Management and Medical Information System.

Table 2
Projection Assumptions

	Incidence Annual Rate of Increase			Dialysis Mortality Annual Rate			Graft Survival			
							Cadaver		LRD	
Group	Low	Middle	High	Low	Middle	High	Middle	High	Middle	High
0 to 14	0.0%	0.2%	0.3%	5.9%	6.6%	7.2%	62.7%	80.0%	91.0%	92.0%
15 to 24	0.8%	1.5%	2.3%	4.6%	5.1%	5.7%	71.7%	80.0%	87.4%	92.0%
25 to 34	-1.0%	-1.0%	-0.9%	8.6%	9.6%	10.5%	74.6%	80.0%	92.7%	93.0%
35 to 44	3.6%	4.6%	5.6%	10.3%	11.4%	12.6%	75.0%	80.0%	87.9%	92.0%
45 to 54	5.4%	6.6%	7.9%	13.4%	14.9%	16.4%	75.5%	80.0%	88.2%	92.0%
55 to 64	3.0%	4.4%	6.0%	17.5%	19.5%	21.4%	74.4%	80.0%	89.5%	92.0%
65 to 74	3.1%	4.8%	6.6%	23.5%	26.1%	28.7%	75.7%	80.0%	80.0%	92.0%
75 and over	6.5%	8.9%	11.6%	32.1%	35.7%	39.3%	50.0%	80.0%	80.0%	92.0%

Table 3
Summary of Midline Projections for ESRD Program

	Year				
Category	1980	1985	1990	1995	2000
Incidence	18,400	29,000	41,500	54,200	61,700
Transplants					
Total	4,500	7,000	9,100	11,600	14,700
Cadaver	3,300	5,300	7,200	9,200	11,600
LRD	1,200	1,700	1,900	2,400	3,100
Total Population	66,600	104,600	147,800	198,500	245,000
Dialysis	57,300	86,000	114,200	153,800	187,300
Functioning Graft	9,300	18,600	33,600	46,700	57,700

Table 4
Variations of Medicare ESRD Program Projection Estimates

Projection Model	Incidence	Total Transplants	Dialysis	Functioning Graft	Total Population
Midline	61,700	14,700	187,300	57,700	245,000
High Incidence	78,100	14,700	213,900	57,700	271,600
Low Incidence	49,800	14,700	157,400	57,700	215,100
High Transplants	61,700	25,300	167,000	80,600	247,600
Low Transplants	61,700	8,400	201,100	41,900	243,000
High Dialysis Mortality	61,700	14,700	175,200	57,700	232,900
Low Dialysis Mortality	61,700	14,700	200,500	57,700	258,200
High Transplant Graft Survival	61,700	14,700	185,000	60,100	245,100
Low Projection	49,800	25,300	124,200	84,200	208,400
High Projection	78,100	8,400	242,800	41,900	284,700

(1) High Incidence - Incidence rate increases do not reach zero by the year 2000.
(2) Low Incidence - Increases in the incidence rates stop by the year 1993.
(3) High Transplants - Numbers of transplants increase at a 10 percent annual rate.
(4) Low Transplants - There are no increases in transplants.
(5) High Dialysis Mortality - Mortality rates for dialysis patients increase gradually by 10 percent.
(6) Low Dialysis Mortality - Mortality rates for dialysis patients decrease gradually by 10 percent.
(7) High transplant survival - First year graft survival rates increase gradually to 80 percent for cadaver grafts and 92 percent for living donor grafts
(8) Low Projection - Combination of (2), (3), (5), and (7) above.
(9) High Projection - Combination of (1), (4), and (6) above.

ISCHEMIC HEART DISEASE MORTALITY: INSIDE THE AGE-ADJUSTED RATE

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INTRODUCTION

Adjustment for age in the analysis of population disease rates is the standard mechanism for epidemiologic comparisons. The age-specific rates in the population of interest are applied to a "standard" population, thereby generating the number of cases that would have occurred in the standard population. When summed over the age groups and divided by the total in the standard population, the resulting age-adjusted rate (AAR) can then be compared with similarly generated rates from other populations of interest.

Calculation of age-adjusted rates for a given disease by geographic unit (say, states) generates a set of rates that can be rank-ordered. Perforce, one state will be first, one will be last, and the rest will fall in between in some sort of distribution. The question which naturally arises is: why is a particular state high in the rankings and another low, and what are the factors that influence the relative ranking? To be more specific, why does New York State have the highest rate of ischemic heart disease (IHD) in the nation? An equally valid, and possibly more interesting, question would be: why is Washington, D.C., 49th in the ranking?

METHODS

We used the multiple-cause-of-death data provided by the National Center for Health Statistics for 1968-1986. We paid particular attention to the years 1979-1986, during which the Ninth Revision of the International Classification of Diseases (ICD-9) was used. All mentions of IHD (ICD-9 410-414) that appear on death certificates were counted, and the 1980 total U.S. population was used for standardization. Age-sex-race specific rates for IHD and age-sex-race specific proportions of the population were calculated, and the rank order of states for these parameters were compared. Using several algebraic manipulations (see below), we determined the contribution of age, sex-race groups, sex-race group rates, and sex-race group proportions to the overall AAR were determined. These contributions were used as independent variables in a multiple regression model that examined the relative importance of components of the AAR.

Components of the age-adjusted rate

The standard formula for age-adjusted rate may be expressed in notation as:

$$AAR = \frac{\Sigma \frac{c_i}{d_i} s_i}{S} \qquad (1)$$

where c-sub-i is the number of cases in the ith age group,

d-sub-i is the population in the ith age group,

s-sub-i is the standard population in the ith age group,

and S is the total standard population.

To examine the components of the AAR, we use the following algebraic transformation, substituting:

$$w_i = s_i/_S$$

to get

$$AAR = \Sigma \frac{c_i}{d_i} w_i = \Sigma r_i \; w_i \qquad (2)$$

In words, this simply means that the AAR is the sum over the age groups of cases divided by population and multiplied by the weight for the age group and is equivalent to the sum of the age-specific rates times the age-specific weights.

Both cases and population may be further specified by sex and race group. Thus, within an age stratum there are four types of cases and four types of populations (two sex groups and two race groups are used for convenience here): white male, white female, black male, black female. Obviously, the sum of cases in the ith age group is:

$$C_i = C_{WM} + C_{WF} + C_{BM} + C_{BF} \qquad (3)$$

If each of the four sex-race groups within an age stratum is multiplied by the proportion of that sex-race group in the population of the stratum and is then multiplied by the weight for that stratum, the formula reduces to (2):

$$AAR = \sum_{ijk} \left[\frac{c_{ijk}}{d_{ijk}} \cdot \frac{d_{ijk}}{d_{i\cdot\cdot}} \right] w_i$$

$$= \sum \frac{c_i}{d_i} w_i \qquad (4)$$

The purpose of this algebraic identity is to make explicit the nine components of the AAR: 4 age-sex-race specific rates, 4 age-sex-race specific proportions, and an age-specific weight. Given 18 age groups, 2 race groups and 2 sex groups, the AAR may be viewed as the linear combination of 162 quantities, 143 of which are independent of each other (72 independent rates; 72 proportions, 54 independent; 18 weights, 17 independent).

$$AAR = \sum_i \sum_j \sum_k r_{ijk} \; p_{ijk} \; w_i \qquad (5)$$

This formulation lets us examine the proportional contributions of components of the AAR. The proportional contribution may be considered at three levels.

First, the contribution of an age stratum to the overall AAR is:

$$PC(\text{age-stratum}) = \frac{\sum_j \sum_k r_{ijk} \; p_{ijk} \; w_i}{\sum_i \sum_j \sum_k r_{ijk} \; p_{ijk} \; w_i} \qquad (6)$$

Second, the contribution of a specific sex-race group within an age stratum is:

$$PC(\text{sex-race}) = \frac{r_{ijk}\, p_{ijk}\, w_i}{\sum_i \sum_j \sum_k r_{ijk}\, p_{ijk}\, w_i} \qquad (7)$$

Third, the contribution of rates or proportions must be assessed by a log transformation. Since the rate, the proportion, and the weight are multiplied, the relative contribution of each may be determined by dividing the log of each component by the sum of the logs of the three components. For example:

$$PC(\text{prop}) = \log(\text{prop})/(\log(\text{rate}) + \log(\text{prop}) + \log(\text{weight})) \qquad (8)$$

$$PC(\text{rate}) = \log(\text{rate})/(\log(\text{rate}) + \log(\text{prop}) + \log(\text{weight})) \qquad (9)$$

$$PC(\text{weight}) = \log(\text{weight})/(\log(\text{rate}) + \log(\text{prop}) + \log(\text{weight})) \qquad (10)$$

This quantity, multiplied by the proportional contribution of the sex-race group, provides the proportional contribution of rate, proportion, and weight to the overall AAR:

$$PC(\text{PROP}) = PC(\text{sex-race}) \times PC(\text{prop}) \qquad (11)$$
$$PC(\text{RATE}) = PC(\text{sex-race}) \times PC(\text{rate}) \qquad (12)$$
$$PC(\text{WEIGHT}) = PC(\text{sex-race}) \times PC(\text{weight}) \qquad (13)$$

Note that (13) represents the proportional contribution of the weighting system. Though the choice of standard population can have an important influence on the AAR, the standard is arbitrary and affects all comparisons uniformly. A markedly different weighting system could affect these results, but it should be noted that the use of 1970 or 1940 as the standard has only minimal effect on the relative ranking of states' AARs. The proportional contributions of rate, weight, and proportion can be converted to mutually exclusive segments (or "pieces") of the AAR by multiplying the proportional contribution by the AAR. This decomposition of the AAR is shown diagrammatically in Figure 1.

RESULTS

Description of age-adjusted rates

Using data from 1986, we found that the AARs for IHD by state were approximately normally distributed, with a mean of 265 per 100,000, a median of 261 per 100,000, and a range from 61 (Hawaii) to 379 (New York) per 100,000. As shown by box plot (Figure 2), Hawaii was the only true outlier; there were none at the high end of the scale.

Though substantial changes in ranking occurred between the periods 1968-1978 and 1979-1986, within the latter period, the comparative ranking of states was relatively constant (Table 1). The first four (New York, Rhode Island, New Jersey, Michigan) and last four (Utah, Washington, D.C., New Mexico, Hawaii) states changed very little. During the 8-year interval from 1974 through 1986, the average maximum change in rank for all states was 6 places. With some exceptions, those states with the greatest change (greater than 10) tended to have the smallest populations (Delaware, Iowa, Nevada, North Dakota, South Carolina, South Dakota, Virginia, and Wyoming). In addition, the average difference in AAR between any two states that were one rank apart was 6.4 per 100,000.

Proportional contribution of age

As noted, the proportional contribution of each age stratum to the overall AAR is equal to the age-specific rate times the age-specific weight divided by the AAR. The pattern of proportional contributions by age is thus very different from the pattern of the weights themselves and is much more heavily influenced by the rapidly rising age-specific rates (Figure 3). For example, though the weight for the group 85 years and older was 0.0099, the proportional contribution of that group was, on average for the states in 1986, 0.2122. In general, there was little variability in the proportional contributions of age strata over states (Figure 4). Though the differences were small, the highest ranked states tended to exhibit somewhat larger contributions from the older populations.

As expected, then, since age-specific rates have considerable influence on the proportional contribution of age to AAR, they are important determinants of the relative rankings of states. In general, New York State had the highest age-specific rates for IHD among the older age groups (Table 2). The next three states in rank order, although generally highly ranked for age-specific rates, were not uniformly high, nor was there a clear progression from first- to fourth-ranked state in the set of age-specific rates. New York had, in general, high age-specific rates for each sex-race subgroup as well, though it was clearly not the highest in each category (Table 3). In contrast, Washington, D.C., had the lowest rates in whites and ranked in the lower half of the distribution for its rates in blacks. It would appear that the particular constellation of age-specific rates determines a state's relative position. Though New York's position might be intuitively apparent from an examination of the data, the relative ranking of the other states would be difficult to predict a priori.

Proportional contribution of sex-race groups summed over age-groups

As expected, white males made the largest contribution (51.8 percent) to the overall AAR, followed by white females (40.6 percent), black males (3.9 percent), and black females (3.8 percent) (Table 4). The proportional contribution contrasted with the actual proportions in the populations: white males constituted 41.4 percent of the total population; white females, 43.3 percent; black males, 7.3 percent; and black females, 8.0

percent. In general, states with the highest AARs had a smaller than average contribution from white males, and those with the lowest AARs had a higher than average contribution; but, as shown in the multivariate model, this is not generally the case. Conversely, those with the highest ranks had proportionally greater contributions from black men and women, but there were several notable exceptions. Rhode Island, which ranked second in 1986 in AAR, had a minimal contribution from blacks. Washington, D.C., which ranked 49th, had a pattern drastically different from every other state, with black men and women contributing about two-thirds of the AAR.

Proportional contribution of sex-race group components summed over age groups

The contribution from sex-race groups is the result of the interaction of their components: the rate in the group, the proportion of the group in the age stratum, and the weight. (As noted, since the weight is both arbitrary and uniformly applied, its effect will not be considered specifically). On average, the white male rate contributed 24.1 percent to the AAR, and the white male proportion, 6.0 percent (Table 5). (Note that with the 21.7 percent contributed by white male weight, these three together account for the 51.8 percent contributed by the white male group (Table 4)). White male and white female rates make a much larger contribution than their corresponding proportions; in contrast, the contribution of black male and black female rates is only twice that of their proportions. As noted, Rhode Island and Washington, D.C., have markedly different patterns from the other states displayed.

Relative importance of proportional contributions

The proportional contributions of sex-race groups and the components of the sex-race groups vary considerably over the states (Table 6). As noted, Washington, D.C., was markedly different from every other jurisdiction in its overall pattern, but even with the exclusion of Washington D.C., (or the exclusion of Hawaii, as the only true outlier in the distribution of AARs), considerable variability remained. The relative position of a state in the AAR rankings thus depends on its particular mix of components.

The relative importance of the four sex-race group rates and the four sex-race group proportions on the AAR were assessed by a stepwise multiple regression procedure that included year as a fixed independent variable in the model (Table 7). The first variable to enter the model, and the one providing the largest partial R-squared value, was the white male proportion, followed by the black male rate, the white female rate, and the white male rate. The other three variables that remained in the model (white female proportion, black male proportion, and black female proportion) made very small, albeit significant, contributions to explaining of the variance. This may be interpreted to mean that the single most important determinant of the relative position of the AAR for a state is the proportion of white males in the state's population. Rates for black males and white females also exerted some influence. It is important in this context to highlight again the distinction between the absolute rate (e.g., the high age-specific rates in New York State) and the proportional contribution of rate, summed over all age groups.

DISCUSSION

The AAR is a time-honored statistic that has enormous value in epidemiologic assessment. It is produced, however, by a complex and changing set of variables within a given population. The specific mix of age-sex-race-specific rates and the proportion of specific age-sex-race groups in a population, coupled with an arbitrary set of weights, determine the magnitude of the AAR. These rates and proportions vary considerably within population subsets (as defined by geopolitical jurisdictions, for example) and demonstrate the need to look beyond the summary statistic (in this case, the AAR) to its components.

The analysis of components provides a framework for assessing the relative influence of this complex mix of factors. The results suggest that, overall, the AAR is most influenced by the contribution of the proportion of white males. That white males dominate the epidemiologic picture of IHD is well recognized. It may be less well appreciated that the specific rank order of states may be influenced by other factors, such as the proportional contribution of the black male rate.

The components analysis is not, however, fully explanatory. In the individual case, it is still more helpful to examine specific rates and proportions per se to be able to define the epidemiologic features of a particular geographic unit. New York State, as noted, owed its lead to its high age-specific rates in the older age groups, which in turn made the largest contribution to the AAR. When examined further by sex and race subgroup (Table 4), New York State had high age-specific rates in all four groups, although its rates in each of the older age categories were not uniformly highest for all groups. Nonetheless, its specific combination of rates, coupled with its population proportions, placed it in first position. In contrast, Washington, D.C., with the highest proportions of black men and women, ranked 49th. This rating may be attributed to the city's very low age-specific rates in white men and women (it ranked 50th or 51st for most of the older age categories) and to its middling to low age-specific rates among blacks.

In fashioning a control program for IHD, it is important to target groups at highest risk. If mortality data can be used to specify population risk, New York State and

Washington, D.C., would seem to require different population strategies. On the other hand, this analysis also suggests that a lowering of the AAR may not be the optimal endpoint for evaluating a program's success. A program that produces important effects on subgroup mortality (e.g., mortality among young black men, whose age-specific rates are in fact higher than those for young white men) may never be reflected in the overall AAR.

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Session H

Preventable Morbidity and Mortality

PHCRS

TYPE II DIABETES MELLITUS AND OBESITY IN HISPANICS

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Introduction

The Hispanic and Health and Nutrition Examination Survey (HHANES) found Mexican Americans to have a total prevalence of diabetes higher than the total prevalence of diabetes for non-Hispanic whites[1]. The total prevalence of diabetes in Mexican Americans surveyed in the HHANES was found to be 2.4 times as great as the rate for non-Hispanic whites in the age group 20-44 years and 2.0 times as great as non-Hispanic whites in the age group 45-74 years[1]. Furthermore, the prevalence rates of diabetes among Mexican Americans were greater for successively higher levels of percent desirable weight[2].

The first epidemiologic studies ever done on Mexican Americans in Texas produced findings similar to those of HHANES with a higher prevalence of diabetes than non-Hispanic whites[3-7]. From these studies conducted in the Southwest, the effect of obesity appears to be more severe among Mexican Americans living in lower socio-economic neighborhoods, along with levels of obesity[5-7].

The HHANES and Southwest studies have strongly agreed in their findings of a high prevalence for diabetes among Mexican Americans[1-7]. Data from HHANES also found a high prevalence of diabetes with increasing levels of percent desirable weight; while the epidemiologic surveys conducted in Texas found Mexican Americans to be more obese than non Hispanic whites within social class[5-7].

The first objective of this paper is to present a descriptive analysis of obesity and glucose tolerance categories and the relationship to physiologic, smoking, education and income characteristics. The second objective is to provide further factual information and understanding of diabetes and obesity in Mexican Americans to the public health community so as to assist in the planning and development of appropriate heath prevention and intervention programs for Mexican Americans.

Materials and Methods

The Hispanic Health and Nutrition Examination Survey was a complex, multi-stage, stratified, clustered sample conducted by the National Center for Health Statistics[8]. Three areas of the United States were sampled between 1982-1984 including Mexican Americans in the Southwest, Puerto Ricans in the New York City area and Cuban Americans in Dade County Florida[8]. This analysis will be limited to the Mexican American population because it is the only group of the three with sufficient numbers to study diabetes in any detail. The survey consisted of an interview and a medical examination. A total of 3,928 Mexican Americans between the ages of 20 and 74 were interviewed and of these, 3,325 were examined. Among those examined, 1,654 were given the oral glucose tolerance test (OGTT) and the results were considered classifiable in 889. Those who answered "yes" to the question: "Do you have diabetes or sugar diabetes?" and to the question: "Did a doctor tell you that you have it?" were considered to be known diabetics. Those with an OGTT fasting plasma glucose less than 7.8 mM were considered "normal"; those with an OGTT fasting plasma glucose value less than 7.8 mM and a two hour plasma glucose value between 7.8 mM and 11.2 mM were considered to have " impaired glucose tolerance"; those with an OGTT fasting plasma glucose value of 7.8mM or greater or a two hour plasma glucose value of 11.2 mM or greater were considered to be newly diagnosed diabetics[9]. These are the four glucose tolerance response categories used throughout this analysis.

Because of the different levels of response leading to these four categories, the survey design was used to produce all of the estimates that we used. Standard errors were estimated by using the SESUDAAN procedure[10]. Age-adjusted rates were used throughout with the age distribution of the total Mexican American population interviewed used as the standard.

The term, "obese" was used to describe a male with a body mass index of greater than and/or equal to 27 and a female with a body mass index greater than and/or equal to 24[11]. Thus, individuals were classified into two categories (obese and non-obese) arbitrarily in this manner.

Results

The relationship between selected physiologic measures, obesity and glucose tolerance category is shown for males in Table 1 and for females in Table 2 . Except for normals, those classified as obese tended to be younger than those classified as non-obese for males and only for obese females with a known history of diabetes. For both males and females, the obese had higher blood pressures for every glucose tolerance category. There was essentially no difference between obese and non-obese women for serum cholesterol level regardless of glucose tolerance category. This pattern was inconsistent for males.

The leukocyte count for both obese males and females was higher than the nonobese. The erythrocyte count for obese males was higher and there was no difference between obese and non obese for females. Mexican American obese males with diabetes had lower serum iron, total iron binding capacity, and transferrin with the normal and impaired glucose tolerance obese males having higher values than the nonobese. Obese females had higher serum iron and serum transferrin levels than the nonobese and obese females with a history of diabetes had lower total iron binding capacity than the nonobese.

Smoking habits among this population are presented in Tables 3 and 4 . Perhaps the most striking finding is that among those with a history of diabetes, whether male or female, a much higher proportion of those who were non-obese had smoked sometime during their lifetime than those who were obese with a much smaller proportion of those smokers currently smoking among the non-obese. The mean number of cigarettes smoked per day for obese Mexican American males is higher than the nonobese males. Obese Mexican American females smokes less cigarettes per day then the nonobese female.

Educational data in Table 5 show obese men with a history of diabetes mellitus to have more more individuals with a college education than all the other groups. Among women with a known history of diabetes, the obese had a significantly higher percent with a college education while the nonobese had none with a college education. For nonobese men within the abnormal glucose tolerance groups, their highest percentages were in the category of less then nine years of education. Obese Mexican American women in all glucose groups were found to have their highest percentages of persons with less then nine years of education.

Income data in Table 6 reveals obese Mexican American men to be more representative in the category above $20,000.00 except in the newly diagnosed nonobese male. Obese and nonobese women are more represented by incomes less than $20,000.00

Discussion

We must emphasize that this is a descriptive analysis. Drawing definitive conclusions based on statistical signifigance is limited because of the small numbers of cases available for analysis in some of the categories being compared. Thus, classifying individuals as diabetics, or as having normal glucose tolerance, involved a reduction in sample size from the original 3,929 to 889. All analyses were carried out separately for males and females and age was taken into account in making comparisons. This resulted in very small numbers in some of the cells resulting from the simultaneous classification of several variables.

The 3,929 Mexican Americans interviewed were a probability sample of the Mexican American population in the communities covered in the survey. The weighting procedures used in our analysis resulted in our making inferences to that total population of Mexican Americans. We were concerned about the possibility of bias resulting from using only those who had a classifiable OGTT as representative of that total population. To examine the possibility of bias, we computed some of the measures used in the analysis for the total group of Mexican Americans interviewed, for those who were not examined, for those who were examined but did not receive the OGTT, for those who received the OGTT for whom the results were not classifiable, and for those for whom the results of the OGTT were classifiable. Since the latter group was the one from which inferences were made, we were interested in whether the measures for it differed from those for the groups that were dropped from the analysis. We made these comparisons for age distribution, systolic and diastolic blood presure, mean body mass index, distribution by educational level, percent with family income greater than $20,000.00, and mean serum cholesterol. None of these differences were statistically significant. As a result, it is likely that we would have obtained the same results if we had been able to obtain classifiable examination data for the total interviewed sample.

Mexican American men who are termed obese differ from nonobese with respect to age, blood pressure, leukocyte count and erythrocyte count. Our results find obese Mexican American men to be younger than the nonobese males in the abnormal glucose tolerance categories. The obese males also have higher measurements with reference to their systolic and diastolic blood pressure, leukocyte counts and erythrocyte count. Obese diabetic men have a lower iron profile than the nonobese. Obese men begin to smoke at an earlier age and smoke more cigarettes per day. Obese men tend to have more years of education and a higher percentage with income greater than $20,000.00. Obese women of all groups are younger in age, have higher blood pressures, higher leukocyte counts and lower iron and transferrin levels. Obese women, except for the newly diagnosed group, have an older mean age at first smoked. All obese women groups smoke less number of cigarettes per day. Income levels find obese or nonobese Mexican American women to be represented by an income of less than $20,000.0.

We believe our epidemiologic findings to be critical to the medical, research, and public health communities. Although our data is a descriptive analysis and must be taken as suggestive, we have provided first time national data which provides information never before known and introduces additional interesting problems for ourselves within the health and scientific community to challenge and address. By the design of the analysis, we have been able to give an initial description of obese and nonobese Mexican American men and women with regards to normal and abnormal glucose tolerance categories. We believe this is of vital importance for those of us who are interested in the phenomena of diabetes and obesity epidemiology on Mexican Americans in the United States. More importantly, this data should give national, state and local public health officials factual epidemiologic information to address their communities' need for public health prevention and intervention with regards to the Mexican American community and their problem of diabetes and obesity. For those public health programs now active in the area of prevention of diabetes and obesity our data will provide new epidemiologic information to build and develop on the programs presently in operation. Most vital to our wealth of epidemiologic information is that others will find the need to pursue this area for fututre investigation and collaboration to better understand why Mexican Americans are at higher risk for diabetes and obesity than the general population. In addressing Mexican Americans with diabetes and obesity, we will adequately demonstrate a public health need to our legislative and policy makers.

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Table 1

AGE ADJUSTED MEANS FOR SELECTED PHYSIOLOGIC VARIABLES BY OBESITY CATEGORY AND W.H.O.CLASSIFICATION/HISTORY OF DIABETES CATEGORY AMONG MEXICAN AMERICAN MALES AGE 20-74 YEARS

MEAN VALUES	NORMAL	IGT	NEW DIABETICS	KNOWN DIABETICS
AGE (YEARS)				
OBESE	37.3(1.6)	44.0(2.9)	45.0(3.5)	51.9(2.0)
NONOBESE	34.5(0.8)	47.7(3.1)	52.6(2.6)	55.7(1.8)
BODY MASS INDEX (Wt. kg/Ht.^{2} cm)				
OBESE	30.0(0.4)	30.6(0.5)	32.8(1.2)	34.2(2.1)
NONOBESE	23.8(0.1)	23.6(0.5)	24.0(1.2)	23.6(0.8)
SYSTOLIC BLOOD PRESSURE (mm Hg)				
OBESE	126.4(1.6)	121.9(2.4)	136.0(7.2)	130.6(2.1)
NONOBESE	116.8(1.3)	124.1(3.3)	128.8(7.2)	112.8(4.0)
DIASTOLIC BLOOD PRESSURE (mm Hg)				
OBESE	79.9(0.9)	82.9(2.1)	82.1(4.7)	80.4(3.8)
NONOBESE	72.2(0.5)	75.9(2.5)	81.3(6.2)	73.5(1.8)
SERUM CHOLESTEROL (mg/dl)				
OBESE	208.0(2.7)	218.0(9.0)	196.7(6.7)	203.3(11.9)
NONOBESE	201.7(3.1)	219.6(13.9)	213.8(15.4)	182.9(2.6)
LEUKOCYTE COUNT (x 10^3/ul)				
OBESE	6.9(0.2)	7.4(0.5)	7.7(0.4)	8.1(0.4)
NONOBESE	6.5(0.1)	7.5(0.7)	6.1(0.6)	6.9(0.5)
ERTHROCYTE COUNT (x 10^6/ul)				
OBESE	5.2(0.04)	5.2(0.1)	5.1(0.1)	5.3(0.1)
NONOBESE	5.1(0.03)	5.1(0.03)	4.9(0.2)	5.3(0.2)
SERUM IRON (ug/dl)				
OBESE	120.0(4.8)	120.7(5.5)	114.8(5.7)	112.6(12.5)
NONOBESE	122.9(3.0)	98.2(5.3)	179.5(35.8)	149.5(22.9)
SERUM TOTAL IRON BINDING CAPACITY (ug/dl)				
OBESE	353.7(4.1)	353.7(10.7)	336.5(22.8)	349.2(7.8)
NONOBESE	346.3(4.3)	336.9(12.5)	343.3(13.0)	352.9(2.9)
SERUM TRANSFERRIN SATURATION (%)				
OBESE	34.1(1.6)	34.3(2.2)	34.5(2.6)	32.1(3.7)
NONOBESE	35.2(1.0)	28.9(1.0)	56.5(10.2)	41.5(6.2)

( ) Numbers in parenthesis are standard errors
IGT is the abbreviation for Impaired Glucose Tolerance

Table 2

AGE ADJUSTED MEANS FOR SELECTED PHYSIOLOGIC VARIABLES BY OBESITY CATEGORY AND W.H.O. CLASSIFICATION/HISTORY OF DIABETES CATEGORY AMONG MEXICAN AMERICAN FEMALES AGE 20-74

MEAN VALUES	NORMAL	IGT	NEW DIABETICS	KNOWN DIABETICS
AGE (YEARS)				
OBESE	38.2(1.1)	45.4(3.4)	55.9(3.0)	51.2(1.0)
NONOBESE	32.1(0.8)	41.4(3.7)	NONE	57.5(2.7)
BODY MASS INDEX (Wt. kg/Ht.^{2} cm)				
OBESE	29.3(0.3)	32.5(0.9)	29.5(0.3)	32.6(1.0)
NONOBESE	21.9(0.2)	22.0(0.4)	NONE	22.2(1.6)
SYSTOLIC BLOOD PRESSURE (mm Hg)				
OBESE	112.7(0.9)	120.1(2.0)	121.8(2.3)	121.6(2.1))
NONOBESE	108.3(0.9)	116.2(1.1)	NONE	110.3(3.8)
DIASTOLIC BLOOD PRESSURE (mm Hg)				
OBESE	71.4(0.5)	74.8(1.9)	78.7(2.7)	76.3(1.7)
NONOBESE	67.3(0.7)	71.2(1.3)	NONE	74.2(1.7)
SERUM CHOLESTEROL (mg/dl)				
OBESE	200.3(3.6)	213.9(3.5)	197.2(7.8)	215.3(8.2)
NONOBESE	199.4(2.1)	211.7(3.9)	NONE	222.6(10.7)
LEUKOCYTE COUNT (x 10^3/ul)				
OBESE	6.9(0.2)	7.5(0.4)	8.2(0.1)	8.6(0.5)
NONOBESE	6.4(0.2)	6.8(0.3)	NONE	6.9(0.4)
ERTHROCYTE COUNT (x 10^6/ul)				
OBESE	4.6(0.04)	4.6(0.1)	4.5(0.1)	4.8(0.1)
NONOBESE	4.5(0.03)	4.6(0.1)	NONE	4.9(0.2)
SERUM IRON (ug/dl)				
OBESE	95.5(2.7)	99.9(3.8)	92.9(1.5)	95.2(9.6)
NONOBESE	103.6(2.7)	110.3(9.6)	NONE	106.9(16.8)
SERUM TOTAL IRON BINDING CAPACITY (ug/dl)				
OBESE	369.9(4.8)	392.1(3.2)	360.2(6.8)	357.5(8.0)
NONOBESE	361.6(4.9)	372.8(4.2)	NONE	360.2(6.9)
TRANSFERRIN SATURATION (%)				
OBESE	25.9(0.7)	25.2(1.2)	25.3(0.4)	26.5(2.8)
NONOBESE	28.9(0.9)	30.6(2.4)	NONE	29.5(5.6)

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Table 3

AGE ADJUSTED MEASURE OF SMOKING BY OBESITY CATEGORY AND W.H.O. CLASSIFICATION/HISTORY OF DIABETES AMONG MEXICAN AMERICAN MALES AGE 20-74 YEARS

CATEGORY	NORMAL	IGT	NEW DIABETICS	KNOWN DIABETICS
PERCENT WHO HAVE SMOKED AT LEAST 100 CIGARETTES IN THEIR ENTIRE LIFE (%)				
OBESE	62.2(3.7)	72.5(8.5)	94.2(5.2)	67.4(16.5)
NONOBESE	68.9(2.3)	72.2(9.1)	86.0(12.8)	94.2(2.6)
MEAN AGE SMOKED FIRST CIGARETTE (YEARS)				
OBESE	16.0(0.3)	15.7(1.0)	18.0(1.8)	19.5(2.3)
NONOBESE	16.6(0.2)	15.4(0.9)	16.7(1.6)	18.5(1.3)
PERCENT WHO ARE CURRENTLY SMOKING (%)				
OBESE	62.3(5.7)	50.6(11.4)	47.7(12.2)	78.9(2.0)
NONOBESE	62.9(3.4)	82.0(4.7)	71.3(15.2)	50.7(24.6)
MEAN NUMBER OF CIGARETTES SMOKED PER DAY				
OBESE	12.9(2.5)	16.9(1.6)	14.3(5.0)	10.9(2.5)
NONOBESE	10.6(0.9)	11.8(5.3)	10.6(3.0)	9.4(1.1)

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Table 4

AGE ADJUSTED MEASURE OF SMOKING BY OBESITY CATEGORY AND W.H.O. CLASSIFICATION/HISTORY OF DIABETES CATEGORY AMONG MEXICAN AMERICAN FEMALES AGE 20-74 YEARS

CATEGORY	NORMAL	IGT	NEW DIABETICS	KNOWN DIABETICS
PERCENT WHO HAVE SMOKED AT LEAST 100 CIGARETTES IN THEIR ENTIRE LIFE (%)				
OBESE	40.2(3.1)	32.4(5.6)	12.1(4.0)	43.2(12.1)
NONOBESE	42.7(4.6)	26.2(7.7)	NONE	67.3(14.7)
MEAN AGE SMOKED FIRST CIGARETTE (YEARS)				
OBESE	21.2(0.9)	22.0(2.7)	22.1(1.7)	17.3(1.1)
NONOBESE	18.9(0.8)	21.0(1.0)	NONE	18.7(0.8)
PERCENT WHO ARE CURRENTLY SMOKING (%)				
OBESE	61.7(5.7)	47.6(14.3)	80.0(10.7)	67.4(13.8)
NONOBESE	69.8(5.3)	60.0(21.4)	NONE	54.8(34.0)
MEAN NUMBER OF CIGARETTES SMOKED PER DAY				
OBESE	9.4(1.3)	9.6(1.3)	6.6(1.5)	9.2(3.0)
NONOBESE	11.0(1.8)	10.4(1.2)	NONE	10.9(2.1)

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Table 5

AGE ADJUSTED PERCENT DISTRIBUTION BY EDUCATIONAL AND INCOME LEVEL FOR OBESITY CATEGORY AND W.H.O. CLASSIFICATION/HISTORY OF DIABETES CATEGORY AMONG MEXICAN AMERICAN PERSONS AGE 20-74

EDUCATION LEVEL

CATEGORY	NORMAL	IGT	NEW DIABETICS	KNOWN DIABETICS
MALES				
PERCENT WITH COLLEGE EDUCATION (%)				
OBESE	18.4(4.6)	21.1(7.5)	5.7(4.9)	49.4(11.2)
NONOBESE	24.5(4.7)	19.3(9.1)	0.0(0.0)	5.7(2.5)
PERCENT WITH 9-12 YEARS OF EDUCATION(%)				
OBESE	48.4(4.6)	59.5(9.3)	64.8(8.5)	26.2(11.8)
NONOBESE	40.5(3.6)	23.7(12.5)	29.0(22.6)	44.3(22.8)
PERCENT WITH LESS THAN 9 YEARS OF EDUCATION (%)				
OBESE	33.2(4.5)	19.4(5.9)	29.5(8.6)	24.4(2.7)
NONOBESE	35.0(3.0)	57.0(16.6)	71.0(22.6)	50.0(24.3)
FEMALES				
PERCENT WITH COLLEGE EDUCATION (%)				
OBESE	14.8(1.4)	5.2(4.3)	40.4(22.5)	16.5(5.6)
NONOBESE	21.6(4.7)	20.3(9.5)	NONE	0.0(0.0)
PERCENT WITH 9-12 YEARS OF EDUCATION(%)				
OBESE	46.8(3.6)	39.3(11.3)	11.0(4.0)	38.7(11.07)
NONOBESE	50.3(3.9)	44.4(7.7)	NONE	77.6(4.9)
PERCENT WITH LESS THAN 9 YEARS OF EDUCATION (%)				
OBESE	38.4(4.4)	55.5(10.8)	48.6(24.8)	44.8(10.1)
NONOBESE	28.1(4.3)	35.4(7.3)	NONE	22.4(4.8)

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Table 6
PERCENT DISTRIBUTION BY FAMILY INCOME/AGE ADJUSTED BY OBESITY CATEGORY AND W.H.O. CLASSIFICATION/HISTORY OF DIABETES CATEGORY AMONG MEXICAN AMERICAN PERSONS AGE 20-74 YEARS

	NORMAL	IGT	NEW DIABETICS	KNOWN DIABETICS
INCOME				
MALES				
PERCENT WITH FAMILY INCOME EQUAL TO OR MORE THAN $20,00.00 (%)				
OBESE	41.3(4.7)	54.0(13.5)	44.3(22.0)	52.8(14.3)
NONOBESE	33.3(4.5)	42.0(6.5)	12.7(11.2)	43.6(20.3)
PERCENT WITH INCOME LESS THAN $20,00.00 (%)				
OBESE	58.7(4.7)	46.0(13.5)	55.7(22.0)	47.2(14.3)
NONOBESE	66.7(4.5)	58.0(6.5)	87.3(11.2)	56.4(20.3)
FEMALES				
PERCENT WITH FAMILY INCOME EQUAL TO OR MORE THAN $20,00.00 (%)				
OBESE	29.3(3.3)	38.0(5.4)	9.9(3.2)	23.0(8.4)
NONOBESE	28.0(1.7)	51.6(10.3)	NONE	0.6(0.5)
PERCENT WITH INCOME LESS THAN $20,00.00 (%)				
OBESE	70.7(3.3)	62.0(5.4)	90.1(3.2)	77.0(8.4)
NONOBESE	72.1(1.7)	48.4(10.3)	NONE	99.4(0.5)

( ) Numbers in parenthesis are standard errors
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THE USES AND LIMITATIONS OF VITAL STATISTICS DATA IN THE ANALYSIS OF PERINATAL REGIONALIZATION

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Perinatal regionalization is predicated on the assumptions that (1) if women at high-risk for serious complications in late pregnancy or intrapartum are transferred to secondary or tertiary perinatal hospitals prior to delivery, better outcomes for mother and infant will result, and (2) in the event of a high-risk neonate born at a primary care facility, neonatal transport to the appropriate higher level hospital will reduce neonatal morbidity and mortality. This concept, originated in the 1960s and gaining widespread acceptance during the 1970s [1,2], suggests that reorganizing health care delivery systems according to maternal/neonatal risk or appropriateness of care can reduce perinatal morbidity and mortality. Although no study has directly quantitated the effect of perinatal regionalization on declining perinatal and neonatal mortality rates, it is thought to be a major contributing factor in the dramatic declines in the United States during the 1970s.

Three general approaches to the study of perinatal regionalization can be discerned in the literature. First, there are clinically oriented studies of perinatal or neonatal outcomes at a single hospital or neonatal intensive care unit. These studies typically examine mortality as an outcome after controlling for perinatal risk factors between infants born at the facility and infants transported there after birth. Some studies examine differences in treatment as well. The general conclusion is that, were a newborn to require neonatal intensive care, outcomes are significantly better for those infants transported to the neonatal intensive care unit in utero [3-5].

A second approach is the regional study of outcomes in an area served by a single perinatal center. These studies are superficially population-based, but complete clinical data on infants born at other hospitals in the region who are not transferred to the perinatal center are typically unavailable. These analyses also suggest that the ´in-born´ neonatal intensive care unit patient will fare better than the infant born in another facility and transferred after birth [6-9].

Neither of the above approaches requires individual vital statistics records to conduct the analysis. The third approach, the population-based analysis of perinatal outcomes, relies almost exclusively on birth certificates, death certificates for neonatal deaths, and fetal death records. Several of these studies have been conducted on a city-wide or statewide basis, including those of Paneth et al. for New York City [10,11], Goldenberg et al. for Alabama [12], Bowes et al. for Colorado [13] and the four-state Robert Wood Johnson study of Louisiana, Ohio, Tennessee and Washington [14]. Hein´s study of changing patterns of neonatal mortality in Iowa is also population-based, but focusses only on death certificate data [15]. In all of these studies the focus is on neonatal and perinatal mortality rates, usually analyzed within birth weight strata.

This paper shows how vital statistics can be used to analyze patterns of perinatal regionalization. Arkansas live births and fetal deaths during 1985-87 are analyzed, with hospitals classified as Level I, Level II and Level III based on the facilities and medical staff available at each institution. Emphasis is placed on identifying the strengths and weaknesses in the analysis imparted by the vital statistics data systems and the statistical evidence contained therein.

Data Sources

The study population consisted of all Arkansas resident deliveries occurring during calendar years 1985, 1986 and 1987. Fetal deaths were included as valid records if they met any of three criteria: 1) clinical estimate of gestation of 20 or more weeks, 2) birth weight of 500 grams or more, or 3) estimated gestational age based on date of last menses of 20 or more weeks.

Resident data formed the basis for the study because broader research objectives include utilization of the dataset for investigating the relationship between perinatal risk factors and postneonatal or early childhood morbidity and developmental delay. The choice of resident data considerably increased the complexity of the study. A sizeable number of Arkansas resident births occur in surrounding states, due to the proximity of Memphis, Tennessee to eastern Arkansas and the lack of a major obstetrical care center in that region, and due to the fact that the only obstetrical hospital in the Texarkana, Arkansas-Texas area is in Texas. All records necessary for the study are included in the interstate exchange agreement among state vital statistics agencies, but Arkansas as with most other vital statistics programs does not key all information from out-of-state vital records concerning residents. Notably lacking are data on county and hospital of occurrence. The error rate on other demographic and reproductive health items is somewhat higher than for Arkansas occurrence records. Further complicating matters was the fact that, in accordance with the interstate exchange agreement, the out-of-state birth and death records for 1985 resident events had already been destroyed prior to the initiation of this study. Data from all surrounding states save one were obtained on computer printouts or floppy disks and added to the database. Since almost all out-of-state events occurring in the one state that proved bureaucratrically incapable of providing prompt assistance occurred in a single hospital in 1986 and 1987, all 1985 events were assumed also to have occurred there. In the course of conducting this study and a related project, several additional neonatal deaths were identified and added to the vital statistics database. It is not known whether the interstate exchange agreement works as well for fetal death records as for birth and death events.

Data Elements

Once the hospital data had been obtained for all records, hospitals were classified into levels of perinatal care. In order to allow for the possibility that a facility provides different levels of obstetrical and neonatal care, two separate variables were created, with each hospital receiving an obstetrical care code and a neonatal care code. Hospitals were classified into Levels I, II, and III based on information in the National Perinatal Information Center guide [16], the American Hospital Association guide [17], Maternal and Child Health specialists with the Health Departments of adjacent states, and leading obstetrical nurses, obstetricians, neonatologists and health facilities specialists in the state of Arkansas. The classification of Arkansas hospitals represents the conclusions of the authors, and does not reflect the official policy of the Arkansas Department of Health or the Departments of Obstetrics and Gynecology and of Pediatrics at the University of Arkansas for Medical Sciences.

Perinatal vital events occurring out-of-hospital were coded as such. For the purposes of the current study all events are classed to place of occurrence, including births and deaths denoted as 'born-on-arrival' or 'dead-on-arrival'. It is assumed that parents or attending physicians intended for the delivery or care to be provided at the facility which filed the birth or death certificate for these cases. Likewise, fetal deaths are considered as occurring at the hospital at which the delivery occurred, regardless of whether fetal demise occurred before labor, during labor or during delivery.

Other data elements selected for analysis included birth weight (coded in grams and classed by 500 gram strata), gestational age (estimated as completed weeks from date of last menses, grouped into five categories), maternal age, race of mother, prenatal care utilization, educational attainment and age of mother, parity and gravidity, and marital status. Age at death was examined, focussing on survivorship to day one, day seven, and day 28 after birth. Causes of neonatal and perinatal death were not examined in this study, although all mortality events are coded by underlying cause of death.

Analysis

The study population included 104,289 live births and 847 fetal deaths. Fetal deaths showed a different distribution by level of hospital than did live births (Table 1).

Table 1: Distribution of Births by Level of Obstetrical Hospital

Level	Live Births		Fetal Deaths	
	No.	%	No.	%
Out-of-Hospital	1,192	1.1	31	3.7
Level I	50,306	48.2	380	44.9
Level II	41,249	39.6	280	33.1
Level III	11,504	11.0	156	18.4
Total	104,289	100.0	847	100.0

As shown in Table 2, despite the higher proportion of fetal deaths delivered at Level III obstetrical hospitals, a smaller share of very low birth weight (VLBW - less than 1,500 grams) fetal deaths occurred at these hospitals. These data suggest that maternal-fetal transport does occur in Arkansas, but by no means all high-risk mothers are referred to Level III obstetrical facilities. Indeed, fewer than half of VLBW deliveries occur at these hospitals. A similar pattern would be seen by gestational age (not shown).

The effect of place of birth on neonatal survivorship was examined through a series of maximum likelihood estimation models in which the probability of surviving the first day, first week and first month of life was estimated from place of birth, place of death, birth weight (less 1,500 g and 1,500-2,499 g), gestational age (less than 32 weeks and 32-36 weeks), maternal race (black) and education (less than high school), first trimester initiation of prenatal care, primiparous birth, and non-marital birth. These analyses were conducted using live birth data only. The results of these models are presented in terms of odds ratios and 95 percent confidence intervals as Tables 3, 4, and 5.

Infants born at Level III hospitals are 1.46 times as likely to survive the first day of life as infants born at a Level I hospital, adjusted for birth weight, race, gestational age, maternal education, prenatal care initiation, parity and marital status. Birth at a Level II hospital also increases the probability of survival, although the effect is not significant. Very low birth weight and moderately low birth weight infants were significantly more likely to die during the first day after birth than normal birth weight infants, adjusted for the other variables in the model. A similar finding by gestational age is also evident. Interestingly, race, first trimester prenatal care, less than high school education, primiparous birth, and non-marital birth exert no significant effect on first day survivorship independent of place of birth, birth weight and gestational age.

As indicated in Table 4, by the first week of life place of birth no longer significantly increases survivorship (for Level III, OR=1.15, (CI 0.97-1.36). The only significant variables in the model are VLBW, MLBW, very preterm, and moderately preterm. By the end of the first four weeks of life, these same variables are the only significant ones in the model, while non-hospital birth (OR=0.67, CI 0.45-1.01) almost reaches

Table 2: Distribution of Births by Birth Weight as a Ratio to the Percentage of Births in Hospital Category

	Out-of-Hospital		Level I		Level II		Level III	
Birth Weight	Fetal Deaths	Live Births	Fetal Deaths	Live Births	Fetal Deaths	Live Births	Fetal Deaths	Live Births
< 1,500 g	1.44	1.08	0.91	0.41	1.10	0.86	0.97	4.08
1,500-2,499 g	0.19	0.75	1.04	0.83	0.88	0.95	1.25	1.95
2,500+ g	0.85	1.02	1.12	1.02	0.93	1.01	0.87	0.89

significance at the 95 percent level of confidence.

Place of birth diminishes as a risk factor for mortality with increasing age in days. Future analyses with these data will attempt to quantitate the effect of place of death on neonatal survivorship by age at death.

Strengths and Weaknesses of Vital Statistics Data

Population-based data from birth certificates, death certificates for infants deaths and fetal death certificates are a necessary component of a comprehensive analysis of perinatal regionalization at a state or sub-state scale. As births are universally registered, with very few exceptions, the population at risk for neonatal transport is wholly known from these data. Neonatal mortality, a common endpoint for research in perinatal health, is also reported well, and moreso since the initiation of the National Center for Health Statistics national linked birth certificate-death certificate file project for infant mortality, which began with the 1983 birth cohort.

Vital statistics data contain many of the sociodemographic and reproductive risk factors of interest in the analysis of perinatal regionalization, including several (for example, maternal educational attainment and, in some states, occupation and industry) that are not commonly found in hospital medical records.

However, vital statistics information provides only part of the story. It is probable that four to six percent of all newborns are admitted to an NICU for stays exceeding an hour. Only a small fraction of these infants die during the neonatal period.

NICU admission is probably more common among inborns at perinatal center hospitals, but this cannot be verified from birth and death certificates, since most of these infants survive the first year of life. Looking at maternal-fetal transport, here too, it is not known why the mother of a stillborn had her delivery at a Level II or Level III perinatal facility. Although many women are referred to these facilities after a determination of high risk, others choose the same hospital on the basis of convenience, location, choice of physician or insurer, or for other reasons. In the analysis of Arkansas perinatal regionalization, we assume that high risk births, as defined by birth weight and estimated gestational age, are delivered where their deliveries occur following an assessment of risk and appropriate referral. An unknown proportion of these infants were not identified as high risk deliveries or neonates, and some high risk deliveries develop into obstetrical problems rapidly.

Additionally, because birth and death are the only times for which a hospital location is known, we must make inferences concerning the interval between birth and death. Where the hospitals of birth and death are the same, we assume that the infant spent his/her entire lifespan there, and in situations where the hospitals of birth and death differ, we similarly assume that the child was transferred from the one to the other. These assumptions are more valid the shorter the interval between birth and death, and when the underlying cause of death is a severe neonatal disorder or one of many serious sequelae of intra-uterine growth retardation, very low birth weight or preterm birth. However, infants discharged from NICUs have relatively high rehospitalization rates and post-discharge mortality [18,19], and back-transported infants who die at the birthing hospital will have vital records which do not indicate an NICU stay [20].

Additional clinical information, from prenatal care provider records and the hospital charts would be necessary to sort these different groups of deliveries into appropriate categories. This information is unlikely to be available on a statewide basis, and would be difficult to obtain even for a multi-center analysis of NICU patients.

At the state level, however, it should be possible to organize a Neonatal Intensive Care Unit discharge summary data system. This would include, at a minimum, sufficient information to link each NICU patient to birth and, if appropriate, death certificates, together with more detailed physical measurements at birth, admitting diagnosis, maternal diagnoses, hospital of birth, treatments in the NICU, infant discharge diagnoses, and discharge destination. Such a database would fill in many of the missing links in the analysis of perinatal regionalization, and could also serve as one of several inputs into statewide high-risk infant follow-up or P.L. 99-457 Child Find programs.

Table 3: Analysis of Probability of Surviving the First Day of Life

RESPONSE LEVELS (R) = 2 POPULATIONS (S) = 98 OBSERVATIONS (O) = 95,379

EFFECT	ESTIMATE	STANDARD ERROR	P-VALUE	ODDS RATIO	95 % CONFIDENCE INTERVAL	
					LOWER	UPPER
Out of Hospital Birth	-0.5123	0.2783	0.0657	0.60	0.35	1.03
Birth at Level II Hospital	0.1126	0.0969	0.2454	1.12	0.93	1.35
Birth at Level III Hospital	0.3782	0.1121	0.0007	1.46***	1.17	1.82
Birth Weight < 1,500 g	-2.3206	0.1749	0.0001	0.10***	0.07	0.14
Birth Weight 1,500-2,499 g	-0.6298	0.1797	0.0005	0.53***	0.37	0.76
Race of Mother Black	0.1251	0.1048	0.2323	1.13	0.92	1.39
No First Trimester Prenatal Care	-0.0988	0.0965	0.3060	0.91	0.75	1.09
Mother's Education < High School	0.1513	0.0945	0.1092	1.16	0.97	1.40
Gestational Age < 32 Weeks	-0.9861	0.1786	0.0001	0.37***	0.26	0.53
Gestational Age 32-36 Weeks	-0.4058	0.1661	0.0146	0.67*	0.48	0.92
First Order Live Birth	0.0953	0.0834	0.2533	1.10	0.93	1.30
Mother Unmarried	-0.1589	0.1075	0.1396	0.85	0.69	1.05

* Significant at < 0.05.
*** Significant at < 0.001.

Table 4: Analysis of Probability of Surviving the First Week of Life

RESPONSE LEVELS (R) = 2 POPULATIONS (S) = 98 OBSERVATIONS (O) = 95,379

EFFECT	ESTIMATE	STANDARD ERROR	P-VALUE	ODDS RATIO	95 % CONFIDENCE INTERVAL	
					LOWER	UPPER
Out of Hospital Birth	-0.2771	0.2564	0.2797	0.76	0.46	1.25
Birth at Level II Hospital	0.0790	0.0748	0.2906	1.08	0.93	1.25
Birth at Level III Hospital	0.1399	0.0872	0.1088	1.15	0.97	1.36
Birth Weight < 1,500 g	-2.1656	0.1269	0.0001	0.11***	0.09	0.15
Birth Weight 1,500-2,499 g	-0.8545	0.1097	0.0001	0.43***	0.34	0.53
Race of Mother Black	0.0916	0.0823	0.2658	1.10	0.93	1.29
No First Trimester Prenatal Care	-0.0336	0.0735	0.6473	0.97	0.84	1.12
Mother's Education < High School	0.1319	0.0734	0.0725	1.14	0.99	1.32
Gestational Age < 32 Weeks	-0.7816	0.1253	0.0001	0.46***	0.36	0.59
Gestational Age 32-36 Weeks	-0.2616	0.1113	0.0188	0.77*	0.62	0.96
First Order Live Birth	0.0175	0.0640	0.7844	1.02	0.90	1.15
Mother Unmarried	-0.0431	0.0847	0.6112	0.96	0.81	1.13

* Significant at < 0.05.
*** Significant at < 0.001.

Table 5: Analysis of Probability of Surviving the First Month of Life

RESPONSE LEVELS (R) = 2 POPULATIONS (S) = 98 OBSERVATIONS (O) = 95,379

EFFECT	ESTIMATE	STANDARD ERROR	P-VALUE	ODDS RATIO	95 % CONFIDENCE INTERVAL	
					LOWER	UPPER
Out of Hospital Birth	-0.3936	0.2045	0.0542	0.67	0.45	1.01
Birth at Level II Hospital	0.0921	0.0643	0.1520	1.10	0.97	1.24
Birth at Level III Hospital	0.0970	0.0765	0.2051	1.10	0.95	1.28
Birth Weight < 1,500 g	-1.9545	0.1068	0.0001	0.14***	0.11	0.17
Birth Weight 1,500-2,499 g	-0.7470	0.0902	0.0001	0.47***	0.40	0.57
Race of Mother Black	0.0921	0.0721	0.2015	1.10	0.95	1.26
No First Trimester Prenatal Care	0.0397	0.0620	0.5223	1.04	0.92	1.17
Maternal Education < High School	0.0585	0.0623	0.3484	1.06	0.94	1.20
Gestational Age < 32 Weeks	-0.8383	0.1059	0.0001	0.43***	0.35	0.53
Gestational Age 32-36 Weeks	-0.3222	0.0904	0.0004	0.72***	0.61	0.86
First Order Live Birth	-0.0326	0.0552	0.5551	0.97	0.87	1.08
Mother Unmarried	0.0104	0.0739	0.8886	1.01	0.87	1.17

*** Significant at < 0.001.

The 1989 Standard Birth and Death Certificates

The new national standard birth and death certificates contain additional information intended to aid in the analysis of patterns of perinatal regionalization. These include separate questions on maternal transport and fetal transport, with space in which to indicate the facility from which the mother was transferred and to which the infant was transferred. If implemented appropriately at the state level, these items might fill in many of the missing gaps of vital records for the analysis of perinatal transport patterns. Each state must develop instructions, a list of facilities and clinics for obstetrics and neonatal intensive care, and procedures for ensuring that this information is reported accurately and completely. Of special importance is the requirement that admissions to an NICU at the facility of birth be indicated as a neonatal transport on the birth certificate. Maternal referrals for high-risk pregnancies must also be indicated, even if the patient is resident of the community or metropolitan area in which the referral hospital is located. These referrals should include all such cases, not only those transported after an obstetrical event such as placenta praevia, premature rupture of membranes, preterm labor, or preeclampsia. State vital statistics agencies should consult with state MCH staff and leading high-risk obstetricians, perinatologists and neonatologists in their state for advice on how to identify and code maternity clinics and perinatal facilities, and impress the importance of this information upon the hospital staff charged with the responsibility for completing the birth certificates.

One significant problem in the reporting of neonatal transfer is that of timing. Most high-risk neonates that are transferred to Level III hospitals are moved within a few hours after birth. The birthing hospital retains the responsibility for completing the birth certificate, yet rarely will detailed clinical information concerning that infant be provided to that hospital in time for completion of the vital records document. This means that the questions on abnormal conditions of the newborn and congenital anomalies will be inherently incomplete.

It is unfortunate that the new national standard fetal death certificate does not also include the question on maternal transport. These events are all high risk, as all are adverse outcomes, yet we cannot assume that the perinatal referral system has functioned properly for these pregnancies.

The checklists for medical risk factors for this pregnancy, complications of labor and/or delivery, and abnormal conditions of the newborn all contain items that might indicate a need for maternal-fetal or neonatal transport. This information does not indicate a need for perinatal transfer in and of itself, but could be used for validation in a birth certificate query process.

Summary

Vital statistics data are a necessary but not sufficient component of any comprehensive, population-based study of perinatal regionalization. Additional information concerning infants admitted to NICUs who survive, clinical data on treatment and diagnoses, information on length of stay in the NICU, and on subsequent rehospitalizations are necessary to complete the data set. For the analysis of maternal-fetal transport, additional information concerning the medical conditions which necessitated the transfer, and concerning the antepartum and intrapartum care and treatment are also necessary.

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OUTCOMES OF OBSTETRICAL CARE IN CALIFORNIA: A COMPARISON OF MEDICAID AND NON-MEDICAID DELIVERIES IN OCTOBER OF 1983

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This paper describes a study assessing the outcomes of obstetrical care among Medicaid and non-Medicaid women who delivered in October of 1983 in California. The research design and analyses were guided by two policy questions:

- Does Medicaid increase the use of prenatal care among enrollees vis-a-vis other non-Medicaid women?
- Does Medicaid improve the birthweight of infants born to enrollees compared to non-Medicaid women?

Three data sources were used to identify study groups and create a comprehensive analysis file:

- A file containing mother/infant paid claims for the prenatal, delivery and postpartum periods for 8,194 Medicaid-financed deliveries in October of 1983. This file was derived from the 1983-84 Medicaid Tape-to-Tape enrollment and claims database, developed by SysteMetrics under contract to the Health Care Financing Administration.
- The 1983 California Birth-Death Cohort File which contains linked birth and death records for calendar year 1983. In this file, there were 35,322 singleton live births in October.
- The 1980 census file containing information on poverty status by area of residence.

Four study groups were identified for our analyses using these three data sources. We linked our Medicaid file with birth certificate data using several matching criteria, including mother's first and last names, mother's age at delivery, infant's last name, and infant's date of birth. We matched 7,492 Medicaid delivery records (or 91.4% of the original Medicaid sample) to the birth/death records, excluding in the process all Medicaid fetal deaths and multiple births. The Medicaid sample was subdivided into two groups: (1) short-term enrollees--those with 3 or fewer months of enrollment during pregnancy, and (2) long-term enrollees--those who had 4 or more months of enrollment during pregnancy. Group 1, the short-term Medicaid enrollees, represents a population of eligible mothers who did not enroll in Medicaid until late in pregnancy. Nearly all of these women (92.2%) initiated enrollment in Medicaid during the third trimester (62.2%) or at delivery (30.0%). In contrast, 71.4% of Group 2, the long-term Medicaid enrollees, initiated Medicaid enrollment during the first trimester of pregnancy or were enrolled prior to conception. The remainder of Group 2 were enrolled by the end of their second trimester.

Among the non-Medicaid singleton live births in the Birth-Death Cohort file, we identified two comparison groups: (1) non-Medicaid mothers who lived in low-income areas, and (2) non-Medicaid mothers who lived in high-income areas. We used poverty status indicators at the census tract and zip code levels to designate specific areas as low-income or high-income. In the low-income areas, there were 4,054 non-Medicaid mothers who made up Group 3. There were 1,464 non-Medicaid mothers in high-income areas, comprising Group 4.

The pattern of demographic characteristics across the 4 study groups gave us confidence that our methods were reasonably accurate for identifying non-Medicaid births to women who were at different income levels. For example, most members of Groups 1 - 3 were minorities (55.7 to 69.3%), especially hispanics, compared to the over three-fourths of Group 4 who were white. Similarly, about one-fourth of the Medicaid mothers were teenagers in contrast to much smaller proportions among the other two groups. About 14% of Group 4 were over age 34 at delivery. The overall incidence of complications across all four groups was relatively low (ranging from 8.7% to 10.0% for pregnancy complications and 14.8% to 18.0% for complications of labor/delivery). Group 4 members had slightly higher rates of complications which may reflect their older age distribution. Only 57.3% of Group 1 received first trimester care versus about two-thirds for both Groups 2 and 3 and almost 90% of Group 4. Low birthweight rates were 7.9% for Group 1, 6.3% for Group 2, 5.4% for Group 3 and 4.2% for Group 4.

Table 1 shows a series of odds ratios developed from a set of multivariate logistic regressions assessing the probability of late prenatal care (initiated after the first trimester or no care) among the four study groups. Group 4 served as the comparison group for all analyses and was assigned an odds ratio value of 1.0. The other ratios in this table represent the relative risk of receiving late prenatal care vis-a-vis Group 4. Following a methodology used by Kleinman and Madans (1985), we show the successive effects of adjusting for specific sets of control variables on the odds ratios for each study group.

Adjusting for race/ethnicity resulted in the greatest reduction in the value of the odds ratios for all groups. Other sets of variables were also introduced successively including

Table 1

Odds ratios for receipt of late prenatal care by Medicaid enrollment, residence, and selected maternal/child characteristics: Singleton Live Births, California, October, 1983

	Group 1: Medicaid; Enrolled for 0-3 Months of Pregnancy		Group 2: Medicaid; Enrolled for 4+ Months of Pregnancy		Group 3: Non-Medicaid; Residents of Low-Income Areas		Group 4: Non-Medicaid; Residents of High-Income Areas
	Odds Ratio	95% Confidence Interval	Odds Ratio	95% Confidence Interval	Odds Ratio	95% Confidence Interval	Odds Ratio
Unadjusted	7.78	6.31-9.60	5.06	4.16-6.16	4.75	3.89-5.81	1.0
Adjusted for Race/Ethnicity	6.84	5.52-8.46	4.47	3.66-5.46	3.94	3.21-4.84	1.0
Adjusted for Race/Ethnicity, Maternal Age, and Parity	6.13	4.95-7.61	3.80	3.10-4.65	3.71	3.02-4.56	1.0
Adjusted for Race/Ethnicity, Maternal Age, Parity, and Complications of Pregnancy	6.13	4.94-7.60	3.79	3.09-4.64	3.68	2.99-4.52	1.0

Note: When the 95% confidence interval for a given odds ratio excludes 1.0, the difference between the corresponding study group and Group 4 is statistically significant at the .05 level or greater.

maternal age, parity (first live birth versus higher-order birth) and complications of pregnancy. After all adjustments, those enrolled in Medicaid for a short-time during pregnancy (Group 1) were over 6 times as likely to have late prenatal care when compared to mothers who resided in high-income areas (Group 4). Groups 2 and 3 were almost 4 times as likely to get late care.

These findings indicate that all low-income groups were at substantially increased risk of receiving late prenatal care over non-Medicaid residents in high-income areas. This was especially true for Group 1.

Support for the potential positive effect of Medicaid enrollment on initiation of care comes from comparing Groups 1, 2 and 4. Recall that Group 1 were late enrollees in Medicaid versus Group 2 who were early enrollees in Medicaid. In comparison to Group 4, Group 2 had a substantially lower risk of receiving late prenatal care than did Group 1, suggesting a positive association between early Medicaid enrollment and early use of medical care during pregnancy. Overall, these results point to the importance of separately analyzing short-term and long-term Medicaid enrollment when assessing initiation of prenatal care.

We conducted similar analyses assessing the effects of Medicaid on the incidence of low birthweight. Multivariate logistic regression was used to predict the probability of a low birthweight birth (< 2,500 grams). In addition to those variables used in the prenatal care logistic regressions, two other control variables were included: sex of the infant and complications of labor/delivery. As before, we computed successive models introducing sets of control variables and calculated adjusted odds ratios comparing Groups 1 - 3 with Group 4.

Table 2 shows unadjusted and adjusted odds ratios for the low birthweight analysis. Unadjusted figures show that the relative risk of low birthweight for Group 3 was not significantly different from 1.0, indicating no increased risk of low birthweight for non-Medicaid residents of low-income areas over residents of high-income areas.

After all adjustments, only the short-term Medicaid enrollees (Group 1) had a significantly increased risk of low birthweight compared to Group 4. This association as well as the vastly different prenatal care pattern for Group 1 suggests that short-term Medicaid enrollees should be targeted for special interventions.

The two remaining low-income groups--long-term Medicaid enrollees and non-Medicaid residents of low-income areas --did not differ from the non-Medicaid residents of high-income areas in their risk of having a low birthweight newborn. Thus, these results are inconclusive regarding Medicaid's unique effect on birthweight. Recall that all low-income groups were more likely to receive late care than the non-Medicaid residents of high income areas. What then could have caused two of these low-income groups (Group 2 and 3) to have comparable birth outcomes to upper-income women? We speculate that quality and quantity of care could possibly have made up for the relatively later start. In the early 1980s in California, there was a concerted effort to improve the quality of prenatal care for all low-income women, regardless of Medicaid status.

Table 2

Odds ratios for low birthweight, by Medicaid enrollment, residence, and selected maternal/child characteristics: Singleton Live Births, California, October, 1983

	Group 1: Medicaid; Enrolled for 0-3 Months of Pregnancy		Group 2: Medicaid; Enrolled for 4+ Months of Pregnancy		Group 3: Non-Medicaid; Residents of Low-Income Areas		Group 4: Non-Medicaid; Residents of High-Income Areas
	Odds Ratio	95% Confidence Interval	Odds Ratio	95% Confidence Interval	Odds Ratio	95% Confidence Interval	Odds Ratio
Unadjusted	1.93	1.42-2.62	1.53	1.16-2.01	1.30	0.97-1.73	1.0
Adjusted for Race/Ethnicity	1.76	1.29-2.40	1.25	0.94-1.67	1.17	0.86-1.57	1.0
Adjusted for Race/Ethnicity, Maternal Age, Parity, and Sex of Child	1.69	1.23-2.32	1.25	0.93-1.67	1.17	0.87-1.59	1.0
Adjusted for Race/Ethnicity, Maternal Age, Parity, Sex of Child, Complications of Pregnancy, and Labor/ Delivery Complications	1.70	1.24-2.35	1.25	0.93-1.68	1.19	0.88-1.62	1.0

Note: When the 95% confidence interval for a given odds ratio excludes 1.0, the difference between the corresponding study group and Group 4 is statistically significant at the .05 level or greater.

We plan to conduct additional analyses to further examine the relationships between Medicaid enrollment, use of prenatal care, and the incidence of low birthweight. Currently, a draft report is being prepared for review by project staff at the Health Care Financing Administration. By the end of 1989, we expect to have a final report detailing the methods and results of this study.

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Second Plenary Session

Enhancing Federal/ State/Local Relations

PHCRS

FUTURE OF PUBLIC HEALTH: IMPLICATIONS FOR EPIDEMIOLOGY, SURVEILLANCE, AND STATISTICS

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(Not available for publication)

THE FUTURE OF PUBLIC HEALTH: THE STATE PERSPECTIVE ON SOME DATA ISSUES

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"The disarray of public health, a threat to the health of the public"; "The current public health system: a shattered vision". These gloomy words leap out as one peruses the IOM Report, "The Future of Public Health". If we believe this assessment, surely the future must be brighter than the present. Do we have problems? Of course. Are they serious? Yes. But disarray and a shattered vision? I think not. Consider these remarkable trends:

- Infant mortality is falling and the gap between white and non-white is narrowing in certain parts of the nation.[1] The National Commission on Infant Mortality and expanded Medicaid eligibility for prenatal and obstetrical care reflect an on-going momentum to make further progress.
- Teenage pregnancy rates are beginning to level off or decline in many regions. A variety of creative efforts are underway in various parts of the nation to deal with this problem.[2]
- Death rates due to myocardial infarction and stroke continue to decline in large part because of healthier lifestyles and the treatment of hypertension.[3]
- 43 million Americans have quit smoking and per-capita cigarette consumption continues on a downward trend.[4]
- Lung cancer incidence in white men has peaked and may begin to decline.[5]
- Alcohol consumption continues to moderate and crusades against drunk driving sustain their momentum.[6]
- Traffic deaths since the early 70s are down 26% and will further fall as more and more people wear seatbelts, as auto safety improves, and as drunk driving becomes less common.[7]
- 100 million Americans had their blood cholesterol checked in 1988. Millions will restrain their consumption of dietary fat and others will come under medical management to reduce cholesterol.[8]
- Breast cancer screening is beginning to take hold.[9]
- New HIV infections among gay men have begun to decline.[10]
- Reyes Syndrome has virtually disappeared (from several hundred case reports a year during the 1970s to only twenty in 1988) since the association with aspirin became evident and was publicized.[11]
- Measles is making a spotty comeback but is really not having much success in breaching the immunization barriers.[12]
- Chemical and radiation hazards are becoming more sharply defined and public health professionals are learning how to discuss them with members of the public.[13]

If this is a record of disarray, then let's have more of the same.

I sense among many people in all walks of life an enormous interest in, and commitment to, the mission of public health: namely, the prevention of disease and the promotion of health. Or as I like to say to lay audiences: to give people a generous life expectancy with as few miseries as possible along the way. Government, professional societies, voluntary agencies, and individuals are coming together to tackle problems which affect the public health. Obviously the scope of the problems, the intensity of commitment and degree of success have and will vary greatly in different regions of the country. Perhaps it is this remarkable variability, so common in American life, which leads to a perception of untidiness or, if you will, to one of disarray.

Science is tidy and orderly. A profession such a medicine or nursing is discrete and reasonably well-defined. On the other hand, politics is messy and untidy. This dichotomy leads some health professionals, prone to orderliness, to react aloofly. Such a reaction evokes suspicion and invites failure. The successful public health professional must learn to live within the tensions, conflicts, and confusion inherent in the cauldrons of our politics. At the same time he/she must never abandon the scientific and professional base, including the collection and analysis of relevant data, which is indispensable to sound public health practice. In this regard I concur fully with the IOM Report's call for government to carry out the functions of assessment, policy development, and assurance. For some of us this process needs to become explicit, systematic, and part of a mind set. For others who have had some practice at it, improvement is always possible and always should be sought.

Good and timely data are, of course, indispensable in order for there to be coherence in the process of assessment, policy development and assurance. All of the issues, which I previously mentioned, are informed by data from various sources be they "quick and dirty" surveillance on measles; be they obtained from our vital statistics of births, deaths, and induced abortion; be they from elegant interview surveys on smoking and other health habits; be they from well-executed case control studies such as those that confirmed the relationship between aspirin and Reyes' Syndrome.

Over the past twenty years I believe that all levels of government have enhanced their capacity to obtain fairly decent data, and to use them appropriately to inform policy choices. This has occurred because we have more sophisticated people than ever before to do the work, and the microcomputer revolution has played a major role in liberating smaller governmental units from dependence on larger organizations which could afford a mainframe.

Also, our productivity in data generation has grown enormously. In the severe recession of the early 1980's many agencies faced a major loss of funding from both the federal and state governments. This was certainly true for the Rhode Island Department of Health. Were it not for the microcomputer and the people who knew how to use them, our statistical systems would have fallen into genuine disarray when the funding cuts came.

The new power and sophistication have produced new problems. The ease with which we now capture and manipulate data has brought demands for more and more variables to be included in data sets. For example, the revised birth certificate, in my judgment, has become a small medical record. While there are persuasive arguments for collecting all this information, its gathering becomes much more time consuming and expensive. Many of my clinical colleagues make no bones about its being downright onerous. And much of the data, I fear, remains unanalyzed or published in massive compendiums of impenetrable tables.

Amidst this plenty are some serious gaps in our knowledge about the most disadvantaged among us. We have gained considerable knowledge about children in school; yet we are ignorant about the homeless and rootless among us. How to improve our understanding of these groups is a major task for the future.

To deal with some of these issues I have several suggestions:

1. For routine data sets we should limit the number of variables collected to twenty or twenty-five. If there is a compelling reason to add new variables, an old one should be dropped.
2. We should review and revise all data sets every five years. I know some of this is already done, but I suspect it could be more systematic. We should make nothing perpetual.
3. We should make greater use of probability samples, especially in medical care settings where the collection of data on each clinical encounter becomes unduly burdensome. This principle needs particular application at the state and local levels.
4. We should seek to get those who have the greatest stake in obtaining accurate data, namely the data analysts, more intimately involved at the point of data collection. In the interview survey this is usually not a problem. However, it is an issue in the clinical setting. I am not sure how to accomplish this. Surely it will cost some. We need to think about how to proceed.

One final point. Success in public health comes in keeping bad things from happening to people. We celebrate, if you will, "non-events". Yet the message of our success is often drowned out by the clamor of daily occurrences, good and bad. Good statistics, pithily presented, are crucial to our ability to persaude those who fund us to sustain and expand their commitment to disease prevention and health promotion. To accomplish this we need to jazz up our presentations. Perhaps we should explore the techniques of Madison Avenue.

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NEW FEDERAL INITIATIVES FOR ASSURING ACCESS TO HEALTH CARE

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As one of the seven agencies of the United States Public Health Service, the Health Resources and Services Administration (HRSA) is one of the younger components of this country's Federal health structure. However, our mission of providing health services to vulnerable persons is directly related to this nation's almost two-hundred year old public health tradition of caring for vulnerable populations. The majority of HRSA health care programs are dependent on State and local entities for implementation. Therefore, the topic of this session, "Enhancing Federal/State and Local Relations", is a very important one for our agency.

Much of the national attention on health issues these days is around the cost of providing care. There are, indeed, some serious dilemmas regarding the affordable provision of good health care to all Americans. However, barriers to health care also include the following:

- <u>Geographic/situational barriers</u> - A number of isolated rural communities and disadvantaged urban areas have insufficient health care resources such as physicians, nurses and appropriate facilities.
- <u>Structural barriers</u> - Certain structural problems relating to providers and programs also inhibit access. Financial coverage is uneven -- e.g., the Medicaid program's eligibility and services are different in each State.
- <u>Special population/cultural barriers</u> - Some people face language, cultural or special health problem barriers to receiving care in the private sector. Included in this group are some racial minorities, individuals with HIV infections, migrant farm workers, the homeless, etc.

Because of HRSA's particular public health mission, our agency is currently concentrating on the problem of access to health care which so many Americans are experiencing. HRSA is seeking to improve the delivery of primary health care at the community level in all possible ways.

First of all, HRSA is seeking to improve access through the programs that we fund directly. Then, recognizing the significant presence of State and local government and non-government funded and administered primary health care programs, HRSA is seeking to increase and improve coordination efforts between our Federal programs and those funded from other sources. At a time when so much of our national resources are going towards health care, it is essential that stronger partnerships be established between and among those responsible for the access and affordability of health care.

To understand some of HRSA's current initiatives, it is useful to have an overview of the major programs we administer. I shall highlight the State and local roles. Then, I would like to describe some of our current efforts to enhance relationships between and among our part of the Federal government with State and local organizations.

<u>Maternal and Child Health</u>

Currently a formula block grant to States, the Federal maternal and child health program dates back to 1922 and the Sheppard-Towner Act which established the Federal Board of Maternity and Infant Hygiene. Funds were provided to States to establish programs in maternal and child health. This act was the first to establish direct Federal funding of personal health services. In order to receive Federal funds, States were required to develop a plan for providing nursing, home care, health education, and obstetric care to mothers in the state; to designate a State agency to administer the program; and to report on operations and expenditures of the program to a Federal board. The Sheppard-Towner Act was the impetus for the Federal practice of setting guidelines for public health programs and providing funding to States to implement programs meeting the guidelines. Although federally-initiated, the programs were fully State-run.

Under today's block grant arrangement, States have similar leadership responsibilities in that they determine how the maternal and child health block grants will be used. Implementation is carried out, for the most part, by local public health departments.

Community and Migrant Health Centers

The mid-sixties saw another wave of concern for improving the health status of American citizens. The largest national initiative, namely, the passage of Medicare and Medicaid, was focused on the financing of health care for the elderly, the disabled and some of the poor. At the same time, the Congress was also enacting legislation providing Federal support for health care infrastructures. The Hill-Burton legislation increased the availability of hospital-based care. As part of the War on Poverty, the Economic Opportunity Act supported the development of neighborhood health centers for disadvantaged Americans.

The latter program continues today as the Community and Migrant Health Center program of the Public Health Service Act. Over 600 local grantees, primarily non-profit clinics, provide primary care in underserved urban and rural areas. The most recent reauthorizing legislation includes funds for infant mortality activities and requires special consideration for "frontier areas".

Funding continues directly from the Federal government to local grantees. State and sub-State governments have no formal role in the allocation of funds and oversight of the program unless they have been selected as grantees in a competitive process. However, encouraging closer relationships between community and migrant health centers and State/sub-State public health networks is a high priority for HRSA.

Community and migrant health centers are strongly involved with several new HRSA programs and demonstration involving the homeless, health care in the home, substance abuse and AIDS. As examples of the varying administrative relationships Congress bestows on HRSA: the Health Care for the Homeless program is a direct Federal-local program with 109 local grantees and no State involvement while the Health Care in the Home program provides grants to States for demonstration projects.

Health Manpower

HRSA has a number of responsibilities designed to increase and improve the supply of health manpower. The National Health Service Corps (NHSC) provides physicians and other health professionals to areas with shortages of these providers. It relies on a variety of mechanisms to encourage health professionals to locate in underserved areas including loan repayment programs, scholarships and recruitment of volunteers.

In accord with a new legislative mandate, the NHSC is focusing on a program to recruit practitioners who serve in return for repayment of their educational loans and also a grant program to develop State loan repayment programs.

The Area Health Education Center (AHEC) program addresses problems of geographic maldistribution and over-specialization of health professionals by fostering changes in the traditional pattern of health professions education and the educational environment. AHECs link the resources and training programs of health science centers to community hospitals and other local educational institutions to provide training which specifically addresses the health personnel needs of particular communities.

The National Practitioner Data Bank (NPDB) receives and disseminates information on certain adverse actions taken against licensed health practitioners. The purpose of the Bank is to contribute to the improvement of the quality of health care by restricting the ability of incompetent and unethical practitioners to move from State to State without disclosure or discovery of their previous poor performance. State medical and dental boards must report to the NPDB disciplinary actions taken against physicians and dentists.

New Directions

During the past several years, HRSA has pursued a strategy of expanding partnerships with States, State-related organizations, and private entities which share responsibility for caring for the underserved. From the HRSA perspective, each of these new relationships has the potential to advance one or more of the following goals:

1. To strengthen relationships between HRSA and HRSA grantees with the private sector and with States.
2. To facilitate more effective use of limited Federal funds by promoting coordination among public and private providers; efficient approaches to financing, organization and management of care; and increasing the proportion of

HRSA funds going to technical assistance.

3. To broaden the understanding of the leaders of influential organizations outside the Department of health care needs of the medically underserved and related Departmental programs.

These initiatives include advocacy and marketing, dialogue with health industry officials, and participation in major demonstration programs of private health foundations. Brief descriptions of some of these activities follow:

o As of FY 1988, HRSA had entered into 32 cooperative agreements with statewide organizations for the purpose of providing assistance in the planning and development of comprehensive primary health care services in areas with inadequate health manpower or with populations lacking access to primary care services. These activities emphasize coordination of Federal and State efforts and maximization of non-Federal resources.

o The National Governors' Association cooperative project assists States in planning and implementing policies concerning public programs aimed at mothers and children by: (1) disseminating information about practical and innovative approaches and (2) identifying opportunities for collaboration at the State level between programs funded by HRSA and the Health Care Financing Administration (HCFA).

o Since the fall of 1987, HRSA representatives have been meeting with senior staff of the Group Health Association of America (GHAA) about the possibility of expanding member plans to low-income populations. As commercial prepaid managed care organizations, most of these plans have not been involved in caring for large numbers of the medically underserved.

o The Robert Wood Johnson Foundation/ Health Care for the Uninsured Program demonstrates ways of improving access for uninsured populations by modifying financing and/or delivery arrangements. The Foundation has funded 14 projects including several that involve community health centers.

o On the initiative of HRSA, the American Enterprise Institute created a small working group which met in October 1986 to evaluate the potential of private initiatives for meeting more of the health care needs of the medically indigent. An outgrowth on this process was an invitational seminar in July 1988 in Columbia, Maryland. The proceedings reflect multiple views and recommendations to improve the complementarity of public and private health services financing and delivery policies.

Summary

The collaborative efforts described here are designed to enhance the productivity of both public and private programs while maintaining a health system that reflects the pluralistic American society. These types of partnerships will continue to be a focus for the Agency during the next few years with an increasingly significant role for States and State-related organizations.

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CDC RESPONSE TO THE INSTITUTE OF MEDICINE REPORT ON THE FUTURE OF PUBLIC HEALTH

Martha Katz, Centers for Disease Control

Introduction

Thank you for the opportunity to join this distinguished panel this morning. The 1980's have been a time of intense pressure for public health. We started the decade with tremendous competition for public resources, beginning with proposition 13, the consolidation of public health programs into block grants with reduced funding and then the demand for new resources for AIDS programs. We have been forced to make hard choices but we have used two important tools of our trade - our information bases and our national prevention objectives to set priorities - to make our public health agenda quite clear.

I think we all recognize the stresses associated with the AIDS epidemic - it has highlighted both the strengths and weaknesses of our public health system. Think about this decade for just a moment. We have not just coped with AIDS, we have also built chronic disease control programs, injury prevention centers, environmental health programs, behavioral risk factor surveillance systems, and a host of other programs that were just dreams in 1980. But in 1989, they are reality in many States and growing nationwide.

So for CDC, one statement in the Institute of Medicine Report rings truer than any other, "The wonder is not that public health has problems - but that so much has been done so well with so little."

CDC Action on the Report

During the last 9 months, CDC has reviewed and analyzed the report carefully. With 52 different recommendations, it is easy to find some or many to debate - but we have concluded that the debate is far less important than the consensus on the two most important issues: (1) that the mission of public health is to assure each American the full opportunity to be healthy; that is, free from illness and injury to enjoy a better quality of life, and (2) that government at all levels shares the three major functions defined in the report:

- assessment
- policy development
- assurance

At CDC, we feel responsible for taking action to strengthen the capacity of the public health system in these three areas - so that we can attain the National Health Objectives for the Nation and thereby come closer to meeting the overall goal or mission of public health.

We have formed an internal work group to develop a preliminary plan for strengthening public health in the United States. Dennis Tolsma, Assistant Director for Public Health Practice and chair of the group, is responsible for putting together not only the concept papers but also the strategy for involving our many partners - our colleagues in other federal agencies, State and local health departments and the many other facets of society who contribute to public health. Many of these groups are represented here today. We realize that only with a strong coalition of partners can we design this vision of public health for the 21st century.

We are now developing the draft of an implementation plan. And as you might imagine, much of our thinking has focussed first on assessment, the topic most important to many of you.

Challenges

Our discussions regarding assessment, in particular, but the other functions as well, make me think that there are at least three major challenges ahead.

1. Seeing the Big Picture

Having just celebrated the tenth anniversary of the landing on the moon, I am reminded of the astronauts' amazement when they first saw earth from a space ship. It is a unique opportunity to truly get the "big picture" of life. Like the astronauts, we must step back to get the complete view of our public health data needs. It will not be enough to patch together our existing systems. In fact, if aliens visited us, they would be

systems that we now use. We need to ask ourselves several questions: What information do we need for a comprehensive public health intelligence system?
What changes are needed in federal data systems, how can we make them more efficient, how can we fill gaps? What information do states need? What type of data is essential yet practical for local health agencies to collect and analyze? How do these pieces fit together to form a national public health data set? We cannot simply tinker with what exists. We must work together --national, state, and federal leaders-- to see the big picture and establish a national public health data set that will position us to detect, prevent, and control the public health problems of the future.

2. Adapting Assessment to Different Localities

What is "local?" It is a term we throw around rather lightly, but it means many different things throughout this country. On one end of the spectrum is the Fulton County Health Department which provides a full range of preventive and treatment services for people in the City of Atlanta. At the other end is Abbeyville, South Carolina. Abbeyville is a classic southern town--with a central square that boasts several restaurants, antique stores, an opera house, and perhaps the most popular spot, a turn of the century pool hall. The town is served by a public health nurse and several part-time staff who worry about everything from teenage pregnancy to hypertension to sexually transmitted diseases. So, when we develop recommendations regarding data sets at the "local level" we will need to bear in mind these differences, and develop standards that are both useful and feasible in different settings.

3. Implementing New Technology

We have talked a lot the past couple of years about technology and its potential for streamlining and expanding the capability of public health data systems. The comment that distressed me the most was the statement by one public health leader that, "we have the technologies on the shelf but we do not have the resources to implement them." That is unacceptable. As Denny Scott said just a few minutes ago, we need good statistics, "pithily" presented, to attract investors to public health.

We need to think broadly about the opportunities for automation--not just ways to process data tapes faster. We need to use contemporary computer technology to automate our systems from the point of initial collection through analysis and publication. This means finding ways to automate information collection in hospitals, doctors' offices, from vital records, and during household and telephone surveys. Data from these primary sources should be transmitted electronically to local, state and federal health agencies.

I am struck by the ease with which high school and college students use computers and related technology. This is the talent we need to change our institutional cultures by making automation a top priority. Rapid adoption of technology is an essential ingredient if we are to achieve our vision of an effective national public health intelligence system.

I am confident that if we work together, we can find creative approaches to these three challenges. Thank you.

Session I

Legal Issues

PHCRS

HIV INFECTION AND THE FUTURE OF CONFIDENTIALITY POLICY

John P. Fanning, U.S. Public Health Service

The appearance of acquired immunodeficiency syndrome (AIDS) and human immunodeficiency virus (HIV) infection produced sudden and dramatic attention to issues of use and disclosure of health information about individuals. AIDS was first identified in 1981.[1] It was first perceived as connected with gay men, intravenous drug users, and Haitian immigrants in 1982. A commercially-available test for antibodies to the causative virus, HIV, appeared in 1985. The appearance of a contagious disease among stigmatized or vulnerable groups, together with the availability of a blood test to identify "carriers" who were not overtly ill, raised complex and pressing questions about the use and disclosure of information about individuals. Health officials and other governmental officials at local, State and Federal levels, as well as health practitioners, were faced with decisions about how to deal with information. There was an existing body of analysis and thought to guide their policy choices.

Sources of Policy Guidance

There were four main sources for this. First, there was a body of State public health law dealing with contagious diseases that had not been very visible since the 1920s, largely because of improved public health and therapeutic measures that had reduced the impact of contagious diseases.

Second, there was analysis and experimentation in the 1970s relating to privacy and confidentiality issues, that included consideration of medical information, and offering principles applicable to such information.

Third, there was a body of ethical principles embodied in the general consciousness of health professionals and in the pronouncements of professional associations. They were often not detailed, and of course not did not address the specialized problems created by HIV infection.

Fourth, there was a body of legal controls on health information. Mainly State law, it varied substantially in its protective power, ranging from comprehensive statutory schemes to narrow testimonial privileges. A few States had laws providing well-organized protection for records held by practitioners. There were laws in all States specifically governing information held by public health departments; these laws were generally, but not universally, very strong in their protective power. There was a small body of case law, creating obligations (under several legal theories) on health care providers not to disclose private information about patients. There was Federal law protecting information about drug and alcohol abuse patients. There was some Federal law governing information held by Federal agencies.

The existing body of policy thinking was helpful, but not completely so. The existing body of law was helpful, but not completely so. States in many instances set out to legislate about the use and disclosure of information about persons with AIDS and HIV infection. This was to some extent connected with the organization of testing programs. With improved testing for antibodies to HIV, and some encouragement of testing from public health authorities, there developed specialized centers for testing, as well as some testing in regular medical practice and facilities.

These developments presented for resolution basic issues of confidentiality policy. The issues included the classic balancing, involving two theoretical interests and a related practical and empirical question: the privacy rights of the individual, the needs of the society generally, and the actual effect of confidentiality protections in inducing people to act in a way that meets the needs of the society generally. These issues were considered in State legislatures and in the United States Congress. The Presidential AIDS Commission addressed the issue, framing it in terms of encouraging voluntary testing, and recommended Federal HIV-information confidentiality legislation.[2]

The policy discussions of the 1970s and early 1980s provided some help, but they had not included full, separate debates on issues of communicable diseases. The issue was addressed, but must have seemed relatively insignificant at the time, in view of the minimal societal attention to communicable diseases generally. In many instances they took as a given that there were State laws requiring the reporting of communicable disease, and recommended or designed privacy protections that allowed disclosures to comply with those laws. The effect was to leave to separate legislative debate the specifics of disease reporting and related confidentiality protections. The Privacy Protection Study Commission, in a fairly detailed analysis of the issues, accepted that there was such reporting, recommended that comprehensive medical privacy legislation permit its continuance, and recommended that statutes protecting such reports in the hands of health departments be strengthened.[3] Federal medical record legislation considered (and defeated) in the 96th Congress in 1980 would also have permitted such reporting as well as other disclosures for public health purposes, with some restrictions on further use of information so obtained.[4]

The Uniform Health-Care Information Act promulgated by the National Conference of Commissioners on Uniform State Laws took a similar approach. The explanatory material of the drafters shows a generous acceptance of existing State law choices to require and permit physicians to communicate freely with health departments.[5]

Features of HIV Confidentiality Laws

After about seven years of attention to this, there are few States that have do not have laws dealing with HIV-related information. About a dozen have comprehensive schemes, addressing such information in many settings, and dealing at length with allowable disclosures and imposing restrictions on redisclosure. At the other end of the scale, there are a few with one or two requirements for particular disclosures. Several features or themes are visible in this body of law:

1. The protections are rarely absolute. The recommendations of the Privacy Protection Study Commission, the Federal attempt at national medical confidentiality law, and the Uniform Health-Care Information Act, all envisioned that, for health records generally, there would be many types of disclosures without the consent of the patient. The statutes governing HIV-related information often follow the same pattern. Even laws regarded as highly protective, like those of California,[6] New York,[7] and Rhode Island,[8] have long lists of allowable disclosures. Many read in this regard like general medical record statutes. The Rhode Island HIV information law, for example, is explicitly designed to complement the general medical record statute,[9] and permits some, but not all of the same disclosures. Massachusetts seems to be alone in having a statute with no exceptions.[10]

These laws have met with general acceptance, although debate continues. Some have been modified to permit disclosures that were initially not seen as necessary or desirable. The acceptance of these laws, despite the many disclosures they permit, can be seen as based on two factors: First, the concerned public may be satisfied when there are explicit and distinct <u>control</u> mechanisms for information about them, even when the information is not kept absolutely confidential. Second, there is increasing recognition that legal controls on information are not the only protection available or needed. The ethical traditions of health professionals and administrative practices and policies governing use of information are also relevant. There will be always be some disclosures without patient consent, often to serve the needs of the patient. In many cases the patient will authorize disclosure by a health care provider, or disclose his or her condition to others. Other laws and protections (like anti-discrimination laws and their attendant enforcement and conciliation apparatus) help protect against misuse of the information.

2. There are some imaginative approaches to sensitive disclosures. Some of the laws address the issue of notification by physicians or health departments of sexual partners of persons who are found to be infected with HIV. A few of them are not content to simply permit the notification. They set out specific conditions and circumstances, often involving

medical judgment, before the notification can be made. The physician must believe that the partner is in danger, must try to persuade the patient to notify the partner, must be convinced that the patient will not do so. Only then may the physician notify the partner. In New York the physician must even give the patient the choice of notification by the physician or the public health department.[11]

Earlier confidentiality statutes in general simply permitted disclosures, sometimes suggesting controls or referring to medical judgment or practice, but rarely attempting to structure in any detail judgments of this level of subjectivity. The Uniform Health-Care Information Act, for example, permits disclosure "if the health-care provider reasonably believes that disclosure will avoid or minimize an imminent danger to the health or safety of the patient or any other individual". In another attempt at requiring medical judgment, that act would permit disclosure to close relatives "if made in accordance with good medical or other professional practice".[12] This more developed approach to partner notification found in a few HIV information laws derives from the need to assure persons being tested that a positive HIV test would not result in automatic, immediate, unthinking notification to a spouse or partner with no acknowledgement of the concerns of the patient. To that extent, these laws are sound and sensitive reflections of the human factors in the situation: the need to protect vulnerable partners; the fear and apprehension of the infected person; and the need to involve the infected person, in some way, in the communication. They demonstrate that such factors can be accounted for in confidentiality legislation, and may serve as a model for conditions for other especially sensitive disclosures.

3. The applicability of the protection is somewhat at odds with traditional ways of writing confidentiality protections. The new HIV infection laws often cover a particular type of information wherever it is located, as distinguished from covering all information held by particular classes of persons or institutions. This is partially because the confidentiality issue in this case is a <u>disease- and information-specific</u> one: it is disclosure of HIV test results that worries people, without regard to where the information is written down and who discloses it.

<u>Questions Raised</u>

The special attention to legal and other protection for information related to HIV infection will continue, and it raises questions applicable to the future of all policy for the protection of personally identifiable medical information about people. There are several aspects of this worth reviewing.

1. Disease-specific legislation has certain inherent limitations that need to be recognized. It necessitates complicated administrative and management arrangements to maintain medical records, since different requirements apply to different types of information -- often information that logically belongs in the same record or file. The problem is not serious if the statutes apply to specialized facilities, e.g., to special testing sites for HIV infection. But it can be serious when applied to medical care generally. With earlier interventions and some ameliorative treatments, HIV infection is becoming a chronic disease for which patients will receive regular medical care over a long period of time, perhaps beginning with a test for HIV infection in a general medical care setting. Other aspects of that medical care will in some instances not produce "HIV-related information" or "HIV test results" as such but the patient's infected status will be a factor in the treatment, and other information in the record may demonstrate or suggest that the patient has HIV infection. A strategy employing different sets of rules for different bits of information in what ought to be one record may not be the best way of managing records.

A related problem is the fact that a special set of rules for sensitive bits of information of itself communicates that the patient in question has a sensitive condition. This is not of itself an argument against specialized rules, since they can still serve a protective purpose (e.g., the fact that there is a special rule may lead to inference, but is not conclusive and communicates no details). But it is an additional limitation in such an approach.

Experience with the special confidentiality rules governing drug and alcohol abuse patients led to changes that eliminated the rules' applicability to drug and alcohol treatment that was integrated with regular medical care, i.e., the rules now apply only to specialized, separately identified, drug and alcohol treatment facilities or activities.[13] In another instance, Congress sought to prevent the hazard of telegraphing the fact that a patient had a sensitive illness. Drug and alcohol abuse and sickle-cell anemia patient records held by the Department of Veterans Affairs have long been subject to special confidentiality legislation, requiring a special consent form if the patient wishes to authorize disclosure. Congress recently added HIV-related information to this, and in addition forbade disclosure of the fact that a special written consent is required for such records to be disclosed.[14] The practical result, if absurdity is to be avoided, would seem to be for the Department of Veterans Affairs to require the special detailed, consent form for <u>all</u> records, not just those covered by the special rules.

2. As indicated above, some laws governing use and disclosure of HIV-related information cover information of the designated type, wherever it goes, as distinguished from covering all information held by a particular type of person or agency. Like disease-specific legislation, this creates special management problems, since records in one file or system may well be subject to several, and differing, sets of legal controls, depending on the origins of particular bits of information.

3. Comprehensive protection for health records generally is still a relevant and important issue. HIV infection does raise unique problems and special legislation is understandable, but those who are interested in full protection for all health records may want to consider the effects of continued enactment of narrow protections in leaving other health information with the same fragmented or inadequate protection that it had before.

4. Laws regarding confidentiality of HIV-related information have addressed research, but not extensively. In general, laws covering HIV-related information, such as test results, appear on their face to cover such information gathered for research, with protections indistinguishable from those for treatment records.

States do not generally provide for disclosure with identifiers for research purposes, the way confidentiality laws often do. Many laws explicitly allow disclosure without identifiers.[15] It is unclear why such a disclosure would have to be explicitly permitted. At least one State, in integrating its HIV-specific legal protections with its general medical record confidentiality protections has explicitly not permitted HIV-related information to be disclosed for research purposes in the same fashion as its general law permits for other medical information.[16] Florida appears to be unique in permitting disclosure for research purposes with identifiers.[17]

The research community has always been at pains to be sure that medical record confidentiality laws permitted disclosure for research without patient consent and it has generally been accommodated.[18] The absence of research disclosure provisions in HIV infection confidentiality laws may reflect some greater concern about confidentiality and patient sensitivity for this illness. In addition, researchers' need to look at records without consent arises in one important instance in retrospective studies in which the patients are not identified in advance, and where getting consent would be impossible because the patient is not identified until the record is seen. In the case of HIV infection, the patients are generally currently identified and are in contact with the health care and research systems. To the extent that their information is needed for research purposes, they can be asked for consent, and so the need for a statutory base for access without consent is less pressing.

In one State, California, there are specific statutory confidentiality protections for HIV-related research, which are not absolute, but differ somewhat from the protections for other HIV-related information.[19] In New York, research activities conducted under the auspices of the State Department of

Health are brought under an existing general confidentiality protection for public health research.[20] Two States that otherwise require all instances of HIV infection to be reported to the State health department make an exception for such information developed in a research project.[21]

One other development is not explicitly directed to HIV research, but should assist it significantly. Under a new section 301(d) of the Public Health Service Act, the Secretary of Health and Human Services can grant certificates of confidentiality to research projects to protect the identities of their subjects against compulsory demands for information under, e.g., subpoena. Such authority has existed for many years for research on drug and alcohol use and mental health; the recent enactment extends this more broadly.[22] Certificates have already been granted for some HIV infection research projects.

The special research needs of HIV infection may need further attention. Most confidentiality laws protecting HIV-related information assume fairly broad, if controlled, use for identifiable information, and are based on the principle that persons will seek care even if confidentiality protections are not absolute. But since participation in research is often voluntary, a higher degree of protection may be needed to induce participation. Further, absolute or near-absolute protections for such information causes little loss of information needed for other purposes. Information assembled in research projects would often not be collected except for the research. Research projects are not widely identified as sources of information about individuals, as are treatment records. It is, in effect, a "cheap" form of confidentiality.

The Future

Further systematic investigation would help to explicate the benefits and disadvantages of existing HIV confidentiality law. Many States are continuing development of their laws, building on experience.

Existing confidentiality policies are built upon certain theoretical principles and on judgments about human behavior that may or may not have empirical support. All need further inquiry.

The standard analysis that balances the individual's right to privacy against the society's right to protection from disease may be a correct one as far as it goes; it is the underpinning, for example, of the constitutional justification for State public health laws.[23] But as a basis for making policy it may not be adequate. It does not take account of the practical issue of how people will actually behave when there is confidentiality protection and when there is not confidentiality protection. The Presidential AIDS Commission described the record confidentiality issue realistically in its report when it notes that public health strategies for fighting the epidemic require voluntary cooperation, and that an effective guarantee of confidentiality is "the major bulwark" against fear that keeps people from coming forward for testing.[24] Another discussion by H. Tristram Engelhardt, Jr. points to this empirical issue by noting that reporting requirements, and other threats to absolute confidentiality, can do more harm in the long run (by discouraging seeking of treatment) than the harm caused by failure to report or disclose in a particular instance.[25] Whether reporting and lack of confidentiality does in fact discourage testing for HIV is worth further discussion. There is some indication that in Colorado required reporting to public health authorities of HIV-positive persons does not discourage testing. In that instance, there is strong confidentiality protection for information held by public health authorities, and pseudonyms are accepted.[26] The increasing possibility of medical intervention to prevent or minimize some of the effects of HIV may cause some people to come forward for testing even without strong confidentiality protections. There is mixed evidence about willingness to provide information about oneself in the related area of survey research.[27] In any case, both theoretical considerations of rights, and experience of public behavior, are necessary to address HIV-related information confidentiality issues adequately.

The views expressed in this article are solely those of the author and do not represent the views of the

U.S. Public Health Service.

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5. § 2-104(b)(2), 9 U.L.A. 475 (1988).
6. Cal. Health & Safety Code §§ 199.20 - .40 (West 1989 Supp.).
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8. R.I. Gen Laws §§ 23-6-10 to 23-6-24 (1988 Supp.)
9. R.I. Gen. Laws §§ 5-37.3-1 to 5-37.3-11 (1987).
10. Mass. Ann. Laws. ch. 111, § 70F (Law. Co-op. 1989 Supp.). There is provision for notifying emergency workers of possible exposure to communicable disease, without patient identifiers, although the *patient* involved must be told that the notification has been made. Mass. Ann. Laws. ch. 111, § 111C (Law. Co-op. 1989 Supp.).
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12. Uniform Health-Care Information Act § 2-104(a)(4) and (5).

13. 42 C.F.R. § 2.11 (1988). The 1987 revision of this regulation included this change, which is discussed in the preamble to the final regulation. (52 Fed. Reg. 21796, 21797 (June 9, 1987)).
14. 38 U.S.C. 4132(a)(2), as amended by Veterans' Benefits and Services Act of 1988, Pub. L. No. 100-322, § 121(a), 102 Stat. 487, 502.
15. North Carolina's law is typical. It permits disclosure "...for statistical purposes in a way that no person can be identified". N.C. Gen. Stat. § 130A-143(1) (1988 Supp.).
16. R.I. Gen. Laws § 23-6-17(c) (1988 Supp.), dealing with disclosure of AIDS test results, indicates that the research disclosure provisions of the Confidentiality of Health Care Information Act, R.I. Gen. Laws §§ 5-37.3-1 to 5-37.3-11 (1987), the general medical record confidentiality statute, do not apply to HIV-related information.
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LEGAL ISSUES OF PRIVACY, CONFIDENTIALITY, AND DISCLOSURE
RECENT EXPERIENCES IN VITAL STATISTICS

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Introduction:

The information on birth and death records is protected from public disclosure in most states. Forty three of the nation's 52 registration areas restrict access to birth records; 34 restrict access to deaths.[1] In recent months, the news media have brought successful challenges to obtain identifying information from specific death records in several states. These events have occurred both in states that have a tradition of allowing public access and in those that have historically placed restrictions on who can obtain the personal identifiers on vital statistics.

This situation has large implications for the vital statistics program and for the accuracy and completeness of the medical certification on the death record. This paper presents two "case studies" of recent state experiences in Vermont and Missouri, as well as a discussion of some issues that must be addressed if state health departments are to insure the integrity of their data.

Vermont:

In October 1988, a reporter from a local television station approached the Vermont Health Department and requested access to 1987 teen suicide deaths. The reporter was doing a story on the preventability of teen suicide and wanted identifying information about these events so that he could contact and interview the decedents' families.

Vital records are public documents in Vermont, open under the state freedom of information statute. In the past, the Health Department had interpreted this to mean that if a person can identify a record, that is, provide the decedent's name and date of death, the Department would issue a copy. At the time of this request we did not provide access to records based on a request for "all suicides" or "all 1987 deaths". Consequently, while we offered to provide the reporter with statistical information, we verbally refused to provide him with the names of the decedents.

In December, the TV station followed up with a formal freedom of information request for copies of the death certificates of all persons age 19 and under who died during 1987 and whose deaths were determined to be the result of suicide. After conferring with its attorney and the Attorney General, the Health Department decided that it had no choice but to release the requested records.

The Vermont freedom of information statute specifies that a custodian must release, or provide access to, a public record upon request. However, it forbids the release of lists. The attorneys determined that if we simply provided the television station with the requested certificates we would, in effect, be providing them with a list of people who had committed suicide. Consequently, they advised the Department to provide the reporter with access to the records - that is, he was allowed to come to the office, and inspect all of the 1987 death certificates, and request copies of any record in the book that he wanted. We contacted the television station and set up a time for this inspection.

The Department decided that before we provided this access all records that were considered "protected" should be removed from the books. Thus, we removed all of the AIDS deaths from the volumes.

Upon investigation, the reporter discovered that some records were missing. After he finished inspecting the volumes and getting copies of the suicide records he asked to see the missing records. We of course refused.

In January, the Department received another freedom of information request for copies of the missing certificates. In the request, these certificates were identified by the state file number. The requested documents fell into three categories: records that did not exist (voided numbers), records that had been out for copying, and AIDS records. The Department responded to the request (in writing) by identifying the voided records and explaining that they were not available, providing copies of the records that had been out, and denying access to the AIDS records, citing the confidentiality provisions of the sexually transmitted disease statutes as the authority to deny.

The station appealed our denial. In Vermont, the first appeal for a freedom of information denial is to the Agency Secretary. The Secretary of Human Services refused to uphold the Department's denial on the grounds that the sexually transmitted disease statutes were not intended to include information on death certificates.

The letter providing access indicated that the station should contact the Health Department for copies of the records. To date, this has not happened. Since the station had no plans for an AIDS related story, they did not exercise their option to obtain copies of these records.

One result of all this activity was the introduction of legislation to restrict access to the cause of death information. In retrospect, the bill was not a good one. It was constructed under pressure and did not adequately address some of the administrative issues in a state with 251 local registrars and records at the state level split between the Health Department and the Department of Public Records.

In addition, the Health Department did not anticipate the extent and nature of the press response to this bill. The articles in the press stated that if the bill passed, the information on death certificates would be "secret" and it would be impossible to determine if there were health hazards in the area of the state's nuclear power plant, or if a community had a hazardous waste problem that was resulting in untimely deaths, or if there was an excess of teen suicide somewhere in the state.[2,3,4] The key word in the press campaign was "secret". The fact that the bill had strong provisions for research access to the data was ignored. The Health Department was unable to counter these allegations and the bill died a quick, albeit painful, death.

Missouri:[5]

The Missouri vital records statute is derived from the Model State Vital Statistics Act.[6] Persons seeking access to vital records are required to demonstrate a "direct and tangible interest" in the record. The statute also stipulates that the State Registrar may disclose information from vital records for research purposes - although the term "research" is not defined either in statute or regulation.

In the late 1960s, a young man, who was later determined to be the first known case of AIDS in the United States, died in Missouri. A national magazine heard of this case and went into one of the local registration offices in the state for information. At the time, this local office was letting the public inspect its death indexes. The magazine was able to identify the record through the index and to obtain a copy of it.

When the State Health Department learned that the office was letting the public into the indexes they instructed the local office to change its policy. Consequently, when a Missouri newspaper tried to obtain a copy of the record through the same method used by the national magazine, the newspaper was denied access.

At the same time, the state Health Department was involved in another vital records access issue. The Department had been denying companies who locate heirs access to identifying information from vital records. Several of these firms felt that they had a grievance with the Department.

Therefore, the newspaper and a company that traces missing heirs joined together in suing the Health Department. In January, 1989, the court ruled on this case, finding that:

(1) There was no definition of the term "legitimate research purposes" either in Missouri law or in the Model State Vital Statistics Act from

which the Missouri statute was derived.

(2) Had the General Assembly wished to limit access for research purposes to only scientific, medical, or statistical research, it would have included such terms in the statute,

Because of this lack of definition the court concluded that

(3) Reporters, when investigating news stories, have a "legitimate research purpose" and are therefore to be allowed access to the vital records.

(4) The heirship research business constitutes a legitimate research purpose and these firms are therefore entitled to access to the records,

In summary, the court determined that

(5) The only restriction on access to vital records in the statutes are those concerning illegitimate births and adoptions.[7]

This decision constituted a major change. Missouri, which had been a state that restricted access to identifiers, suddenly became an open records state. Since January, Missouri has implemented regulations to open its records and death indexes to the press and heirship firms. The state has, to date, protected its birth indexes because the adoptions and illegitimate births are identifiable in the indexes.

After the court decision, Missouri drafted legislation to define the term "research" in statute. This would have had the effect of allowing the department to deny access to the press and other researchers on a case by case basis. However, the Health Department did not pursue this course after the news media began lobbying against it. It's interesting to note that the editorials that appeared in the Missouri press were similar to those printed in Vermont - despite the fact that the press in Missouri had not had access to this data prior to February of 1989.

The Situation in Other States:

The experiences in Vermont and Missouri are not unique. Over the past 18 months similar issues have arisen in Indiana, South Carolina, and New Hampshire.

On the other hand, there are states that have managed to tighten up access - using the AIDS crisis as grounds for the need for new legislation or regulations. The most successful were states like New York, that started with a tradition of restricted access, although some open records states (e.g., Florida) have also managed to restrict access to at least the cause of death.

Where does this leave us?

Our public health system needs accurate cause-specific mortality statistics. We must find a way to balance the public good - and the availability of information for legitimate researchers (including those in the press), with the privacy rights of our citizens. However, recently the balance between the individuals' rights to privacy and access for the public good is being settled in favor of access. This is of genuine concern. We know that there is an issue regarding the accuracy and completeness of the medical certification of death. Many vital registrars have heard anecdotal reports of physicians modifying their medical certification to avoid recording sensitive diseases such as AIDS, suicide, alcohol related deaths, and even some cancers. About 2 years ago, the medical staff at Johns Hopkins Hospital decided that AIDS would not be cited as a cause of death on any death certificate originating from that institution "out of respect for the privacy of the patient's family".[8] Hopkins physicians use terms such as "pneumonia" due to "immunodeficiency" secondary to "retrovirus infection" to identify the case as AIDS, without mentioning the word AIDS. Unfortunately, some physicians might choose to certify to the pneumonia and omit the remainder of the diagnosis.

Currently, there are two activities underway to address these issues. The National Committee on Vital and Health Statistics has expressed its concern about the quality and completeness of death certification - and is planning a seminar on this topic in the fall. The National Center for Health Statistics, working with the Association for Vital Records and Health Statistics, has convened a group to plan for the revision of the Model State Vital Statistics Act.

Both the National Committee and the Model Law Group are expected to draft recommendations regarding confidentiality provisions for vital records that realistically meet the needs of researchers while protecting the rights of the individual. The challenge to State Health Departments will be to develop a constituency that will enable them to implement these recommendations - some of which will be legislative. This means we will have to obtain the support of physicians, special interest groups (including the press), legislators, and the public at large. While this is not an easy task, it is necessary if we are to enter the 1990s with a vital statistics system that is responsive to the nations public health needs.

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CONFIDENTIALITY: PERSPECTIVES FROM STATE EPIDEMIOLOGISTS

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To discuss the confidentiality of notifiable diseases, it is important to first discuss the development of disease reporting in state health departments. Infectious disease reporting began in the late 1800's where specific infectious diseases such as smallpox were reported to temporary local and state health boards. The creation of the Vermont Department of Health is typical of development of health departments around the country. In 1886, a 3-member State Board of Health was created to educate people on the principles of hygiene and how to avoid contagious diseases. In 1894 the State Board of Health addressed "an epidemic of nervous disease" which was later determined to be polio. This was a typical activity of the precursors of our contemporary health departments.

The development of the federal response to communicable diseases came much later. The Centers for Disease Control was formed in 1946 to control endemic malaria in the United States. In 1951, states asked the CDC to be the repository of notifiable disease reports to detect national trends for these diseases.

The responsibility for reporting notifiable diseases has always rested with state health departments under state statutes rather than with the federal government. All state health departments have a list of notifiable diseases which are required to be reported. Currently, Vermont has approximately 50 conditions that are considered notifiable. The infectious disease section of the Vermont Department of Health monitors the incidence of these diseases to determine whether outbreaks are occurring.

With the advent of reporting to state health departments and to CDC, officials were very careful to protect name-identified information. However, single cases of smallpox or clusters of cases of anthrax or plague have been routinely reported by the CDC and state health departments in a fashion that failed to mask potentially identifying information.

A report that was published in the January 20, 1989 edition of the Morbidity and Mortality Weekly Report identifies a 42-year-old male from Colorado who developed cholera after eating oysters from Louisiana(1). The report further states that the individual was treated in an emergency room in Rifle, Colorado on August 17, 1988. The population of Rifle, Colorado was estimated to be 4480 in 1986. This case report demonstrates the possibility of a breach in confidentiality because of the potentially identifying nature of the information presented. It has not been determined whether informed consent was obtained from this patient or whether the patient self-disclosed his condition. However, the report shows the potential for disclosure that could be very damaging to an individual's privacy.

States with "open records" laws have had different problems with confidentiality of deaths caused by diseases considered notifiable. In 1980, Vermont had the second largest outbreak of Legionnaires' disease ever recorded in history which resulted in 85 cases and 17 deaths. The Epidemiology division was approached by an investigative reporter who requested the dates of death of reported cases. By reading the obituary and using the dates of death provided by the Health Department, the reporter was able to identify almost all of the deaths in the county. He was able to obtain further information by visiting the town clerk's office and requesting the death certificates on these individuals under our "open records" law. The local newspaper had a 3-page story detailing the interviews of family members of the deceased patients. Needless to say, dates of death for notifiable diseases are no longer provided.

State epidemiologists discovered that disclosing few numbers of cases in specific age groups or in specific geographic areas could produce apparent breaches of confidentiality, as well. County-specific case counts are usually reported for our notifiable diseases. The Vermont Department of Health confirmed to the press that there was one case of AIDS in a county in Vermont which had a small population. Subsequent to that disclosure, an angry letter was received from the attending physician who stated that everyone in the hospital who took care of this patient now knew of the status of the patient and that the patient felt betrayed by the medical care system. AIDS cases are no longer reported by county in our state.

These are some of the examples of issues that state epidemiologists grapple with routinely with information that is entrusted to them. Health departments have had an excellent record of protecting name-identified information for all notifiable diseases. For example, it has been noted that state health departments have never disclosed names of individuals reported to have sexually transmitted diseases. However, state epidemiologists were not prepared for the innovative approaches that could be used by reporters and the general public to identify patients.

Recently, state epidemiologists have been challenged with providing potentially identifying information to state policymakers. Policymakers are asking about AIDS case counts in specific cities and counties for the purpose of health care planning. In addition to state requests, the CDC AIDS program began receiving multiple requests for state and county-specific AIDS case counts. Government agencies, in an attempt to develop funding formulas for states, have needed state-specific AIDS information to: 1) determine the number of living AIDS patients for distributing AZT money, 2) the number of IV drug abuser cases for IV drug user outreach programs, etc. The Centers for Disease Control requested assistance from the state epidemiologists in determining what should and should not be released. All of these concerns prompted a review of the confidentiality policies to determine how well state and federal governments could protect identifying information.

Several individuals have been reviewing state laws on confidentiality. Professor Gary Smith of the Emory University School of Law (2) and the AIDS Policy Center of the George Washington University (3) published reports on this subject. Both studies reviewed the confidentiality statutes for notifiable diseases in each state. It was soon discovered that there was a wide interpretation of confidentiality in state statutes and regulations. The major findings were:

1. All states have some form of freedom of information, similar to the federal freedom of information statute.

2. All states have confidentiality of information under physician-patient privilege.

3. 31 states cloak research data and identifiers with confidentiality statutes.

4. 25 states have general confidentiality statements without many specifics on the definition of the term.

5. 7 states require written consent prior to release of any information.

6. 5 states exclude information from court subpoena.

7. 7 states supply civil and criminal penalties for unlawful disclosure of sexually transmitted diseases; 3 states have similar penalties for all communicable diseases.

It was clear that protection of information varied in the different states. In all instances, however, the laws do not extend to information that is shared with other state or federal agencies. Therefore, state disease reports sent to the Centers for Disease Control would be protected under federal laws and not under state statutes.

In 1988, a Centers for Disease Control-Council of State and Territorial Epidemiologists working group was convened to review the federal confidentiality protections. The major points of concern listed by the group included:

1. There is a need to maintain the confidentiality of data concerning cases of AIDS.

2. There are increasing numbers of requests for access to Government research data.

3. There are no state laws which cover the confidentiality of notifiable disease data provided to CDC.

4. There are surveillance systems at CDC that collect name-identified and county-specific data.

5. There have been publications of case reports with information that could compromise the privacy of an individual.

6. There is a potential to compromise confidentiality with the use of large public access data tapes.

7. There are reports in the MMWR and other CDC publications that contain few numbers of cases, which may identify specific individuals.

The two federal statutes that were most germane to the issues of confidentiality of notifiable diseases were reviewed: the Privacy Act and the Freedom of Information Act. The Privacy Act provides for the confidential treatment of records that are maintained by a Federal agency according to either an individual's name or some other identifier. It requires that such records at CDC be protected from uses other than those purposes for which they were collected. In contrast, the Freedom of Information Act requires Federal agencies to make records available to the persons who request them, with some exceptions including: 1) "personal and medical files and similar files, the disclosure of which would constitute a clearly unwarranted invasion of personal privacy," and 2) matters specifically exempted from disclosure by statute.

At first glance, the two different legislative acts seem to be competing against one another. On closer look, they appear to protect the confidentiality of patient-identified information and identifying information that could be constructed through the presentation of information in various tables.

The CDC and states have had a long history of reporting few cases of disease within state jurisdictions. It was felt that because of precedence, it would be impossible to refrain from reporting small numbers of cases of notifiable diseases by state. However, it was agreed that supplying potentially identifying information about these single or small numbers of cases, such as the examples given earlier, could be problematic.

It was felt that it was important to develop an agreement between the state epidemiologists and the Centers for Disease Control on the confidentiality of disease reporting. It was decided to draft recommendations of the CDC-CSTE Working Group on Confidentiality of Surveillance Data. These recommendations were presented to officials within CDC and also presented to the CSTE membership at their annual meeting in Oklahoma City which was held in June, 1989. The major findings of the review were:

1. The current CDC confidentiality guidelines are adequate.

2. CDC should regularly review the data systems that require names. Each surveillance system is supposed to be reviewed every 3 years.

3. Disease frequency by state will continue to be published independent of cell sizes. In other words, few cases of rare diseases such as cholera will continue to be reported by CDC. Historical precedence helped to dictate this action.

4. State epidemiologists should secure informed consent before releasing identifying information on case reports.

The state epidemiologists voted unanimously on a position statement which formally accepted the recommendations of this working group.

Issues surrounding the confidentiality of AIDS cases and HIV infection were addressed separately by state epidemiologists and the surveillance section of the CDC AIDS Program. After careful consideration, the two groups signed a joint agreement that addressed specific issues surrounding the release of AIDS surveillance data. Generally, AIDS data will be released by CDC using the standard CDC guidelines. Other major points of this agreement were:

1. States with fewer than 100 cases will not have two- and three-way cross-classifications presented.

2. CDC will only produce one- and two-way same cross-classifications for cases from an SMSA with a 1980 census population greater than 500,000 and having 100 or more cases of AIDS.

3. All cells with 3 or fewer patients will be deleted from the tables of cross-classifications.

In summary, the AIDS epidemic has clearly prompted reviews of confidentiality at both the state and federal levels. As a result of these reviews, it is clear that the federal laws and policies regarding confidentiality are much more developed than most state laws and policies. The states have a variety of statutes that protect confidentiality at the present time. There is a clear need to develop more uniform legislation for protection of information within state health departments. However, it will take a considerable amount of time and effort for states to review their laws on confidentiality and adopt more rigorous legislation. The process is far from complete, but there has been progress, to date.

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Session J

Collaborative Programs

PHCRS

MICHIGAN CHILDHOOD MORTALITY STUDY: A COOPERATIVE STUDY BASED ON MATCHED SOCIAL SERVICE AND VITAL STATISTICS

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(Not available for publication)

MONITORING TRENDS IN PREGNANCY RISKS AND OUTCOMES: THE CDC PREGNANCY NUTRITION SURVEILLANCE SYSTEM

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INTRODUCTION

The 1990 Health Objectives for the Nation set goals for reductions in infant mortality largely through lowering the incidence of low birth weight (LBW). Specifically, the Objectives state that "low birth weight babies should constitute no more than five percent of all live births."[1] Current data indicate that this objective is unlikely to be met, despite the steady, gradual decline in the LBW rate during the 1980s.[2]

Several nutritional and behavioral factors are determinants of LBW. Nutrition-related factors include prepregnancy weight status and inadequate weight gain during pregnancy. Anemia in pregnancy, a condition often associated with iron deficiency, is another nutrition-related factor associated with adverse pregnancy outcomes.[3] Preventable behavioral factors which adversely affect fetal development include maternal smoking, alcohol consumption, and late entry into prenatal care. Early assessment of nutritional status is desirable so that intervention efforts can have maximum impact.

Low-income pregnant women -- many of whom have additional demographic risks -- are eligible to participate in the U.S. Department of Agriculture's Supplemental Food Program for Women, Infants, and Children (WIC). Although requirements vary somewhat from state to state, the WIC program enrolls pregnant women who are at medical/nutritional risk and meet income requirements. Participants receive monthly vouchers for supplemental food packages and, during visits to WIC clinics, obtain nutritional and risk factor reduction education relating to their pregnancies.

WIC programs and the public sector maternal and child health (MCH) clinics provide mechanisms for monitoring the prevalence of nutrition-related problems in pregnancies. This monitoring is an example of surveillance, the close and continual scrutiny of a disease or condition through data collection, analysis, and application. The Centers for Disease Control's (CDC's) Pregnancy Nutrition Surveillance System (PNSS) uses data collected when pregnant women visit clinics participating in public programs, such as WIC. States voluntarily submit these data to the CDC. The principal objectives of the PNSS are to develop state capacity to conduct standardized, program-based pregnancy nutrition surveillance, and to monitor trends in several known factors related to infant mortality and LBW.

NEW SURVEILLANCE INITIATIVE

Pregnancy nutrition surveillance activities were begun at CDC in 1979. After years of steady growth in both the number of participating states and the number of individual pregnancies monitored, the PNSS was enhanced as a result of the Public Health Service's Infant Mortality Initiative of 1987. The authorizing legislation required that the PNSS address more specific nutritional and behavioral risk factors in pregnancy. The bill stated the PNSS "will significantly increase state capacity to monitor health-related behaviors associated with poor pregnancy outcome and to use the information to direct intervention efforts more precisely and efficiently to those areas and populations in greatest need."

The bill resulted in the modification of the PNSS in two essential ways. First, whereas PNSS states had previously participated without financial assistance from CDC, the initiative provided funds to nine states in 1987 for a two-year period through cooperative agreements. Applicants eligible for funding include the official public health agencies of states and the District of Columbia, recognized federal tribes of Native Americans, and all U.S. territories. Second, data on behavioral factors, such as smoking and alcohol consumption, were added to the PNSS data set.

Another mechanism made possible through the Infant Health Initiative is the Pregnancy Risk Assessment Monitoring System (PRAMS), which provides population-based estimates of maternal behavior during pregnancy and early infancy. In participating states, PRAMS identifies a sample of mothers from recent birth certificates and, four months after the mothers' dates of delivery, administers mail or telephone questionnaires to the sample of mothers. Presently funded in six states, PRAMS is coordinated by CDC's Division of Reproductive Health, a sister division of the Division of Nutrition in the Center for Chronic Disease Prevention and Health Promotion.

SYSTEM CHARACTERISTICS

The PNSS uses public health program data collected at prenatal and postpartum clinic visits. The process ensures that each participant's pregnancy data can be directly associated with the mother's infant outcome data. Data, which are submitted to the PNSS, are already being collected by public health programs and quantify behaviors that are responsive to educational efforts.

PNSS data include information on smoking, alcohol consumption, prepregnancy weight, weight gain, hemoglobin or hematocrit levels, demographic indicators, and infant outcome. Smoking and alcohol data reflect behaviors during the three months before pregnancy, during pregnancy, and at the postpartum visit.

Data are submitted either quarterly or annually to CDC. In October of each year, state-specific summaries, based on infant birthdate during the prior year, are generated at CDC and distributed to participating states. Systemwide summaries are also generated and distributed. States make these summaries available to their counties and clinics.

PNSS INFORMATION SUMMARIES

The PNSS provides both demographic and risk factor information. For example, in 1987, when approximately 88,000 records from 16 states including the District of Columbia were submitted for analysis, 37% of the women were between 20 and 24 years of age, whereas 30% were younger than 20 years of age (table 1). White women represented 55% of the total, while black women accounted for 32%. Approximately 20% of the women made their initial clinic visit during the first trimester of pregnancy, while 46% and 34% made their initial clinic visits during the second and third trimester, respectively.

White women were much more likely to smoke at all ages than were black and Hispanic women, and the highest prevalence of smoking for white, black, and Hispanic women were in the 25 to 29 year-old age group (figure 1). As their age increased, women who smoked and who were classified as underweight by their prepregnancy weights were increasingly likely to have LBW infants.

PNSS EPIDEMIOLOGICAL ANALYSES

The PNSS is also a potential source for epidemiological analysis. One analysis (Sullivan, *et al*: unpublished) conducted at CDC examined the effects of smoking on birth weight and whether the effects were homogeneous across subgroups of women stratified by age. Researchers examined data from 230,000 PNSS records for which smoking status had been recorded, and who had live, singleton births from

1979 through 1987. Overall, 10.2% of the mothers who reported smoking during pregnancy had a LBW infant, compared with 5.9% of the mothers who did not smoke. This 4.3% difference is the "risk difference," and associates smoking with an excess of 4.3 LBW infants per 100 live births. This risk difference increases with age. However, the risk differences are not equal for all race/ethnic, age, and prepregnancy weight groups. For example, the underweight women who smoked and were older than 35 years of age had an excess of 11 LBW infants per 100 live births (controlling for race/ethnic category, previous live births, and trimester of first clinic visit).

In addition, the prevalence of LBW deliveries among nonsmokers decreases and finally levels off with age, but the prevalence among smokers markedly increases with age (figure 2). Thus, the overall increase of LBW deliveries associated with age suggests that, in this population, the LBW increase may be partially related to smoking.

In a similar investigation, data from 77,000 WIC participants from 1979 through 1987 who met the previous criteria and who were between 10 and 19 years old were analyzed.[4] Smoking prevalence increased as age increased and rose to 30% for 19-year-olds, for an average increase of 3.4% per year of age. Overall, smoking was more prevalent among whites, at 41%, than among blacks or Hispanics, each at 13%. The increase in smoking prevalence by age was mostly attributable to the increased prevalence of white women who started smoking.

Among white adolescents who delivered a LBW infant, 55% smoked: however, among those who delivered a normal birth weight infant, 40% smoked. This risk ratio of 1.4 was similar to the ratios for blacks and Hispanics, and it indicates that women in this population who deliver a LBW infant are 1.4 times more likely to smoke than women who deliver a normal weight infant. Risk differences were highest among 18- and 19-year-olds. In that age group, white smokers had a risk difference for LBW of 4.4%, while the risk differences for black and Hispanic smokers of the same age were 4.9% and 3.6%, respectively. However, overall, black adolescents were about 50% more likely to have a LBW infant than adolescents who were not black. This analysis indicates that smoking is associated with LBW even among adolescent mothers who have been smoking only a short time.

Another recent analysis used PNSS data to investigate the relationship of prepregnancy weight and macrosomia (infants with a birthweight greater than 4,000 grams).[5] Macrosomia is associated with a variety of adverse intrapartum and perinatal outcomes. Controlling for a number of potential covariates, the researchers found that obese women (defined as having a prepregnant body mass index (BMI), i.e. weight/height^2, ≥ 95th percentile of the NHANES II reference population)[6] had a two times greater likelihood of having a macrosomic child compared to normal weight mothers (BMI between the 25th and 75th percentile).

Although information from the PNSS is a valuable resource, these data should be interpreted cautiously. The data are program-based and represent only women attending WIC and MCH clinics from a nonrandom selection of states. Historically, the number of states involved in the PNSS have varied from year to year. The Infant Health Initiative should encourage greater continuity of states participating. Moreover, the percentage and composition of available data submitted by each state have also varied from year to year. These considerations indicate the need for caution in interpreting trend data from the PNSS.

STATE-BASED APPLICATIONS

Although the previous analyses were carried out on systemwide data, state personnel can perform similar investigations by using state-specific data. PNSS data can be useful in needs assessments, program planning, patient care, quality assurance, and program evaluations. State-specific information summaries can be used in needs assessments to target populations and geographical areas of highest risk for LBW. PNSS information can be used to target objectives for planning programs or for developing a state health plan. For assisting in patient care, PNSS risk factor information can indicate subject areas in which to train clinic staff members so they can be responsive to client needs. The PNSS is also useful for quality assurance. Program staff can examine the data for incompleteness and recording errors and determine the reliability of client measurements, such as height, weight, and hematocrit. More importantly, the PNSS can be used in program evaluations to measure both program successes and failures. Many states, such as Georgia and New Hampshire, use PNSS data in nutrition newsletters, or in published annual summaries, as is done in Florida.

To emphasize further the state-based importance of the PNSS, the Division of Nutrition, which coordinates the PNSS, is readying plans to develop a microcomputer version of its mainframe computer software that manages PNSS data. This software, which will be available in 1991, will provide agencies with immediate and flexible access to their PNSS data using microcomputers. It should also provide better opportunities for linking PNSS data with state-based vital statistics data so that relationships between prenatal care and birth outcomes can be further examined.

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TABLE 1

COMPOSITION OF THE 1987 PNSS FROM 16 STATES THAT SUBMITTED 88,000 RECORDS

Age composition		Race/ethnic composition	
<20 years	30.0%	White	55.3%
20-24 years	36.8%	Black	32.4%
25-29 years	21.0%	Hispanic	10.9%
30-34 years	8.8%	Native American/Asian	1.4%
>34 years	3.4%		

Figure 1

Smoking Prevalence
by Race and Age

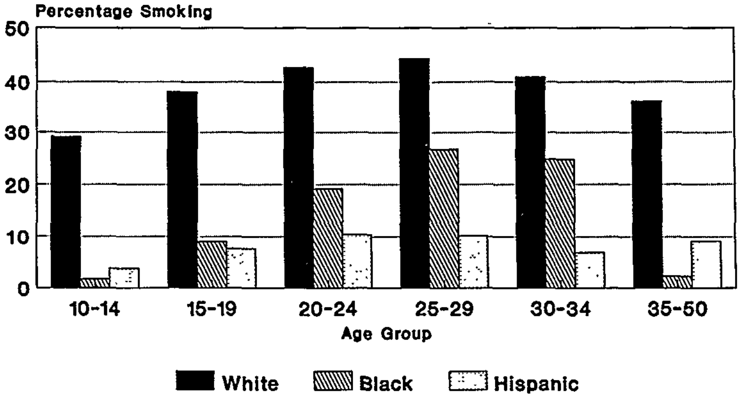
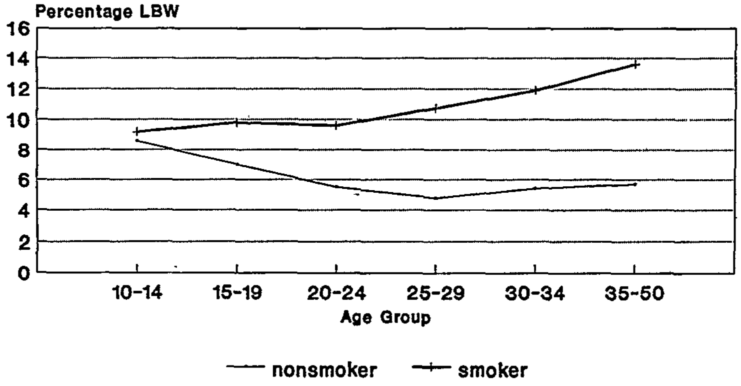


Figure 2

Low Birth Weight
by Smoking Status and Age



DEVELOPMENT OF STATE CHRONIC DISEASE SURVEILLANCE SYSTEMS

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INTRODUCTION

In recent years the public health community and the American public in general have shown increasing interest in ways to reduce mortality and morbidity from chronic illnesses--those diseases characterized by long induction periods, prolonged clinical course, no known cure, and debilitating manifestations. This important development in public health is hardly surprising, coming as it has at a time when acute infectious diseases account for only a small portion of all adult mortality.

In response to this development many state and local health departments are positioning themselves for prevention by hiring chronic disease specialists, by establishing special units devoted to chronic disease, or by setting up programs designed to reduce the burden of these diseases. However, progress is often impeded by an absence of information about the magnitude and distribution of chronic health problems in their particular state.

What is needed are disease surveillance systems that estimate both disease frequency and mortality, are accessible to those in greatest need of the information, and can be used to identify emerging health problems and help direct scarce public health resources.

This paper summarizes work under way in two states, Maine and California, to develop chronic and sentinel disease surveillance systems. Although the focus of this session is on evaluation, we believe the establishment of surveillance systems is an important step toward achieving effective program evaluation. In fact, we see surveillance and evaluation as two of the cornerstones of any integrated public health program aimed at improving the health of the population. When fully operational, the surveillance systems being developed will help to isolate health problems and identify potential interventions by generating hypotheses about the causes of disease patterns. They then may be used to evaluate those intervention programs, by documenting changes in the level of disease occurrence, associated costs or risk factors.

These two projects, the California Chronic and Sentinel Disease Surveillance Program and the Maine Chronic and Sentinel Disease Surveillance Project, are managed by state health departments and affiliated state agencies with financial and technical assistance from the Agency for Toxic Substances and Disease Register (ATSDR) and the Centers for Disease Control.

We will briefly examine some characteristics of the systems under development, and present some preliminary results. We examine process as well as results here because the systems are still under development, and because we believe many readers have or will consider in the future some of the same process issues considered by these two states.

SELECTION OF DISEASE GROUPS

Typically a surveillance system is established to monitor one particular disease such as diabetes or a set of related diseases such as malignant neoplasms. However, we are interested in monitoring a number of chronic diseases--the major killers and disablers in this country--along with sentinel diseases--those illnesses, often rare, that may serve as a warning of possible exposure to an environmental contaminant. Recognizing that few health systems have the capacity to immediately integrate data for a complete set of chronic and sentinel diseases, the state investigators worked with CDC to develop a list that would include diseases of particular relevance to their state,as well as some that have national priority because of their prevalence and potential for intervention.

Maine and California went about the task of developing a disease list in slightly different ways. In Maine, the project staff assembled a list of diseases with the goal of developing a pilot chronic disease surveillance system with an environmental focus (Figure 1). Some of the 34 disease groups were chosen because of potential association with exposure to Maine's hazardous waste sites or industrial facilities. The remaining disease groups were chosen because they were of interest to Maine or the Centers for Disease Control.

As seen in Figure 1, the 34 disease groups are organized into four major categories: selected neoplasms; selected pulmonary diseases; selected neurologic disorders; and miscellaneous disorders.

In the case of California, a list of diseases and conditions was developed out of project staff discussion and consultation with our office, but primarily through deliberation of a 25-member task force including epidemiologists, program managers, and representatives of a variety of health organizations. As shown in Figure 2, the California list focuses on four sets of diseases and conditions, selected malignant neoplasms, selected pulmonary conditions, selected cardiovascular diseases, and other conditions including diabetes and hepatic cirrhosis.

The variety in the disease lists used by the two states is apparent. Our approach has given the states the freedom in this initial stage to tailor the project to their own needs, and to provide a laboratory to eventually test the applicability of the available data sets for surveillance. Later, as we continue our work with states and localities to develop national chronic disease surveillance, we hope to implement a standard disease list based, in part, on our work with California and Maine.

DATA SETS

What are the sources of information these systems employ to track these chronic and sentinel diseases? Using official hospital discharge data as the core of the systems, each of the states incorporates mortality data and uses other health information to provide a broader picture of disease patterns.

MAINE. A major objective of the projects is to maximize the use of available health data, and thereby minimize data development costs. In the case of Maine, there are six existing data bases that have statewide coverage and are of relatively high quality. Of these, hospital discharge data, the cancer registry, and mortality data have been brought into the system; birth, fetal death, and linked birth and death records may be brought into the system at a later date.

1. Hospital discharge data-Maine was one of the first states in the country to develop a data base of hospital inpatient records covering all patients discharged from its general hospitals. Included in the data base is information on, most importantly, principal and secondary diagnoses, and on procedures, patient residence, patient disposition, and admission and release date. One attractive feature of this state's hospital discharge data is that it represents a very high proportion of the inpatient care provided to residents of the state. This is because the vast majority of Mainers receive their hospital care within the state.

Two events critical to the development of this system are worth noting here both of which occurred before the surveillance project began. In 1978, the discharge data became accessible to the public following legislation,and then in 1983, Maine's Health Care Finance Commission, was empowered by law to collect a completed discharge abstract for every patient in all Maine hospitals.

Complete coverage, essential information, and access are keys here. It should be noted that according to the National Association of Health Data Organizations, only a minority of states have regular statewide discharge systems, computer based with principal and other diagnoses, that are available to the public.

2. Cancer Registry-Maine's cancer registry, begun in 1983, is primarily an incidence reporting system.

3. Mortality data-Death records are processed by the Office of Data, Research, and Vital Statistics, in the Maine Department of Human Services. In 1985, Maine had a total of 11,400 resident deaths. The Maine computerized death record contains both underlying and all other causes of death.

Maine's chronic disease surveillance system attempts to bring together applicable data from all three sources for the set of 34 diseases and conditions on an annual basis, and provide case counts and rates for the state, the 16 counties, and 66 health planning areas. Important aspects of the system as it is now constituted include:

1. Frequencies based on all mentions of the disease of interest-For hospitalizations, counts based on principal and all secondary diagnoses, and for deaths, all listed causes.

2. Unduplicated counts of hospitalizations-As a first step toward estimating prevalence from discharge data for a particular period, it is necessary to separate readmissions for the same individual from first admissions for the same disease or condition (that is an unduplicated count). In Maine, this is accomplished by a matching protocol using personal characteristics, such as birthdate, sex, town of residence, and dates of admission and discharge to estimate probable first- visits. It is important to note that in the absence of a universal identification code, such as a social security number or a unique state-wide hospital code, these can only be regarded as estimates.

3. Unduplicated system estimates-The Maine system also estimates an unduplicated case count for all three data bases by matching, through the same procedure indicated before, on personal characteristics across the three data bases. This measure is the frequency with which a case appeared in any of the three systems within a specified time period. For example, if an individual was diagnosed as having lung cancer and was picked up on the cancer registry, was hospitalized several times during the year, and died in that same year, the system has the ability to unduplicate these events (with high probability) and produce a system prevalence count of 1.

4. Computation of age-adjusted rates-Frequency rates are computed for the state, counties and health areas each year using annual population estimates provided for these entities by the Office of Data, Research, and Vital Statistics

CALIFORNIA. California has a wealth of data to draw from in the development of their chronic disease surveillance system. At the core of the system are the statewide hospital discharge and the mortality data sets.

The California data sets provide information on multiple diagnoses and multiple causes of death. Complete statewide coverage of hospital discharges has been in existence since 1983; in that year there were roughly 3.5 million discharge abstracts recorded.

Unique to California's system is the inclusion of information from the Human Population Laboratory, a widely respected research facility within the California Department of Health Services that over the years has conducted a number of field surveys measuring the health status of residents in Alameda County. Although HPL does not provide annual data to be used for surveillance purposes, its investigations allow for a broader understanding of the health status of this urban community, and the interrelationships among the various physical, social, and psychological factors influencing health status.

In the past year, California has initiated analyses of death and hospitalization rates for a subset of chronic diseases for 1985 and will continue surveillance for the following years to examine temporal trends of disease. Rates by race and ethnicity are computed, as are county level rates. The California project is planning for geographic analyses at even smaller levels involving, for example, the monitoring of disease rates in census tracts or zip code areas adjacent to environmental hazards. At present, one major difference in the hospital discharge rates in California, as compared with those in Maine, is that they are duplicated counts; that is, there may be more than one hospitalization for a patient during the year, and it's not possible to distinguish which patients have had multiple hospitalization. Recently, however, legislation has been enacted which will allow for a unique personal identifier--the social security number--to be included in the discharge file. This will facilitate the separation of initial from recurrent hospitalizations in the data set within the coming years.

RESULTS

We view the various data components of a surveillance system as fitting into a public health model that starts with estimates of disease occurrence in the community and leads through various phases to the identification of associated risk factors. In otherwords, surveillance leads to identification of high risk groups and the focussing of analytic studies to elucidate risk factors for the disease under surveillance. These two components are followed, ideally, by intervention efforts in a population to reduce these risk factors and the associated diseases, and then by evaluation to assess the effectiveness of these interventions.

Thus, eventually the success of these systems will depend upon how effective they are in identifying public health problems and evaluating programs designed to ameliorate these problems. Some preliminary results from these projects may provide early evidence of the potential these systems have for fulfilling the expectations of the public health model.

Maine. A number of pulmonary diseases were included in Maine's disease list because of interest in air quality and its effect on the health of citizens. Also, there is considerable interest in the state in the potential adverse health effects of poor air quality in several industrial areas.

One unpublished study done before the surveillance system was established found that there were higher rates of hospitalizations for asthma in selected mill towns than in a set of control towns; however, the study was unable to separate hospital readmissions from first admissions, something that can now be done.

It also should be noted that an analysis of underlying cause of death by state for the period 1979-81, by NCHS, showed that Maine had one of the highest death rates in the country for chronic obstructive pulmonary disease. Clearly there is reason for concern here.

As noted above, the Maine surveillance system collects mortality and morbidity data for a set of pulmonary diseases, specifically bronchitis, chronic bronchitis, emphysema, and asthma. Rates are computed each year, and may be combined across years, and plotted on maps.

Preliminary analysis of data for the period 1983-85 shows that the prevalence of these diseases as measured by the unduplicated system count varies across county and health planning areas. A group of communities mostly in the center of the state had system prevalence rates for two or more of these diseases that were significantly higher than those for the state as a whole for the combined three-year period and for two or more of the component years.

Of course, more analysis needs to be done. In addition to further statistical evaluation, state analysts will launch followup activities including an examination of geographical variation in diagnoses and admission practices, environmental assessment of these areas, and possibly case control studies. However, the important point to note here is that this surveillance system, which is still in a developmental stage, has sounded an alarm and precipitated further investigation.

California. We believe that an important aspect of surveillance involves not only the charting of disease trends but also assessment of disease burden and its related costs. We provide an example of how the California project has been able to incorporate data from the surveillance system along with cost estimates to determine the impact of a major risk factor, smoking, on the health and welfare of California residents, to present these results in a public forum, and to assist in directing intervention efforts.

The CCSDSP project estimated the number of smoking attributable deaths in 1985 for 24 underlying causes of death and the number of years of potential life lost to age 80 (1). These were derived from U.S. prevalence estimates on current and former smokers and nonsmokers and estimates of the relative risk of mortality for these groups. The same proportions were then applied to 1985 California hospital discharge data to estimate the number of smoking attributable hospitalizations and their cost.

More than 31,000 deaths in California in 1985 were attributed to smoking, roughly 16 percent of all deaths. Of these, roughly 30 percent were from lung cancer, 24 percent from respiratory diseases, and about 22 percent from heart disease.

This mortality may be characterized in terms of potential years of life lost, a measure of premature mortality. Results show that approximately 310,000 years of potential life were lost in California due to smoking, with lung cancer accounting for the most years of life lost.

Additional estimates were made of discharges attributable to smoking. Project investigators concluded that roughly 14 percent of all non-pregnancy related hospitalizations among adults were due to smoking; and of these more than 40 percent were for respiratory diseases.

Finally, the group estimated that hospitalizations and other medical expenses due to smoking cost California residents $4.1 billion in 1985 alone. Of the $2.3 billion estimated for hospital care, roughly 77 percent, about $1.8 billion, was paid from public funds. The estimate of total burden, that is direct medical costs, lost productivity due to illness and disability,and lost future earnings due to premature death was over $7 billion for 1985.

CONCLUSION

Surveillance is the monitoring of disease and related events in persons, places and over time. The patterns revealed often can help us identify high-risk groups, geographically correlated environmental and lifestyle exposures, and temporal trends.

The states involved in this collaborative effort are extending this essential person, place, time basis of surveillance to explore health patterns in their populations, and have begun to integrate important sources of data to implement comprehensive surveillance systems, and to look at these data in innovative ways.

In summary, we believe there are several important aspects of the systems being established in Maine and California that need to be emphasized.

1. These systems use existing data to present as complete a picture as possible about the mortality, morbidity, and burden from a set of chronic and sentinel diseases. Using available data reduces the cost of the program.
2. These are ongoing systems whose value will increase as a temporal baseline is established.
3. These are systems to be used; They are "data dressed in working pants", if you will, and the worth of these projects will be established when they are part of a public health process that has as its endpoint the reduction of premature mortality and morbidity.

ACKNOWLEDGEMENT

This report was supported in part by funds from the Comprehensive Environmental Response, Compensation, and Liability Act trust fund through an interagency agreement with the Agency for Toxic Substances and Disease Registry, U.S. Public Health Service, Department of Health and Human Services.

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Figure 1. Maine Chronic and Sentinel Disease List

Selected Malignant Neoplasms

Hemangiosarcoma of the liver
Lymphoma - Hodgkins
Lymphoma - non-Hodgkins
Leukemia - Total & components
Bladder
Kidney
Oropharynx
Nasopharynx
Hypopharynx
Ovary
Brain
Lung
Pleura
Breast
Cervix

Selected Pulmonary Diseases

Bronchitis
Chronic Bronchitis
Emphysema
Asthma
Extrinsic Allergic Alveolitis
Pneumoconiosis & other lung diseases due to external agents

Selected Neurologic Disorders

Toxic Encephalitis
Peripheral Neuropathy
Multiple Sclerosis

Miscellaneous Disorders

Systemic Sclerosis
Aplastic Anemia, other & unspecified
Agranulocytosis or Neutropenia
Toxic Effects of Lead & its components

Figure 2. California Chronic and Sentinel Disease List

Selected Malignant Neoplasms

- Lung, Trachea, Bronchus
- Female Breast
- Cervical
- Liver
- Leukemia

Selected Pulmonary Conditions

- Chronic Obstructive Pulmonary Disease
- Pneumoconiosis & other lung diseases due to external agents

Selected Cardiovascular Diseases

- Ischemic Heart Disease
- Hypertension
- Stroke

Other Conditions

- Diabetes
- Hepatic Cirrhosis

Session K

Linked Files

PHCRS

BUILDING A LINKED HOSPITAL DISCHARGE RECORD DATABASE TO SERVE AS A LONGITUDINAL HOSPITALIZATION HISTORY FOR INDIVIDUALS WITH ASTHMA IN NEW YORK STATE

Gerald I. Kaufman, Ph.D.
New York State Department of Health
Lisa Zeitel, Willine Carr, and Kevin Weiss

(Not available for publication)

LINKING NURSING HOME PATIENT, DEATH CERTIFICATE AND MEDICAID FILES FOR STATE LONG TERM CARE POLICY MAKING

Christine Pattee, Connecticut Department of Health Services

Connecticut is one of a small number of states with an operational data collection system on all nursing home patients, private and public pay. The Department of Health Services (DHS) has gathered these data consistently and entered them in a computer file since 1977. Because we follow patients by name from year to year and facility to facility, it is possible to trace patterns for individual patients from first admission to any SNF or ICF in Connecticut, through discharge and readmission to other facilities or the community, until final discharge. Complete or "true" length of stay can be measured and, it is possible to study complete admission cohorts of both short staying and long staying patients.

Because we could distinguish an individual's first admission from subsequent readmissions, we were able to accurately track new admissions to Connecticut nursing homes over time. (Chart 1) The patient census count per 1,000 elderly on the last day of each reporting year is going down slightly, reflecting the slight decrease in Connecticut in beds available for the growing elderly population. There was a substantial decrease in the absolute numbers in nursing home admissions among people 65 and over. This finding confirmed the effectiveness of Connecticut's "de facto" nursing home construction moratorium in the early eighties.

This longitudinal, complete admissions cohort of nursing home patients over a very long period of time, was of great interest to a Connecticut project titled "The Governor's Task Force on Public/Private Financing of Long Term Care for the Elderly". This Task Force developed into a Robert Wood Johnson Foundation - funded long term care insurance demonstration project titled "The Connecticut Partnership for Long Term Care". This project is directed by the Governor's executive office and the Health Department is the primary source of data.

Under the impetus of these projects, we were able to match the entire nursing home patient file with Health Department death certificates in order to determine the true final outcome of nursing home stays. We also matched this combined nursing home patient/death certificate file with Department of Income Maintenance Medicaid eligibility and convalescent files. With these linkages, Connecticut has an extraordinarily complete picture of the institutional and financing histories of all nursing home patients. The nursing home linkage was completed first, and these data have already been used by the insurance industry to determine their long term care insurance benefit and coverage packages, and by the Department of Income Maintenance to project utilization levels for their Preadmission Screening Program.

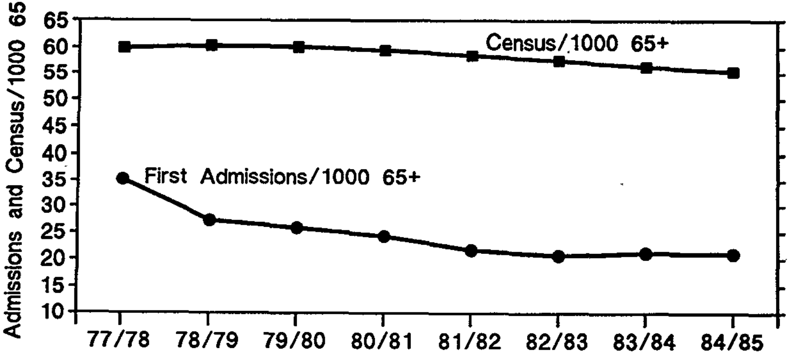
In this session, I want to talk briefly about the mechanics of these linkages and give you some idea of our findings, although the file is so large and so complex that we have just begun analyzing it.

This patient specific data system got started in the early 1970s when health planners wanted to know where nursing home patients came from in order to do small area bed need planning. There was no original intent to maintain a registry of patients. Names were included simply to prevent duplication and maintain quality control of the records. Data was collected annually and we instructed nursing homes to add a new line on the report form for each patient admission, whether or not it was a readmission. Once readmission records were linked, we found that 46%, almost half of all patients, had from 2-16 readmissions, and 19%, one out of five, of all patients entered two or more facilities.

In order to remove the effect of readmissions, and to accurately measure length of stay from date of first admission to date of final discharge, we began the process of linking records across years and across facilities within the Health Department's nursing home file. In practice, this linkage of successive records for individual patients was accomplished by sorting on the basis of an individual's full name and then using SAS "first dot" and "last dot" functions to associate records for the same person. This method required that each individual's name be spelled exactly the same way on each record, and that similarly named individuals be distinguished. We had 14 Carl Andersons, distinguished by a numeric suffix in the middle initial position. This involved many, many months of person hours in which staff and temporary clerical help literally read through all 400,000 patient records to

Chart 1

Rates of First Admissions and Patient Census for Population 65+, Connecticut Nursing Homes RY 1977-78 through 1984-85



correct misspellings.

To further facilitate the matching process, we also developed some computer edits to kick out potential error conditions. We have added social security number to next year's report form, but it may not be be as helpful as anticipated because of confusion between a woman's social security number and her Medicare number, which is usually her husband's social security number. In any case, once all of the names were spelled accurately, the corrections were keyed into the master file. All of these procedures are described in detail in two publications - Connecticut's first report on the longitudinal file and our most recent annual data book.

The second matching task was to link the Health Department's nursing home patient file, over 120,000 individuals, with the Health Department's death certificate file. This was a true one-to one-computer linkage of two different records for the same person. This again was a complex task in which we had only names, and birth year, sex, and dates of admission and discharge to use for parameters in a series of five matching cycles. Fortunately, about 80% of all matches were "automatic" in which one nursing home record matched with one death record without need for further review. The remaining cycles required human input to choose among possible matches. We matched by taking one year of nursing home discharges against two years of death certificate data, the year concurrent with the nursing home discharges and a full year following the last discharge. This made the computer files more manageable, but was done primarily because we felt it was more accurate to associate deaths with nursing home stays within a limited time.

Chart 2 shows the final destination of all discharges from Connecticut nursing homes between 1977 and 1985. A little over half of the discharges are individuals who died in the nursing home. Nineteen percent were discharged to a general hospital and 18% were discharged home.

Incidentally, the linkage of multiple records for the same person made a dramatic difference in the apparent pattern of where people were discharged. In our annual nursing home data books, where we were unable to distinguish a final discharge from an interim discharge, 75% of all discharges were to a hospital.

Chart 3 shows the nursing home/death certificate match rate for each of these discharge statuses. This summarizes the success rate of matching records and the true final outcome of nursing home discharges. As expected, 96% of the individuals reported by the nursing home as discharged dead, were matched. Of those individuals discharged to a general hospital, 76% died within a maximum of two years after their discharge from a nursing home. What I find most encouraging is that of the people discharged home, only 22% died within the next year or two.

The final matching task was to link, again using name only, the nursing home/ death matched file from the Health Department with Department of Income Maintenance (DIM) Medicaid files. Medicaid systems are maintained for purposes of client identification and payment, not for research. Furthermore, DIM's programming resources were extremely limited so there was only one round of computer matching. There was a manual effort to look up names coded to Medicaid in DHS records which did not match with DIM records. For example, 78% of the patients whose final payment status was coded to Medicaid by the Health Department. were matched automatically with Medicaid records. The remaining 22% were manually matched, (Chart 4) for a final match rate of 98%. The Health Department files for this match ended in September 1985, but the Department of Income Maintenance files were current through

Chart 2:

Final Destination of Patients
Discharged from CT Nursing Homes 1977-85

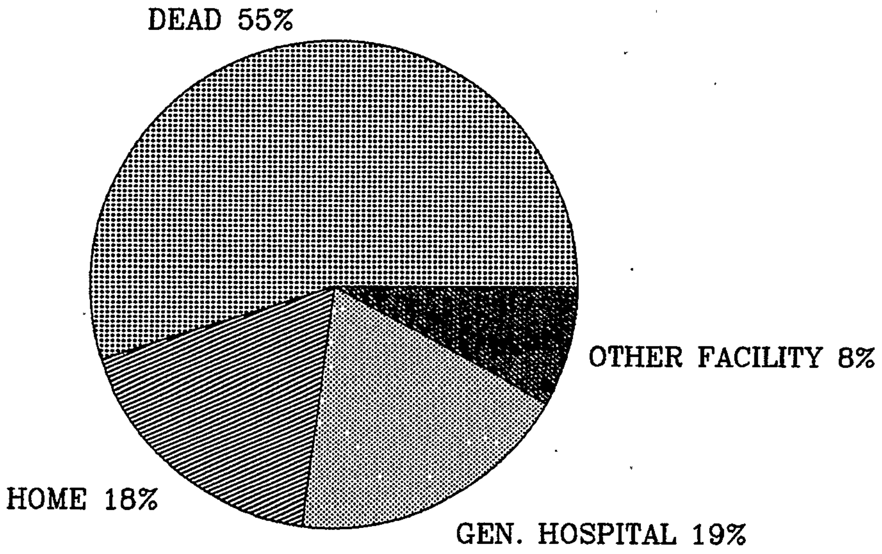


Chart 3:

Match Rate for CT Nursing Home Patients With Death Certificate Within 1-2 Years

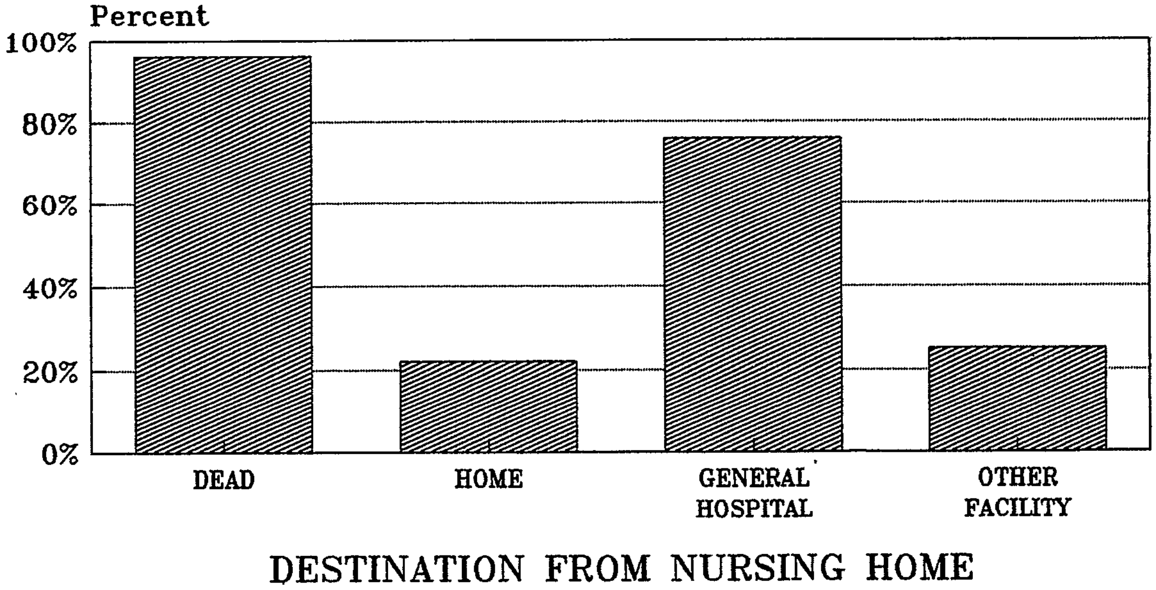
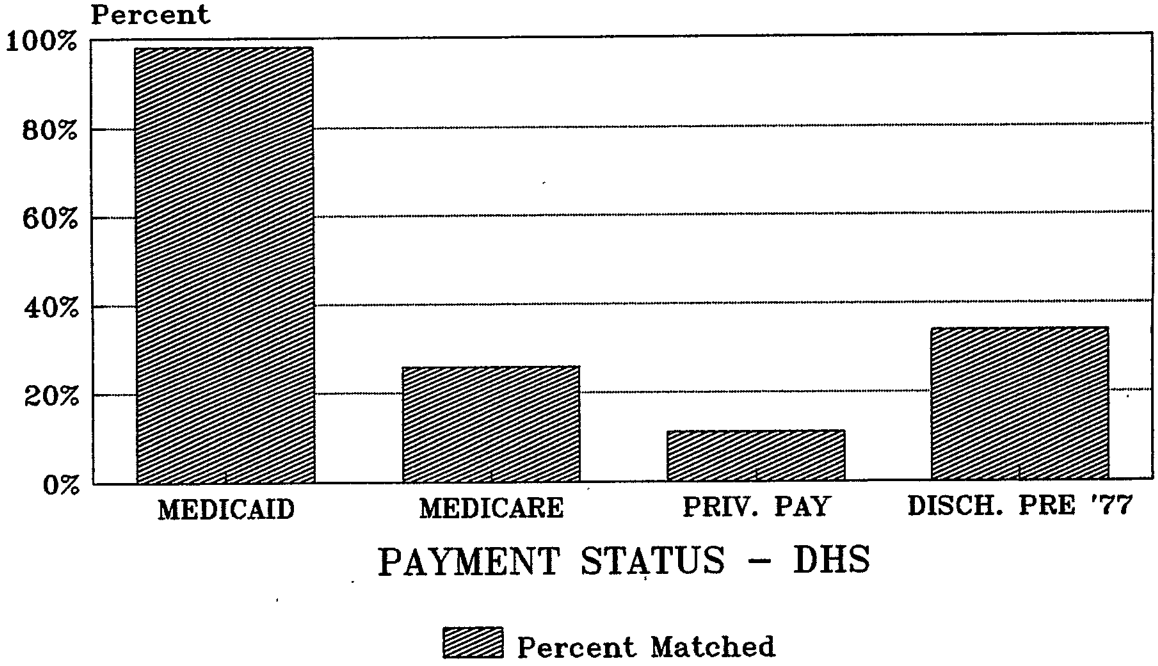


Chart 4:

Match Rate - CT Nursing Home Patients With Medicaid Eligibility Files, 1977-85



September 1988. Therefore, patients had about three years to become Medicaid eligible after Health Department reporting ended.

Of all admissions to a Connecticut nursing home (Chart 5), 54% remained private paying throughout their stay, i.e. never became Medicaid eligible at all. Surprisingly, over a quarter of all admissions, 29%, were eligible for Medicaid immediately at entrance to a nursing home. These individuals never had an opportunity to spend down, and this group will probably be of major interest to state budget planners. Of all admissions, only 17% "spent down", that is, were private pay on admission to a nursing home but spent down their assets and went on Medicaid before discharge.

We're still working on this analysis, but as expected, there was a definite difference in the lengths of stay of these groups. Length of stay for the always-private-pay group was about 400 days, whereas the Medicaid eligible groups had a much longer length of stay of about 1,800 days. We plan to look much more closely at the 29% of immediately-Medicaid-eligible cases, which we are able to do because we have dates of Medicaid eligibility on the file. Some of these people have been on SSI or other Medicaid eligible programs for many years, indicating they are the long time poor. However, individuals whose first Medicaid eligibility date is close to the date of first nursing home admission have probably either spent down their assets in the community immediately prior to nursing home admission, or else they are among the hard-to-identify group of people who may have transferred their assets in order to become eligible for Medicaid. Korbin Liu (personal communication) has also identified another subgroup of the immediately-Medicaid-eligible, those whose income was enough to maintain them at home, but not to pay for nursing home care, so they become Medicaid eligible as soon as they enter a nursing home.

The data books described are:

1. Longitudinal Study of Connecticut Nursing Home Patients 1977-1985, Part 1, Methodology and Tables.
2. Connecticut Nursing Home Data Book, 1986-87 - contains description of data collection instruments and detailed tables describing patient characteristics for each nursing home in Connecticut.

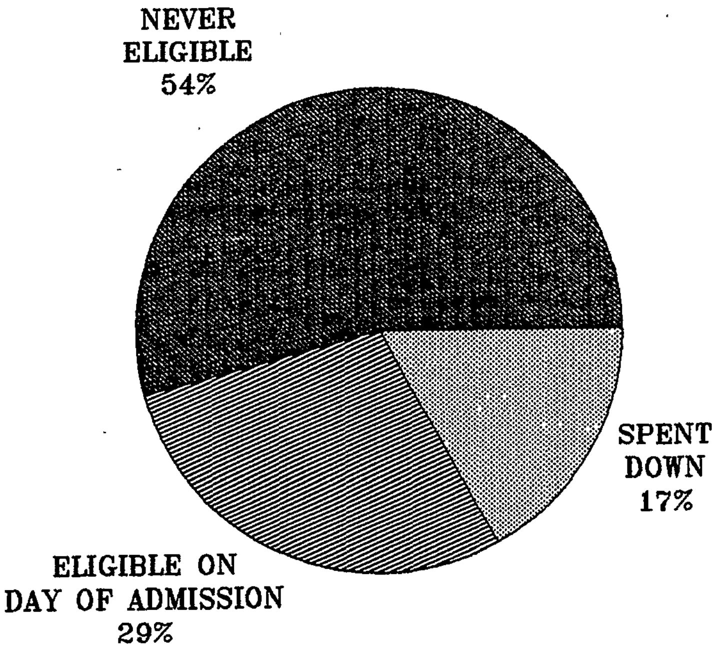
Each book is $20 (free to other health departments).

Please make checks out to "Department of Health Services". Requests should be addressed to:

Dr. Christine Pattee
Department of Health Services
150 Washington Street
Hartford, CT 06106
(203) 566-3729

Chart 5:

Medicaid Eligibility Status of CT Nursing Home Patients, 1977-85



OBSTETRICAL OUTCOMES - THE USES OF DATA LINKAGES MEDICAID - VITAL RECORDS

Gretchen A. Brown, Health Care Financing Administration

Policy interest in the maternal and child health area has increased substantially in recent years. The Bush Administration has made the improvement of health services to two of our nation's most vulnerable populations, low-income pregnant women and infants, a top health care priority. Similarly, Congress and a number of State legislatures have introduced legislation indicating that additional policies addressing issues related to these populations will most likely be taken.

This interest and the legislative and programmatic changes that result from this interest create a need for the development of methodologies by which the impact, outcome and effectiveness of Medicaid eligibility, service or coverage changes can be assessed and evaluated. One method of assessing these impacts is through outcome analyses.

In this paper, methods, issues and analytic benefits of an outcome analysis of Medicaid services to pregnant women and their infants in California will be reviewed. The analysis was conducted by the Health Care Financing Administration's (HCFA) Office of Research at HCFA. The study illustrates two important points: (1) the usefulness of Medicaid administrative claims data for analyzing issues related to services received by pregnant women and their infants and (2) how data linkages between Medicaid administrative data and other sources providing services to these populations can expand and enhance our understanding of the dynamics of these populations and the impact of public health programs on delivery outcome and subsequent health status.

The contents of Medicaid administrative claims and vital record files provide valuable insight into the care and outcomes of care experienced by pregnant women and their infants. Medicaid data provide information on Medicaid charges, payments, service utilization, provider type, diagnoses (primary and secondary) and procedures. Little information, however, is available that can be used as proxies for health outcome. Alternatively, vital records data include information, such as birthweight, gestational age, presence of congenital anomalies and malformations, onset of prenatal care and number of prenatal care visits, that can be used as indicators of birth outcome. The integration of Medicaid and vital record files allows a wider range of analytic outcome-oriented studies for these populations.

This study involved two main components. The first was the development of an analytic file from Medicaid claims data. This analytic file made analysis of Medicaid service use and related expenditures possible. Medicaid administrative claims data is not routinely structured in a manner that facilitates the analysis of obstetrical-related issues. Prior to pursuing any linkages, it was necessary to extract Medicaid information related to prenatal, delivery and post-delivery care. The second was the actual linkage with vital record files.

Medicaid data was obtained for the month of October 1983 from HCFA's Tape-to-Tape project. The Tape-to-Tape project collects Medicaid claims data from State Medicaid Management Information Systems. This data is then restructured into a uniform file format allowing cross-State comparisons. Data is available from California, Georgia, Michigan and Tennessee for the years 1980-86. New York data is available from 1980-84. Due to the availability of vital records data, California was the only State used for this particular analysis. An initial extracting of October 1983 deliveries resulted in pulling 8,503 deliveries. Locating these deliveries in the Medicaid claims file involved: (1) identifying Medicaid-financed deliveries using hospital diagnostic codes and (2) identifying pairs of mothers and infants. It was necessary to identify unique pairs of mothers and infants because in some instances, mothers and infants are on the same claim while in others, they are on different claims. And (3) extracting all claims for those mothers and infants for a 22-month study period. These 22-months were divided into three analytic periods: the prenatal, delivery and post-delivery. After cases that did not result in actual deliveries, such as false labors, 8,194 Medicaid-financed deliveries remained in the study group.

This portion of the study was important in that it tested our methodology for extracting data related to pregnant women and infants from Medicaid administrative claims data; provided descriptive statistics on Medicaid prenatal, delivery and post-delivery care not previously available from the Tape-to-Tape project; and developed a baseline from which to perform subsequent analyses in this area.

Acquisition of vital records data was the next step. Utilizing vital records in analyses such as this raise important issues related to the privacy and confidentiality of information included in the vital records files. State concerns for allowing access to vital record data are understandably rigid. These concerns include assuring that the confidentiality and privacy of individually identifiable information is maintained, limiting unauthorized access to and disclosure of data, assuring that data is used for the purpose for which approval was granted only and obtaining adequate reimbursement to the States.

For this study, a proposal was submitted to the California Office of Statewide Health Planning and Development's Committee for the Protection of Human Subject's and the State's Vital Statistics Advisory Committee. An agreement was made with the State for access to their 1983 birth and death cohort file. Access was granted for research purposes only.

Figure 1 outlines the process by which Medicaid and non-Medicaid births were excluded and matched for the study. There were 37,595 live births and fetal deaths in the file for October 1983. All fetal deaths were excluded from these to allow for a homogeneous (all live births) group of deliveries for analysis. Also excluded were all multiple births and all out-of-state or unknown residence births. Births in Santa Barbara and Monterey Counties were also excluded because Medicaid claims data were not available for those counties. With these exclusions, 35,322 live births remained in the study group.

The Medicaid and vital record files were then linked. The criteria used for matching consisted of matching mother and infant's first and last names and infant date of birth on each of the files. This resulted in an exact match of approximately 50 percent of the files. The next criteria involved matching the files using the soundex of the mother and infant's first and last names. This procedure matched 25 percent more of the files. This approach involves modifying names in limited ways, such as removing vowels, which improve name matching without increasing incorrect matches. The remaining 25 percent were linked using a combination of strategies. These included modifications of the first and last names and a two-day either way relaxation of the infant's date of birth. In cases where two certificates were found for one Medicaid delivery, we performed an additional match on the mother's exact age. Matches were validated by checking for other corresponding information on Medicaid and vital records files.

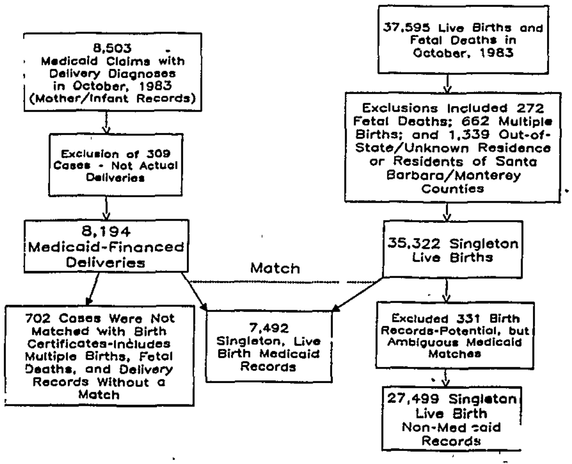
Overall, the matching was quite successful. In the end, 7,492 singleton live births were matched to Medicaid delivery records. While pairs of Medicaid and non-Medicaid births would have been preferred. Due to the relatively small sample size (October births only) this was not possible. This matching process produced a match rate of 91.4 percent. The literature describes other studies that have achieved 90-95 percent match rates using variables such as name, date and place of birth.

An important by-product of this match was the production of a file of non-Medicaid birth certificates. This file will be used to provide a comparison group of Medicaid to non-Medicaid deliveries. Comparisons will be made in terms of outcome indicators such as infant birthweight, gestational age, complications of labor and delivery, onset of prenatal care and demographic information.

In conclusion, linkages between Medicaid and vital records files can produce useful information on the outcomes of delivery and the effectiveness of Medicaid-funded prenatal care in preventing adverse delivery outcomes. Such linkages can also assist in evaluations of the impacts of the recent Medicaid eligibility expansions on improving infant mortality and morbidity. Policy questions that could be addressed through such linkages include how Medicaid and non-Medicaid populations vary in terms of delivery outcomes and receipt of prenatal services and when do women whose deliveries are funded by Medicaid begin to receive prenatal care and how does this vary from non-Medicaid populations. The integration of linkages with other program data, such as WIC, Title V block grant-funded programs and the National Maternal and Infant Health Survey, may further expand our knowledge of the dynamics of public health services on these populations.

Figure 1

Process of Identifying Medicaid and Non-Medicaid Singleton Live Births, California (Excluding Santa Barbara and Monterey Counties), October, 1983



VALIDATION OF RECORD LINKAGE TO 2 CALIFORNIA POPULATION-BASED TUMOR REGISTRIES IN A COHORT STUDY

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INTRODUCTION

The Adventist Health Study (AHS) is a prospective cohort study of 34,198 non-Hispanic white Seventh-day Adventists (SDAs) followed for 6 years (1977-1982) for cancer incidence and all cause mortality (1). These study subjects were all California residents at the time the study began in August, 1974.

Previous reports (1-3) have documented lower age-adjusted sex-specific mortality rates for cancer, cardiovascular disease, and several other chronic diseases among SDAs when compared to either the total United States white population or to a comparable population of nonsmoking whites living in California.

The primary aim of the AHS is to relate diet and other lifestyle characteristics to long-term (10-15 years) site-specific risk of cancer among the study population. During 1973 through 1988, the study has been funded by the National Cancer Institute.

SELF-REPORTING OF HOSPITALIZATIONS

A previous report (1) contains the flow chart of the overall study plan for the AHS. This report refers only to the Incidence Population portion of the larger study. The baseline questionnaire included demographic variables, information of current and past dietary habits, exercise patterns, use of prescription drugs, use of alcohol and tobacco, measures of religiosity, occupation and residential histories, anthropometric data, and menstrual and reproductive histories.

The primary procedure utilized in the effort to monitor cancer incidence in the AHS involved the completion of annual hospital history forms by the study subjects. After collection of baseline exposure data in the Fall of 1976, each member of the Incidence Population received a mailed annual hospital history form beginning in 1977. This form requested participants to record whether they experienced an overnight hospitalization in the appropriate period since last contact and, if so, to provide the name and address of the hospital, and dates of last discharge. They were then requested to sign a consent for the AHS to review these medical records.

Annual mailings of hospital history forms took place between 1977 and 1983. At the close of the study on January 1, 1983, only 1095 subjects (3.2%) had refused to respond to these annual hospital history forms. During the six years of follow-up, 18,053 individuals had reported a total of 32,451 hospitalizations representing 27,929 separate hospital charts in 1658 different hospitals. Many individuals reported multiple admissions for a given hospital.

The AHS sought endorsement from the California Hospital Association as a bona fide research project. This endorsement of the need for the AHS to review medical records for cancer was relayed to each of the California hospitals via the weekly newsletter published by the Association (4).

As members of the Incidence Population began reporting hospitalizations to the AHS, the field operation component of the AHS came into existence. This was responsible for contacting the hospitals reported by study members and sending trained AHS field representatives to these hospitals to review and microfilm pertinent sections of the relevant medical records.

CONFIDENTIALITY AND HUMAN SUBJECTS CONSIDERATIONS

Since 1973, all study procedures and forms have been annually reviewed and approved by the Loma Linda University Human Subjects Committee. All names of subjects were deleted from the copies of the tumor abstract forms obtained from the two tumor registries. The only unique identifier recorded on these forms was the ID number for the Adventist Health Study. Furthermore, these copies were filed separately from the Census Questionnaire (1974) and the annual follow-up forms, which are the only AHS forms that contain names of study subjects.

As a second step the AHS approached the California law partnership of Musick, Peeler & Garrett for a legal opinion regarding whether hospitals' Medical Records Custodians may release patient identifiable information in connection with the Adventist Health Study research project, when there is no patient authorization for the disclosure. The firm concluded that "California law and general federal and national standards of confidentiality permit the disclosures that are requested and, based upon our review of the safeguards provided by this research team for the confidentiality of the data, we have concluded that hospitals should be encouraged to provide the requested information. . . Releasing the requested records in connection with this study [AHS] is lawful, even if there is no patient authorization. In this regard, the California Confidentiality of Medical Information Act, Civil Code Section 56 et seq., provides that hospitals may release patient identifiable medical information to clinical investigators for bona fide research purposes without having any patient authorization. Specifically, Civil Code Section 56.10.c.7 provides that a health care provider does not need patient authorization and may disclose medical information. . ." (5-6).

The AHS followed the code of federal regulations for the protection of human subjects as set forth by the Department of Health and Human Services, the National Institutes of Health, and the Office for Protection from Research Risks (7). These regulations implement the amendments to the National Research Act, Public Law 93-348, July 12, 1974. Ethical principles and guidelines for the protection of human subjects of research ("The Belmont Report") was also followed by the AHS (8).

Epidemiology has made major contributions to the understanding of the etiology of disease through the implementation of studies in which medical records of large populations were used. Gordis and Gold have identified many studies of cancer, cardiovascular disease, infectious diseases and child health where medical record review was an important part of the research (9).

COMPUTER-ASSISTED RECORD LINKAGE

Assembly Bill 136 (September, 1985) made cancer a reportable disease in the state of California. Section 211.3 of the Health and Safety Code states: "The director shall establish a statewide system for the collection of information determining the incidence of cancer, using population-based tumor registries. . . By July 1, 1990, the statewide cancer reporting system shall be fully operational." The state has been divided into 10 regions (Figure 1) and Regional Cancer Registries have been funded by the Department of Health Services to process the cancer incidence data within the 10 regions.

In an initial effort to reduce the cost of sending an AHS representative to each of the 698 California hospitals reported by AHS subjects, it was noted that 289 of these California hospitals reported to two population-based tumor registries. (See Regions 8 & 9 on Figure 1).

The Bay Area Tumor Registry (Region 8) represents 1.6% of the area and 13.0% of the population of California. The Los Angeles Tumor Registry (Region 9) represents 2.6% of the area and 30.1% of the population of California. Approximately 23% of the AHS population ever lived in one of these two regional tumor registries compared to 43% of the general California population.

Study subjects who had cancer diagnosed or treated in one of these hospitals located in a population-based tumor registry were identified by computer-assisted record linkage with the centralized records of the two operating tumor registries in California (Resource for Cancer Epidemiology operated by the State Department of Health and Human Services in Oakland, and the Cancer Surveillance Program operated by the University of Southern California in Los Angeles). For cases identified by record linkage, we obtained documentation of the original tumor abstract which was prepared for the tumor registry by hospital staff or tumor registry staff.

This enabled AHS staff to recode and process the cancer information in a comparable way to the information obtained from hospitals that do not report to a centralized population-based tumor registry.

CANCER SURVEILLANCE PROGRAM

Computer-assisted record linkage with this Los Angeles county tumor registry was performed by software written by the author (WLB) and included the following variables: 1) sex, 2) position 1-4 of last name, 3) position 5-8 of last name, 4) position 9-11 of last name, 5) position 1 of first name, 6) position 2-5 of first name, 7) position 6-8 of first name, 8) middle initial, 9) month of birth, 10) day of birth, 11) year of birth (± 5 years), 12) state of birth. Social Security Numbers were not available in the AHS dataset.

The possible matches were resolved by clerical review by AHS staff of ancillary data including the names of spouses and addresses. Validation of a similar process (same algorithm of matching variables) used for the computerized linkage portion of ascertainment of fatal events (2) from California death certificate files indicated that it ascertained 93.2% of known fatal events and there was no evidence that it would not be similar for nonfatal events.

RESOURCE FOR CANCER EPIDEMIOLOGY

Computer-assisted record linkage with the San Francisco-Oakland Metropolitan Statistical Area composed of the five counties surrounding the Bay area was predicated on a pair-wise comparison of the same variables used in the record linkage with the Los Angeles tumor registry. The computer software for linking was adapted from the Fellegi-Sunter record linkage model (10). Each file is blocked by the New York State Identification Information

System (NYSIIS) surname phonetic code which is assigned to each file according to the surname and sex. NYSIIS is a phonetic coding system that incorporates the best features of many phonetic coding systems including Soundex (11). The computer program generates all possible comparison pairs within each NYSIIS and sex block. Minor variations between the items of identification are accounted for in the numerical algorithm which eventually categorizes each link as: 1) not a match, 2) possible match, and 3) definite match. (12) Possible matches were resolved by tumor registry personnel utilizing ancillary data supplied by AHS.

VALIDATION OF RECORD LINKAGE

Prior to the final record linkage between the AHS and the two above mentioned population-based tumor registries one of the authors (GEF) was awarded a grant from the National Heart, Lung and Blood Institute of the National Institutes of Health to evaluate the relation of many lifestyle and psychosocial characteristics to risk of fatal and non-fatal ischemic heart disease (IHD) in this nonsmoking population.

This study with IHD endpoints was an "add-on" to the already funded study of the same population with cancer endpoints. Overall, the cooperative nature of the studies has been beneficial, with the cost of the cardiovascular study being less the 20% that of the cancer study, due to the joint use of resources.

Ascertainment of suspected hospitalized IHD cases necessitated AHS field representatives to visit hospitals in the above mentioned tumor registry areas (in addition to the hospitals not reporting to a tumor registry already being visited to find cancer outcomes) to substantiate IHD diagnoses with ECG data, cardiac enzymes, doctors notes, etc. While the field representative was reviewing the chart for evidences of IHD he or she made notice as to whether the patient had evidence of malignant neoplasm diagnosed during the study period (Lifestyle Questionnaire return date to 12/31/82).

While in the hospital the field representative completed an AHS Discharge Diagnosis Form (DDF) for each hospital record reviewed. This DDF contained 30 disease categories which were checked by the AHS field representatives for diseases occurring one or more times in a given hospital record. Copies of records for study subjects admitted to one of the 960 non-California hospitals were obtained by mail and the DDF was completed by AHS staff at Loma Linda University.

Table 1 shows the number of hospitals and hospitalizations reported by the study subjects during the six year follow-up period. By the end of the follow-up period, 12.0% of the population had moved out of California. This resulted in 8.6% of the reported hospitalizations in non-California hospitals where medical records were obtained by mail. Of the remaining California hospitalizations, 20.4% were in hospitals reporting to one of two population-based tumor registries.

All of the malignant neoplasms identified by AHS field representatives while reviewing medical records in hospitals that report to one of the two population-based tumor registries were also identified independently by computer-assisted record linkage mechanism (Table 2). However, there were 43 incident cancers (3.1% of total ascertained) that were identified only by the computer-assisted record linkage.

Table 3 itemizes the different reasons why the AHS field representatives did not find these new cancer cases identified only by computer-assisted record linkage. The single most frequent reason (46.5%) was that the AHS was not aware of the hospitalization since the study subject failed to return the annual hospital history forms which should have elicited the hospital stay information.

SUMMARY

Computerized record linkage with population-based tumor registries is an efficient and cost-effective means of identifying incident malignant neoplasms in a geographical region. Cancer cases identified by computerized record linkage were obtained at a fraction of the cost as those obtained by visual inspection of the medical record. In no case did computerized record linkage fail to ascertain a cancer case that was identified by review of medical records by AHS trained personnel. Record linkage also identified additional malignant neoplasms that would have been missed using the traditional personal review mechanism.

ACKNOWLEDGMENTS

The authors wish to thank Judy Boone and Herman Menck at the Cancer Surveillance Program in Los Angeles county and Maggie Chiang at the Resource for Cancer Epidemiology (now the California Tumor Registry) for their cooperation and assistance with record linkage to their respective tumor registries.
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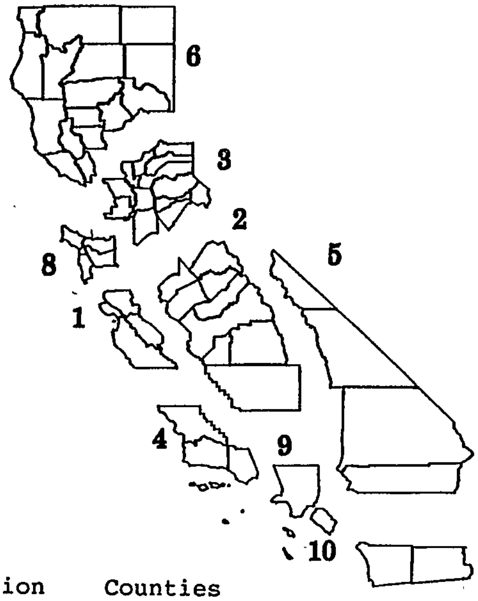
Figure 1

Regional Registry Boundaries in the California Statewide Cancer Reporting System



Region	Counties
1	Monterey, San Benito, Santa Clara, Santa Cruz
2	Fresno, Kern, Kings, Madera, Meriposa, Merced, Stanislaus, Tulare, Tuolumne
3	Alpine, Amador, Calveras, El Dorado, Nevada, Placer, Sacramento, San Joaquin, Sierra, Solano, Sutter, Yolo, Yuba
4	San Luis Obispo, Santa Barbara, Ventura
5	Inyo, Mono, Riverside, San Bernardino
6	Butte, Colusa, Del Norte, Glenn, Humbolt, Lake, Lassen, Mendocino, Modoc, Napa, Plumas, Shasta, Siskiyou, Sononma, Tehama, Trinity
7	Imperial, San Diego
8	Alameda, Contra Costa, Marin, San Francisco, San Mateo
9	Los Angeles
10	Orange

Table 1

Number of hospitals reported by Adventist Health Study subjects by geographical region, 1976-1982.

Geographical Region	Number of Hospitals N	(%)	Number of Hospitalizations Reported by Study Subjects N	(%)
CSP[1]	208	(29.8)	4,731	(16.0)
RCE[2]	81	(11.6)	1,321	(4.4)
Other California	409	(58.6)	23,610	(79.6)
Subtotal California	698	(100.0)	29,662	(100.0)
Subtotal Non-California	960	(100.0)	2,789	(100.0)
Total U.S.	1,658		32,451	

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[1] Cancer Surveillance Program covers the county of Los Angeles.

[2] Resource for Cancer Epidemiology covers the counties of Alameda, Contra Costa, Marin, San Francisco, and San Mateo.

Table 2

Number of new incident cancer cases in the Adventist Health Study (AHS) by geographical region and method of ascertainment, 1976-1982.

Geographical Region	Ascertained Only by AHS Field Rep.	Ascertained Only by Record Linkage	Ascertained by both	Total
CSP[1]	0	34	191	225
RCE[2]	0	9	35	44
Outside the two tumor Registries	1,137	N/A	N/A	1,137
Total	1,137	43	226	1,406

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[1] Cancer Surveillance Program covers the county of Los Angeles.

[2] Resource for Cancer Epidemiology covers counties of Alameda, Contra Costa, Marin, San Francisco, and San Mateo.

Table 3

Reasons why AHS[1] field representatives did not reascertain the new cancer case identified by computer-assisted record linkage

Number of Subjects	TR ICDO[2]	Cancer	Field Representatives Observations
1	153	Colon	Subject located in hospital master file but record is lost
3	169	Hemato-poietic	a) Disease of blood forming organs b) Other circulatory system disease c) Died in Mexico, never reported a hospitalization
2	171	Connective, soft tissue	a) Digestive, genitourinary b) Musculoskeletal or connective tissue
5	173	Skin	a) No hospitalizations reported b) Nose skin cancer(outpatient only) c) Myocardial infarction d) No hospitalizations reported e) No hospitalizations reported
2	174	Breast	a) Acute myocardial infarction b) CVA, other circulatory
1	180	Cervix uteri	Outpatient only (cancer in situ - excised - pt discharged same day)
1	182	Corpus uteri	Moved to Brazil right after hospitalization
1	184	Vulva	Tumor Registry DX = 12/17/82 Field Rep.="All adm. > Dec, 1982" (i.e. after end of study)
5	185	Prostate	a) Benign prostatic hypertrophy b) Benign prostatic hypertrophy c) died < 2 mo. of lifestyle questionnaire return d) Endocrine, Nutritional, Immunity e) No cancer reported (by phone)
1	188	Bladder	Endocrine, Nutritional, Immunity
1	194	Pituitary	Digestive - appendicitis

23 Subjects who returned the annual Hospital History forms

20* Subjects who did not return the annual Hospital History Forms (i.e. No hospitalization reported)

43 Total cancer cases identified only by record linkage

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[1] AHS = Adventist Health Study

[2] TR ICDO = Tumor Registry International Classification of Disease for Oncology code (1976 revision)

* (ICDO=153, n=1), (ICDO=154, n=2), (ICDO=158, n=1), (ICDO=162, n=3) (ICDO=169, n=2), (ICDO=174, n=3), (ICDO=180, n=3), (ICDO=182, n=1) (ICDO=185, n=2), (ICDO=191, n=1), (ICDO=193, n=1)

Session L

Environmental Issues and Ecological Analyses

PHCRS

USING DISEASE REGISTRIES AND VITAL STATISTICS DATA IN A PROGRAM OF ENVIRONMENTAL EPIDEMIOLOGY

J. Fagliano, J. Klotz, and D. Kiel, New Jersey Department of Health

INTRODUCTION

In New Jersey, awareness and concern about the impact of hazardous substances in the environment is consistently high. According to public opinion polls, substantial proportions of state residents consider the environment one of the most important issues facing the state. Considering the wide variety of social ills and public health problems, this environmental concern is a powerful message to the state government.

However, addressing public concerns about environment and health is a formidable task. Our knowledge base about the health effects of hazardous substances in the environment is limited. The challenge to state governments is to respond to community concerns in this information-poor field, and to try to better understand through epidemiologic research the scope of the problems.

In the Environmental Health Service (EHS) we take a three-part approach, a theme which we try to build into all of our activities:

- Public Service - to communities and individuals seeking information;
- Research - small scale efforts that are the focus of this paper, as well as larger more expensive studies;
- Advocacy - to promote a public health focus and use of protective assumptions in environmental decision-making by other public agencies, the private sector, and individuals.

Of these three, epidemiologic research is one of the foundations on which we build our services and advocacy.

But as many states recognize, demands for service to communities concerned about waste dumps, pesticide spraying, noxious air pollution, and drinking water contamination are increasing and are likely to continue to increase while resources diminish.

In these times, states must be creative in their use of available data (usually collected for other purposes) to enable us to begin addressing environmental health questions. Vital statistics, disease registries, and possibly other health data sources can be important tools in this effort.

The purpose of this presentation is to:

1) Describe how we have utilized existing health databases to explore environmental health questions and to provide a basis for advocacy and public service.
2) To illustrate this effort with one example - a study of drinking water contamination and the incidence of leukemia.

It goes without saying that the quality of available data is one critical element that affects the quality of our entire effort.

ENVIRONMENTAL DATABASES

We are fortunate in New Jersey to have several useful environmental databases. Unfortunately, these databases also have serious shortcomings for the purposes of human exposure assessment in environmental epidemiology.

Examples of these databases are:

* Drinking Water Contaminants
* Ambient Air Monitoring
* Air Toxics Emissions
* Hazardous Site Investigations
* Community Right To Know

There is a national effort to analyze the utility of these databases, and we will not elaborate on this effort in this paper. However, a few points are in order:

1) None of these data sets were designed nor implemented with epidemiology in mind. Many assumptions must be made to arrive at estimates of individual or even population exposure levels. For example, air toxics emissions data are stack measurements and require modeling to estimate exposure levels at points in a community.
2) All have limitations in scope, in terms of:
    * Area/population covered. For example, ambient air monitoring stations are widely dispersed and may not reflect exposure of a target population.
    * Frequency/time of data collection. For example, there are no systematic data on volatile organics in public drinking water supplies prior to 1984 in New Jersey. Also, tests on water contaminants are semi-annual and may not reflect short-term variation.
    * Integration with other databases. There are no comprehensive environmental databases. Some data, such as that collected at hazardous waste sites under the Superfund programs, are not stored electronically.

HEALTH DATABASES

Several existing data sources have proven useful in environmentalal health studies.

In New Jersey we have two population-based disease registries:

1) Cancer Registry - a SEER participant - that has been collecting incidence data since 1979
2) Birth Defects Registry - set up by the State and collecting incidence data since 1985.

These registries were not set up for the sole purpose of doing environmental epidemiology -- nor, of course, should they have been. In fact, the cancer registry serves a multiple purpose including establishing bases for prevention and screening programs, and the birth defects registry is closely tied to family and individual services.

Consequently and understandably these data bases have limitations for our specific applications. Some key difficulties include:

- Limitations in time and space:

  Incidence data have only been collected for recent years, making incidence studies of past years impossible. Since New Jersey is bordered by two large metropolitan areas not in the state (Philadelphia, New York City), the completeness of incidence data in adjoining areas is suspect, despite official mechanisms for obtaining incident case information from those two cities.

- Data Limitations:

  Detailed occupational and residential histories are not available. Also, accurate residence coding can be a problem, causing difficulties in interpreting computer-generated rates. For example, the town of Princeton is a desirable mailing address, and residents of many surrounding towns have a Princeton mailing address. The apparent incidence of cancers in such magnet towns is artificially inflated while surrounding towns are artificially decreased.

Vital statistics data have also proven useful, particularly birth certificates for birthweight analysis and certain specific uses of death certificates.

We have begun to explore hospital discharge data to look at certain disease/environment relationships. Of course, this database is limited in its utility to endpoints which would consistently require hospitalization, not a likely outcome for many suspected environmental factors.

Some specific examples of those data source applications have been:

1) Cluster Investigations. We have completed hundreds of disease cluster investigations using our registries, the vast majority prompted by community concerns about cancer. Most of these investigations are unable to reveal any actual clustering, or if so, linkage to an environmental cause. However, even "negative" investigations can serve a purpose by:
   - demonstrating state concern
   - bounding the dimensions of the perceived problem for the community
   - providing an opportunity to interact with and inform the public
2) Lipari Landfill Birthweight Study. We have recently completed a birthweight study of the population surrounding the Lipari Landfill the nation's #1 Superfund site. We observed a birthweight depression related to distance from the site, in a time period coinciding with the heaviest waste dumping at the landfill (1). The significance and plausibility of this result is being explored, but it has demonstrated that, within limits, birthweight may be a useable tool for generating hypotheses about potential adverse reproductive effects.
3) Hospitalization and Air Pollution Episodes. We are exploring the use of DRG data in studying the relationship of ozone air pollution episodes using the ambient air monitoring database with hospitalization for acute respiratory illness.
4) Ecologic-level Cancer Incidence and Mortality Studies. In the absence of systematically collected individual exposure data, we resort to ecologic studies to explore and generate hypotheses for later study.
   We are using the cancer and birth defects registries to study:
   - childhood cancer and radon
   - birth defects and a variety of environmental factors
   - leukemia and drinking water contamination.

   We are using death certificate data to examine links between non-occupational-related mesothelioma death rates in communities near Manville, New Jersey, the asbestos manufacturing center (2).
5) Cohort Mortality Studies - we have studied lung cancer deaths in relation to residence in particular homes in Montclair, New Jersey, where radium-tainted soils were used to fill lots for homes years ago (3).

LEUKEMIA AND DRINKING WATER CONTAMINATION

We wanted to explore this potential relationship in response to the association found in Woburn, MA, (4) and to help provide information to address the many communities in New Jersey concerned about drinking water contamination.

We chose to study an area in the Northeast part of the State defined as all towns completely within a watershed. This area is characterized by a large population (600,000), and is nearly completely served by public water supplies for which high-quality monitoring for volatile organic contaminants has taken place since 1984.

We characterized and grouped each town according to its contamination status in 1984-85 and, separately, obtained incidence data by municipality from the Registry for the period 1979-84.

Then we calculated Standard Incidence Ratios (SIRs) using statewide age-specific rates applied to the town-group population to derive an expected number of cases, for each aggregation of towns by exposure category.

For males, we saw that no SIRs were elevated in any grouping of towns by exposure category. For females, in contrast, the SIR was statistically elevated in the group of most exposed towns. In the six year study period, 28 cases were observed compared to 18 expected. For other town groupings, no elevated SIRs were found.

A more detailed regression analysis of each exposure stratum revealed the same association. A technical report (5) is available from the authors.

This observed association is, of course, limited in its interpretability. We view the findings with extreme concern, however, and publication of this report in the state generated considerable attention. Indirectly, the study provided a sense of importance to the state's pursuit of cleanup schedules in several of the towns with contaminated water, and, we hope, this study will stimulate further research and funding in this area.

CONCLUSIONS

The New Jersey Department of Health's Environmental Health Service considers that existing health databases are useful to explore environmental health associations and can:

- provide service to individuals and communities, in a limited but helpful way
- serve as a pilot to prioritize and determine the feasibility of further, more extensive and expensive epidemiologic study and to help define the limits and dimensions of potential problems
- provide a basis for public health advocacy in the uncertain field of environmental health.

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THE LIMITATIONS OF STATISTICS IN FORMULATING ENVIRONMENTAL HEALTH POLICY:
The Case of Dumpsite Epidemiology

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Just what are the health hazards posed by living near a 'toxic' waste dump? Is there an increased rate of cancer and other diseases in neighborhoods surrounding these sites? If so, is it due to toxic chemicals?

More and more people are asking these questions. And it is often state and local health departments, and sometimes the federal government that are charged with the responsibility of giving them an answer. More often than not, government agencies are called upon to render an 'official' opinion in the face of incomplete information, methodological problems, and inconclusive findings. And yet despite these limitations, that 'official' opinion may play an important role in policy-making on important issues such as:

- whether residents should be notified to keep away from the area, and if so, how far away;
- whether the site should be cleaned up, and if so, how and how quickly;
- what priority should be given to cleaning up one site, compared with all the other hazardous waste sites in that locality;
- and whether the community should evacuate, and if so, how quickly, and who will pay the costs of relocation.

Perhaps no other disease has received as much attention as cancer, and few environmental issues have received as much attention as dumpsites. A new specialization within epidemiology has emerged within the last few years which has been affectionately coined 'dumpsite epidemiology' (Neutra, 1985).

In this presentation, I would like to review some of the history and collective experience in dumpsite epidemiology, and particularly focus on what some of the limitations are and why they exist; and lastly, I would like to offer some thoughts about what is needed. I should also say that my area of expertise is that of a public health nurse epidemiologist, and not that of a statistician. My position as a nurse epidemiologist demands that I listen to, evaluate, and respond to the concerns of community members. It is from that perspective that I make this presentation.

Over the last two decades, there has been growing public awareness and concern about health hazards of waste disposal sites. Why the growing concern? Certainly, the identification of a few egregious incidents has played an important role. We are all familiar with Love Canal, New York, Valley of the Drums in Kentucky, and Times Beach, Missouri. The events in these localities were widely publicized, and as news reached people throughout the country, citizens in various localities began to think about what was happening literally in their own backyards.

An estimated 57 million metric tons of potentially hazardous materials are produced each year in the United States (Roht, et al, 1985). No doubt, there is a real potential for some of these wastes to be released into the environment. As of 1987, over 25,000 hazardous waste sites have been reported to the EPA. Of these, a preliminary assessment was done on approximately 20,000. Out of this number, 6484 were identified as potential threats to human health or the environment (US EPA Journal, 1987).

CERCLA (The Comprehensive Environmental Response and Liability Act of 1980), commonly known as the Superfund Act, RCRA (The Resource Conservation and Recovery Act) and their amendments established government mandates in assessing and cleaning up hazardous sites. And most recently, under SARA Title III, provisions for providing information about potential hazards and health effects to communities were established. Although health assessments are also conducted under these regulations, this activity is not mandated. By and large, requests for epidemiologic studies in communities surrounding hazardous waste sites fall to health departments. A recent survey in the American Journal of Public Health reported that 47 State Health Departments currently conduct cancer cluster investigations (Warner et al, 1988), as do the CDC, and various municipal and county agencies.

I recently had the opportunity to attend a national conference on the clustering of health events, sponsored by the CDC. Although not all reported clusters were related to toxic waste sites, this was a primary area of concern. (Caldwell, 1989). There was a striking similarity in many of the presentations in both the response to and the experience of cancer cluster investigations by federal, state and local agencies.

Typically, these investigations are initiated by citizens and/or community leaders who perceive an increased rate of cancer in their geographic area -- a perceived cluster. The standard response usually involves an initial review, and if the findings warrant it, an expanded investigation. The initial review generally consists of the following steps:

1. <u>Case ascertainment</u>: This is accomplished by doing a preliminary review to determine how many cases occurred in a given population over a given period of time, and collecting basic demographic information on the reported cases, such as age, sex, race, and diagnosis.

2. <u>Case verification</u>: This step involves verifying the reported information

with hospital records or tumor registries; and is essential due to the frequently incorrect reporting of patient diagnosis.

3. Statistical analysis: A variety of statistical approaches have been developed for dealing with the question of clustering (Schulte et al., 1987). These methods are designed to detect whether the number of cancer cases which occurred in a community differed significantly from some 'background', or 'expected' number.

The overall objective of this preliminary review is to determine whether the perceived cluster is confirmed by statistical analysis. If a cluster is found, an expanded investigation may be conducted to identify potential environmental sources and evaluate individual exposures. The objective of the expanded investigation is generally to determine whether an association exists between the observed cancer cluster and specific environmental exposures.

The overwhelming majority of results of these investigations have followed a similar pattern. During the 22 year period from 1961-1983, the CDC investigated 108 cancer clusters. That is, 108 reports for which there was evidence of a time-space cluster. Fourteen different types of suspected associations were reported, some of which included environmental exposures. Yet no clear cause was found for any cluster (Caldwell, 1989).

Health departments around the country have had similar experiences. For example, the Missouri DOH reviewed a total of 101 cancer inquiries since 1984. After an 'initial review' of these inquiries, only 3 resulted in expanded investigations. Of these three, an associated factor was found in only one study (Devier, et al, 1989).

We at the New York City Department of Health have followed a similar approach and have had similar experiences. I will describe one recent study in order to illustrate some of the limitations inherent in the 'standard' approach.

In 1988, the NYC DOH performed a cancer cluster investigation in response to a community's concern about a perceived increase in disease rates which might have been associated with exposures from a landfill. A telephone hotline was set up in the regional state assemblyman's office to gather information about the extent of diseases possibly related to the landfill. Over the course of a few months, approximately 200 cases of more than 10 different diseases were reported, including several types of cancers, autism, and multiple sclerosis. In particular, residents of the community were concerned about what they perceived to be an excess number of cases of childhood leukemia, and that this was related to toxic exposure from a nearby landfill.

In response, the New York City DOH's Environmental Epidemiology Unit initiated an investigation which focused on childhood leukemia. A potential cluster of 12 cases was identified by the community. Childhood leukemia was the targetted disease because it was the most frequently reported cancer by the community residents. Additionally, other studies have found possible links between childhood leukemia and environmental exposures.

Despite the fact that 10 out of the 12 reported cases of childhood leukemia were confirmed, the overall incidence of childhood leukemia in the area of concern was not elevated: 52 cases were observed, while 51 were expected. We also did not detect an increased incidence among any race or sex subgroups, nor an increased incidence among residents living closer to the landfill compared with those living further away. However, four census tracts out of the 168 studied, did have a statistically elevated incidence of leukemia -- a finding we thought was most likely due to chance. These census tracts were not located near each other nor were they near the landfill.

As might be expected, the community's reaction to these findings and our interpretation was largely frustration and disbelief. In part this was due to their strong belief that the 80 acre garbage pile must be causing diseases. In addition, the community hoped that a positive finding would help them in their political struggle to get the dump site cleaned up more quickly.

Our initial negative finding did not directly serve the community's ends. (Although we are continuing our investigation by conducting follow-up interviews in those four census tracts where elevated rates of childhood leukemia were observed and also examining the other reported cancers in both children and adults).

Should the community's concern about the hazards posed by the landfill be dismissed simply because our study did not find an increased rate of childhood leukemias? Or, to put the question more generally, given that the majority of cancer cluster investigations have been inconclusive in identifying etiologic agents in the environment, what role do these investigations serve in formulating environmental health policy? Even though a cluster investigation may yield negative or inconclusive results, epidemiologists are generally hesitant to dismiss the community's concerns -- especially when there is a known or suspected toxin or other environmental hazard. These studies are generally plagued with substantial methodological limitations, which may make it difficult, if not impossible, to detect a true effect.

The methodological limitations are widely recognized among epidemiologists -- especially problems relating to poor measures of exposure, difficulty in selecting appropriate outcomes, difficulties in defining the population at risk, and in selecting appropriate comparison or control groups. What makes these issues so critical is the fact that they generally tend to bias investigations in the direction of not finding a problem. Our recent landfill investigation serves as a good illustration of some of these issues:

Poor measures of exposure: Testimony

given before a New York Senate Committee on Crime, by a driver for an oil refining company stated that waste oil, metal plating wastes, lacquers and solvents were all illegally disposed of at the landfill site, between 1975 and 1979. Although the exact quantity is not known, it has been estimated that 1.1 million gallons of potentially hazardous waste was disposed of during this period (NYSDEC, 1987:1-1). As far as we have been able to ascertain, no environmental testing was done prior to 1982. Therefore, we really don't know what people were exposed to at the time of the alleged dumping. More recent air and leachate testing did not indicate any 'unusual' contamination. The source of drinking water for the area of concern is not local ground water, but surface water hundred of miles away. Based on this fact, and the environmental assessment, the general consensus was that there was no evidence of current exposure.

Selection of Appropriate Outcomes: If we don't know what people were exposed to during a particular time period, it is difficult to select appropriate disease outcomes. We focussed on childhood leukemias because they have been shown to be related to various environmental exposures and also have a short latency period. But we really had no evidence of leukemogens emanating from the landfill itself.

Defining the Population at Risk: Defining the population at risk poses problems due to in-migration and out-migration of residents. In our follow-up case interviews, we found that 40% of the cases and/or their families had relocated to other neighborhoods, states or countries. Obviously, fewer cases will decrease the power to detect an association.

Selection of an appropriate control or comparison group: Statistical evaluation of disease clusters rests on comparing the occurrence of one set of events with another. But typically, the only conclusions which can be drawn from these types of analyses is that the disease rate is either similar or that it differs. If the rates turn out to be similar -- as they did in our study -- it may be misinterpreted to mean that there is 'no problem.'

Time Sequence: Knowledge of the time sequence of exposure and onset of disease is often difficult to ascertain. The sequence is often clear in the case of an acute disease caused by a specific agent or when there is an obvious effect of short duration that coincides with a sharp environmental change. Time relations are more difficult to establish with conditions that are chronic and especially with conditions of insidious onset, such as cancer.

How much of an effect these biases have is not clear. But despite the inherent biases and the resulting tendency toward negative and inconclusive findings, cancer cluster investigations continue to be an ongoing function of health departments. At the very least, they can be helpful in drawing attention and resources to the assessment of current environmental issues, whether or not a cluster is detected. To ignore one inquiry means taking the chance -- however small -- of missing a common exposure.

The last three decades of experience have lead to a growing consensus among health agencies that statistical criteria alone should not be the guiding force in an investigation. Alternatively, the response should entail several key components. These include:

1. Development of a clear protocol: It is essential that agencies develop a standardized way of responding to inquiries, no matter what the source or concern. This involves a staged response, generally consisting of an initial review and, if warranted, a detailed investigation. The initial review, above all else, should be prompt and efficient. And if the results do not meet the criteria for a cluster, no further investigation should be undertaken.

2. Development of effective channels of communication with communities: Traditional epidemiology has put much emphasis on the need for research subjects to be 'unbiased' and hence uninvolved in the design and conduct of investigations. But in the field of dumpsite epidemiology there is a growing recognition of the need for the affected community to be intimately involved in the process. This means listening actively to a community's concerns and working with them to develop the goals and procedures for conducting investigations, and of course, sharing the results. Too often, when negative or inconclusive results are presented, communities become frustrated and distrustful because they feel that the wrong type of investigation was done -- that the wrong people, the wrong time frame, and the wrong disease were studied -- or that there has been a 'cover up.'

Developing effective channels of communication also means providing on-going education and updates on activities. Explaining difficult concepts such as 'chance', 'random occurrence' and 'statistical significance' to people who may be anxious, or personally affected by life-threatening diseases is as much of a skill as is performing complex statistical analyses.

3. Development of effective channels of communication between those agencies and departments which have some interest in the problem. Thorough investigations involve coordination of environmental and health data from several sources. The need for biostatisticians, environmental health specialists, and cancer epidemiologists to learn to understand each other has become increasingly clear. The enactment of SARA Title III expanded government responsibility to include not only performing exposure assessment and clean-up, but also conducting health assessments and providing information and education to communities. This has provided much impetus for inter-agency and inter-departmental dialogue.

In conclusion, statistical analyses alone are not adequate to deal with the problems of dumpsite epidemiology. Since public health agencies are in the business of responding to citizens' health concerns, and since we live in a society that continues to produce an enormous amount of hazardous waste, it is essential that we continually seek to sharpen the methodologic, statistical, and communication tools available for addressing environmental health concerns. In developing these approaches, the following quote from a text entitled Biomedical Bestiary: seems fitting:

> "The limitations of statistical methods can have two sorts of victims: those who fail to see them and those who only see them" (Michael, et al, 1984).

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RELATIONSHIP BETWEEN EMPLOYMENT DURING PREGNANCY AND LOW BIRTH WEIGHT

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ABSTRACT

The relationship between employment and the type of industries or occupations on birth weight of an infant was studied in a sample of white married mothers who delivered singleton live births. The National Natality Survey, 1980 (NNS) formed the database for the study. Information on sociodemographic and personal characteristics including smoking, alcohol, industry and occupation was collected retrospectively from the mothers by a questionnaire. Employment was not significantly associated with birth weight. However, within the employed group there was a significant relationship between birth weight and "Blue Collar" and "White Collar" workers ($X^2 = 4.97$; $p = 0.03$). The mean birth weight of the singletons among the white collar workers compared to the mean birth weight of the blue collar workers approached borderline significance ($F = 3.6$; $p = 0.057$). After adjusting for the confounding variables using multiple linear regression, collar color was not significant ($p = 0.24$). Although the numbers were small, unadjusted relative risk of women employed in electrical machinery and equipment yielded a significant risk of Low Birth Weight (LBW; less than 2500 grams) singletons compared to the total employed cohort as the baseline reference group ($RR = 1.5$; $p < 0.05$). The relative risk of low birth weight singletons in women employed in electrical machinery and equipment was 1.75 ($p < 0.05$) when compared to the professional category as the reference group. Within specific occupational categories, office machines operators had a significantly higher relative risk of LBW singletons = 1.6 ($p < 0.05$) when compared to the total employed cohort as the baseline reference group as well as the professional group.

Further studies are recommended for quantification of environmental teratogens among a cohort of women employed in industries using electrical machinery and equipment and office machine operators.

INTRODUCTION:

The relationship between work during pregnancy and the birth weight of an infant at birth is poorly understood and has not been studied in national U.S. populations. If working during pregnancy predisposes a woman to adverse reproductive outcomes, the information is critical to health care providers. The magnitude of the impact on the U.S. work force is believed to be great because the number of women employed in the work force has increased steadily. In the 1980 National Natality Survey 54 percent of the white married mothers continued to work during pregnancy. Women now seek employment in all types of industries and occupations such as mining, agriculture, laboratories and other occupations with a potential for exposures to toxic chemicals. Agricultural products such as pesticides and fungicides have been shown to have an adverse effect on reproductive outcomes. (1-7) Maternal exposure to the anesthetic gas, halothane, has been associated with a higher proportion of low birth weight (LBW; < 2500 gms) infants born to the anesthesiologists compared to the physicians in other specialties. (8-14) Other studies have shown that nurses employed in anesthesia had the highest number of Low Birth Weight infants compared to nurses in other areas such as casualty nurses, scrub nurses and the Intensive Care Nurses. (14) Therefore, a study was conducted:

1. To investigate the relationship between employment during pregnancy and LBW infants.
2. To identify occupations with a high risk of LBW infants.
3. To determine the relative risk of LBW infants among specific occupations and industries compared to baseline reference group.

MATERIALS AND METHODS:

The database consisted of the National Natality Survey (NNS) conducted by the National Center for Health Statistics in 1980. Details of data collection have been published elsewhere. (15) Briefly, one out of every 363 live births was included in this national survey. A total of 9,941 birth certificates of live births formed the baseline group. Basic information on the mother's marital status at the time of delivery, education, age and residential status was obtained from the birth certificates. Information on behavior risk factors, smoking and alcohol was collected retrospectively from married mothers only. Of the 9,941 women in the NNS survey, 2,116 (21.2

percent) were not married at the time of the delivery and were excluded from the study because information on the behavior risk factors was not obtained for these mothers. There were 7,825 (78.7 percent) married women of which 6,223 (80 percent) responded to the questionnaire. However, the response rate for the blacks was very low (n=448; 64 percent). The blacks were, therefore, excluded from this analysis. Of the 5,614 white married respondents, 214 mothers had multiple births and were further excluded. The final study sample consisted of white married mothers who delivered singletons only, and on whom all the information on sociodemographic as well as behavior risk factors was available (n=5,400). Of these, 3,381 mothers were employed twelve months prior to delivery; however, information on standard Industrial codes (SIC) was incomplete on 81 records. Therefore, these mother/infant pairs were excluded. The final study sample used for analysis consisted of 3,300 mothers on whom complete employment information was available.

RESULTS

The results of the LBW rate and the mean birth weight by employment status are presented in Table 1. The LBW rate for the infants whose mothers were employed during pregnancy was 14 percent lower compared to that of the unemployed mothers (15 percent). Additionally, there was no statistically significant difference in the mean birth weight of the infants born to mothers employed during pregnancy compared to the mean birth weight of the infants whose mothers were not employed twelve months prior to delivery.

The employed mothers were stratified into two groups based on Occupational Classification System codes used in the 1980 National Natality Survey. Occupational codes 001 through 395 comprising of professional, technical and kindred workers, managers and administrators, except farm, sales workers, clerical and kindred workers formed the white collar group, while all the other employment categories formed the blue collar workers. The distribution of LBW by occupational categories among the blue collar and white collar workers is presented in Figure 1. Among the women employed in white collar professions, women employed as craftsmen had a LBW rate of 16.4 percent compared to the LBW rate of 14 percent in the NNS cohort of employed mothers; while women working in blue collar jobs, operative and service workers, had a LBW rate of 18.2 percent and 15.7 percent, respectively.

The relationship between birthweight and occupational categories stratified by collar color is presented in Table 2. The LBW rate was significantly higher among blue collar workers compared to the white collar workers (p< 0.05). The mean birth weight of the blue collar workers was also significantly lower than the mean birth weight of the infants of the white collar workers (p< 0.05).

TABLE 1 RELATIONSHIP BETWEEN EMPLOYMENT STATUS AND BIRTHWEIGHT OF SINGLETON LIVE BIRTHS IN 1980 NATIONAL NATALITY SURVEY

EMPLOYMENT STATUS	BIRTHWEIGHT			
	LBW	NORMAL	MEAN ± SD	TOTAL
Employed	463(14.0)	2837(86.0)	3285 ± 690	3300
Unemployed	303(15.0)	1716(85.0)	3299 ± 717	2019
Total	766(14.4)	4553(85.6)	3290 ± 700	5319

Figure 1: Low Birth Weight Rates by Occupation Among Employed Mothers In The National Natality Survey (1980)

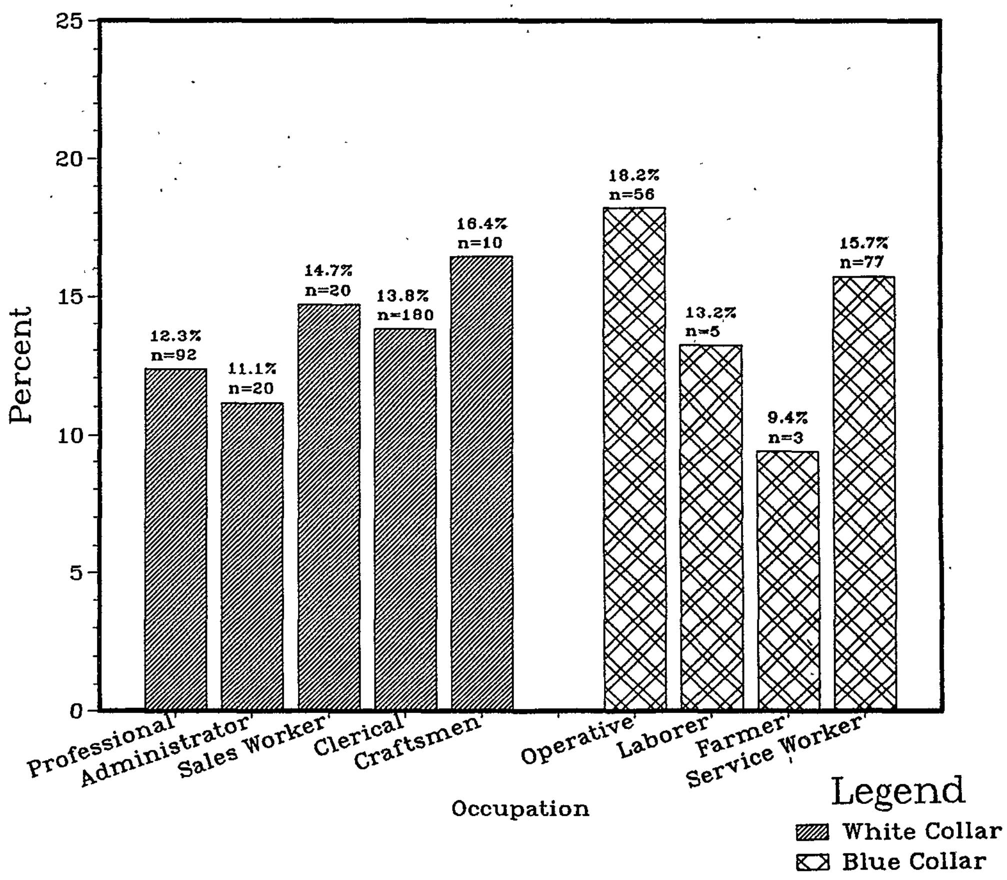

TABLE 2 RELATIONSHIP BETWEEN BIRTHWEIGHT AND OCCUPATIONAL CATEGORIES STRATIFIED BY "COLLAR COLOR" AMONG WHITE MARRIED MOTHERS WHO DELIVERED SINGLETON LIVE BIRTHS IN THE NNS (1980).

	BIRTH WEIGHT			
COLLAR COLOR	LBW	NORMAL	MEAN ± (SD)	TOTAL
	N (%)	N (%)		
White Collar	312(13.2)	2058(86.8)	3299 ± (680)	2370
Blue Collar	151(16.2)	779(83.8)	3248 ± (712)	930
Total	463(14.0)	2837(86.0)	3285 ± (689)	3300

$X^2_{(df)} = 4.97; p < 0.05$

$F= 3.6 [1,3298_{(df)}]; p < 0.05$

The relative risk (RR) of LBW infants compared to the professional group as the referent group is presented in Table 3. There were several occupations with an elevated risk of LBW. Within the white collar occupations, the registered nurses had a higher risk of LBW (RR=1.1) compared to the professional group. Women employed as sales workers and secretaries had a higher relative risk of LBW (RR=1.2); and social and recreational workers had a RR of 1.6. office machine operators had a relative risk (RR=1.6; $p < 0.05$) compared to the professional workers.

Among the blue collar workers, cashiers, (RR = 1.1) craftsmen, (RR = 1.3) operatives, (RR = 1.4) laborers (RR= 1.1) and women employed in the cleaning services (RR= 1.3) had an elevated relative risk compared to the professional women.

TABLE 3 RELATIVE RISK ASSOCIATED WITH OCCUPATION AMONG THE EMPLOYED WOMEN BY SELECTED OCCUPATIONS WITHIN THE "COLLAR COLOR," COMPARED TO THE PROFESSIONAL GROUP

OCCUPATION	LBW	RR
WHITE COLLAR WORKERS (001-395)		
Registered Nurses	19	1.1
Health Technicians	5	0.7
Social & Recreational Workers	6	1.6
Teachers	29	0.9
Sales Workers	20	1.2
Office Machine Operators	13	1.6*
Secretaries	70	1.2
BLUE COLLAR WORKERS (395-995)		
Cashiers	27	1.1
Craftsmen	10	1.3
Operatives	51	1.4
Laborers	5	1.1
Cleaning Service	75	1.3

* $p < 0.05$

The risk of LBW infants was compared to the baseline reference group comprised of all white married women employed during pregnancy who responded to the NNS Questionnaire (all multiple births were excluded). The results of the relative risks are presented in Table 4. Among white collar occupations, the social and recreational workers had an elevated RR of 1.5 compared to the baseline reference group. The risk of LBW among the office machine operators remained significantly higher compared to the reference group of all employed mothers (RR = 1.4; $p < 0.05$).

Among the blue Collar occupations, craftsmen had an elevated risk of LBW (RR = 1.17); women employed in "operatives" had RR = 1.24 and the women employed in cleaning services had a RR of 1.14, slightly higher than the baseline reference group.

TABLE 4 RELATIVE RISK ASSOCIATED WITH OCCUPATION AMONG THE EMPLOYED BY SELECTED OCCUPATIONS WITHIN THE "COLLAR COLOR," COMPARED TO THE EMPLOYED WOMEN AS BASELINE REFERENCE GROUP

OCCUPATION	LBW	RR
WHITE COLLAR WORKERS (001-395)		
Registered Nurses	19	0.98
Health Technicians	5	0.70
Social & Recreational Workers	6	1.50
Teachers	29	0.78
Sales Workers	20	1.05
Office Machine Operators	13	1.40*
Secretaries	70	1.01
Cashiers	27	0.96
BLUE COLLAR WORKERS (395-995)		
Craftsmen	10	1.17
Operatives	51	1.24
Laborers	5	0.94
Cleaning Service	75	1.14

* $p < 0.05$

The results of the relative risk of LBW infants compared to the professional women among selected industries by Industrial Classification System used by the 1980 NNS are presented in Table 5. Several industries had an elevated risk of LBW. Women employed in metal industries had a risk ratio of 1.2; women employed in Textiles had a risk ratio of 1.3; women employed in publishing had a risk of LBW 1.3 times higher than the professional women. Women employed in beauty and barber industrial category had 1.6 times the risk of LBW infants compared to the professional women. Women working with electrical machinery and equipment had 1.75 times the risk of LBW compared to the professional women. ($p<0.05$)

TABLE 5 RELATIVE RISK OF LOW BIRTH WEIGHT SINGELTONS ASSOCIATED WITH INDUSTRY AMONG THE EMPLOYED WOMEN COMPARED TO THE PROFESSIONAL GROUP.

INDUSTRY	LBW	RELATIVE RISK
Metal	6	1.20
Electrical Machinery Equipment	14	1.75*
Textile Mills	5	1.30
Apparel & Textile	7	1.00
Printing & Publishing	6	1.30
Beauty & Barber	12	1.60
Dentist & Physician	52	0.90

* $p<0.05$

Finally the risk of LBW was compared to the baseline reference group consisting of the white married respondents to NNS Questionnaire and who were employed during pregnancy. As shown in Table 6, women employed in metal industries (RR= 1.1), textile mills (RR = 1.1), printing and publishing (RR= 1.1) and beauty and barber industries had a risk of LBW 1.4 times that of the group of employed women in NNS. Women employed in electrical machinery and equipment had a significantly higher risk of LBW infants ($p<0.05$) compared to the baseline reference group.

TABLE 6 RELATIVE RISK OF LOW BIRTH WEIGHT SINGLETONS ASSOCIATED WITH INDUSTRY AMONG THE EMPLOYED WOMEN COMPARED TO BASELINE REFERENCE GROUP

INDUSTRY	LBW	RR
Metal	6	1.1
Machinery	3	0.4
Electrical Machinery & Equip	14	1.5*
Textile Mills	5	1.1
Apparel & Textile	7	0.9
Printing & Publishing	6	1.1
Hotel & Lodging	4	0.6
Beauty & Barber	12	1.4
Dentist & Physician	52	0.9

* $p<0.05$

DISCUSSION

The results of our study are in agreement with the French national survey on births. Our study is indicative of slightly positive effect of work during pregnancy. Women who worked during pregnancy had a lower rate of LBW infants compared to the unemployed women. The mean birth weight of the infants born to the mothers who worked during pregnancy was 3285 g. compared to 3299 g. mean birth weight for women who did not work during pregnancy. The difference between the mean birth weight in the employed and unemployed women was not statistically significant. Again, this finding is also consistent with the French study. (16) Similar results have been observed in several different populations. (17-22)

In our study the preterm deliveries (gestation < 37 weeks) were also less frequent among women who worked during pregnancy than among those who did not: 66.3 percent versus 66.8 percent. However, other studies have shown a significant difference in the rate of preterm deliveries. (20-21)

There were significant differences in the LBW rate and the mean birth weight when the 1980 NNS cohort of employed mothers were stratified into two occupational groups, the blue collar and white collar occupations indicative of the mother's socioeconomic status. Women employed in white collar jobs had more prenatal visits and started prenatal care during the first trimester of pregnancy compared to women in blue collar occupations. (23)
Women employed in white collar jobs had more education and higher percentage of them gained adequate weight gain during pregnancy.(23) On the other hand, a significantly higher percentage of blue collar women were younger and multiparous. A significantly higher percentage of women employed in blue collar jobs smoked more than 10 cigarettes a day during pregnancy. However, the two groups did not differ significantly with respect to alcohol consumption.(23)

Although our study did not find employment itself to be a significant risk factor for LBW, several occupations were identified to be at an elevated risk of LBW infants compared to the professional group or the 1980 NNS cohort of employed women. office machine operators had a significantly higher risk of LBW infants when compared to either the professional group or the baseline reference group (1980 NNS cohort of employed women). Women employed as operatives and in cleaning services had a higher risk of LBW infants also. The women employed in electrical machinery and equipment had a significantly higher risk of LBW infants when compared to the professional group or the baseline reference group. Women employed in beauty and barber industries and printing and publishing had a higher risk of LBW infants also. These results are consistent with McDonald et al (24) who also found increased risk of LBW among chambermaids, cleaners and janitors (RR = 1.42) and women employed in metal and electrical goods (RR = 1.55); clothing (RR = 1.17).

One of the limitations of this study is that it is a cross-sectional survey of several different occupations and industries. It serves the purpose of identifying several occupations and industries that are at a higher risk of LBW infants; however, after stratifying the industries into specific job categories, the numbers tend to be small diminishing the statistical power needed to detect a significant difference if it exists. This study, however, underscores the importance of longitudinal occupational studies and reproductive risk assessment. Additionally, a spectrum of adverse reproductive outcomes such as spontaneous abortion, congenital malformation, early and late fetal deaths need to be examined in relation to occupational exposure in order to fully understand the magnitude of the impact of occupational exposure on reproductive outcomes.

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BLOOD LEAD LEVELS IN 4-11 YEAR OLD CHILDREN: THE HISPANIC HEALTH AND NUTRITION EXAMINATION SURVEY

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Data from the Hispanic Health and Nutrition Examination Survey (HHANES) were used to estimate mean blood lead and percent with elevated blood lead (25 ug/dl) for 4-11 year old Mexican-Americans living in the Southwest, Puerto Ricans living in the New York City metropolitan area and Cuban children living in Dade County, FL. Puerto Rican children were found to have the highest mean blood lead levels (11.5 ug/dl, n=1,390) followed by Mexican-American children (10.4 ug/dl, n=397) and Cuban children (8.6 ug/dl, n=114). Puerto Rican children were also found to have the highest percent with elevated blood lead (2.7%), followed by Mexican-American children (1.6%). Only one of the 114 Cuban children was found to have elevated blood lead.

Despite advances in primary prevention of lead toxicity in children during the past 10 years, there remain many Hispanic children at risk of lead toxicity: approximately 19,000 Mexican-American 4-11 year old children living in the Southwest United States, and 8,000 Puerto Rican 4-11 year old children living in the New York City area, had elevated blood lead levels during 1982-84.

Session M

Integrated Systems

PHCRS

RESEARCH CAPABILITIES OF A COMPREHENSIVE, STATEWIDE HEALTH INFORMATION SERVICE

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INTRODUCTION

A well-designed and operated health information service (HIS) will indicate the health status of the population, point to programs of health promotion and disease control, make possible the evaluation of health services, and serve as a useful research tool. These functions are difficult to quantify in cost-benefit terms, which may be a major reason why the establishment of HIS often ranks low in government priorities.

HEALTH INFORMATION SYSTEM COMPONENTS

Over the past fifteen years, such a health information system was developed in Western Australia (W.A.), divided into strategic, biomedical and management components. Population characteristics, health status, resources, and utilization data are included in the management component.

A comprehensive HIS should include all 3 components, but historically. The management component has often been equaled with "health information" or "health statistics"; resulting in inefficient and inadequate health information systems.

The HIS must be flexible enough to adapt to changes in government policy, user needs, and data sources. Yet it must have continuity of content and stability to permit longitudinal studies. And, of course, all this must be carried out while dealing with problems such as the user-producer gap, the changing political scene, and privacy, patient and provider rights.

Varying types, quantities, and details of data are required at different geopolitical levels, progressing from a many detailed data items at individual or local level, to fewer and less detailed items at national level. It is important to build the data system from the bottom up (data from local units, etc.,) for accuracy of data and interpretation, in order to best serve the needs of the population.

Making information from multiple sources more accessible and useable for measurement, surveillance, research and evaluation of health status, trends and programs requires a comprehensive type of HIS not found in most USA states. In states where some of the data exists, barriers must be torn down for every little improvement. For example, it has taken a small dedicated group of persons five years of dogged effort to make external cause of injury required in the California state hospital discharge survey; and this is only the addition of <u>one</u> item in <u>one</u> data set!

There are a few notable exceptions to the above dismal situation. In the USA, Wisconsin has an excellent system. New Zealand, Sweden and Western Australia are HIS leaders overseas.

THE COMPREHENSIVE HIS

Basically, it comes down to "who's got the data, who owns it, how do I get it (through which political or monetary deal), and how do I use it!" Once this is solved, an even bigger problem surfaces: how to combine all the available data into an effective database? For example, basic demographic data occurs in almost all data systems: vital statistics, hospital discharge data, notifiable statistics, registers, etc, and the same data on the same person must be entered into multiple systems. The goal must be to have a comprehensive system, without unnecessary duplication of data input. If designed right, there will be many sources of data input into one data base, which will have multiple uses. Within the data base the data will move from one system to the other. If the hospital discharge system contains adequate demographic data on the patient, it should not also have to be entered for the Cancer Register, for example. All that is required is duplication of minimal data items to assure the proper patient records are used in each system. The "right stuff" will be output without duplicative entry.

In 1983, Western Australia had such a data base consisting of the following systems: hospital discharge survey, obstetric data, psychiatric case register, cancer register, notifiable diseases, notifiable deaths (anesthetic, maternal, infant), STD, Royal Flying Doctor Service, and human resources (physicians, dentists, nurses, Physical Therapists, health inspectors), community health services' patient record, vital statistics, and Census Data (see figure 1).

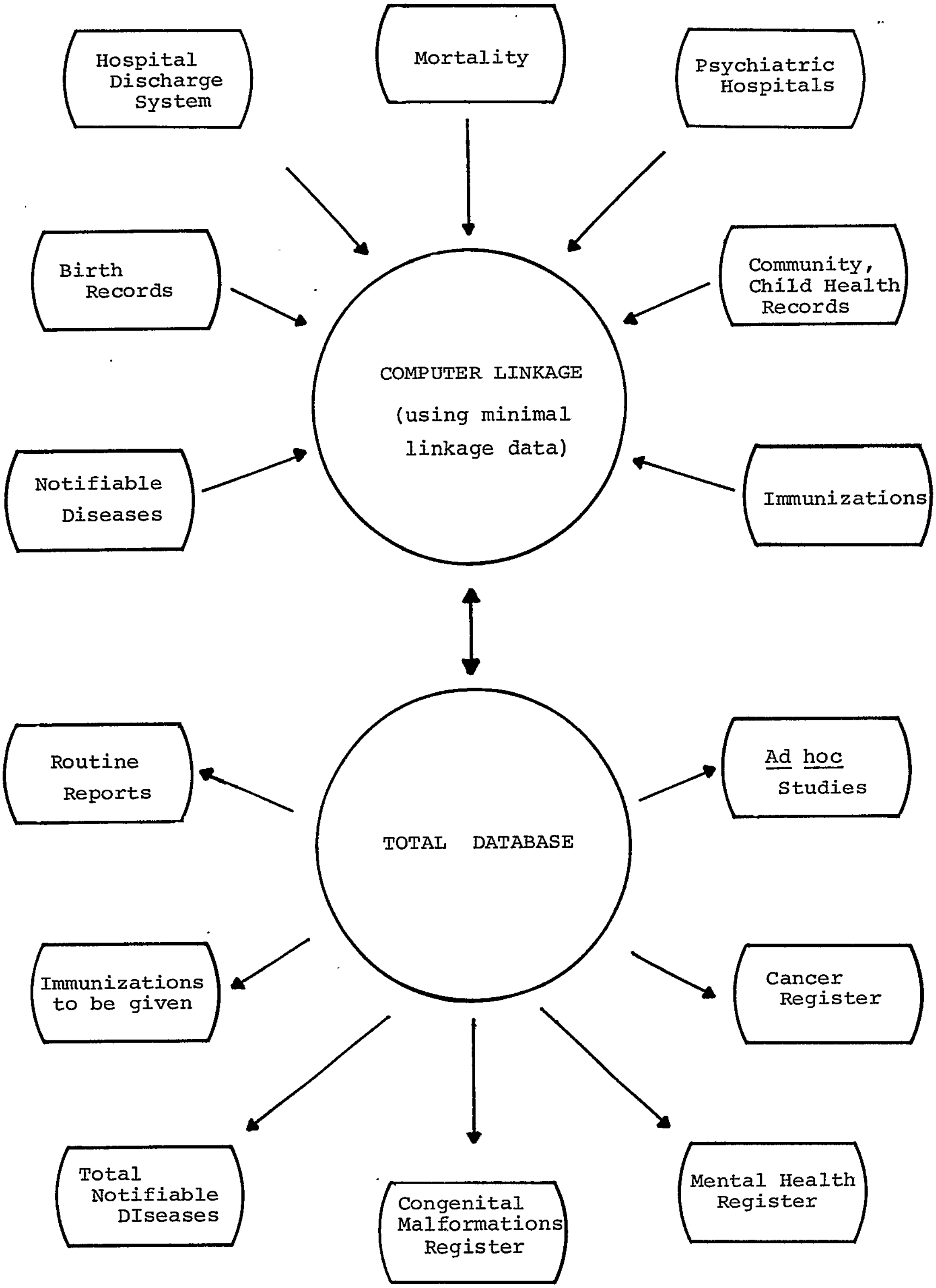
APPLICATIONS OF THE DATA BASE

A few of the major uses of this data base (and there were many) included some real "wins", such as the $150 billion hospital capital budget cut made possible in 1978 thru analysis of demographic projections and the hospital discharge survey, at a cost of only $2,500. computer and staff time. This was possible only because the hospital discharge system was fully operational. It is not possible to set up cost effective systems of this magnitude for ad hoc studies on short notice.

A few examples of effective use of this integrated, comprehensive data system follow figure 1.

figure 1

HEALTH INFORMATION SYSTEM DATABASE



Hospital and Facilities Planning

Hospital utilization data allowed planners to identify the age and sex-specific reasons for hospitalization and types of procedures carried out, in order to plan bed needs and hospital locations. Since 1970, trauma has been the leading cause of hospital admission in the males, followed by conditions of the respiratory, digestive, and circulatory systems (their rank varying from year to year). The female, not surprisingly, is most often admitted for conditions of pregnancy and childbirth, followed by conditions of the genitourinary system, respiratory systems and "symptoms, signs and ill-defined conditions" (again in varying order through the years.) These ranks also vary by age groups. For example, circulatory system conditions overtake trauma as the leading cause of admission in males over 45 years of age, and trauma (mostly due to hip fractures) becomes the main reason for which over-65 year old females enter the hospital.

Procedures closely follow principal conditions. Males most often have operations on the musculoskeletal system, skin and subcutaneous tissue (both often the result of trauma.) The most common procedures on females are those of the genital tract and obstetrics, followed by the digestive system. It is interesting to note that operations on the female genital tract peak approximately five years after the obstetric operation rate. For the over 65 year old males, cardiac procedures and prostate surgery are the leading in-hospital procedures, and orthopedic (hip) operations for females.

Service Areas

Hospital planners need to know about service areas for their own and neighboring hospitals. Do they overlap? Are there implications for more/less beds, what services should the hospital be offering as part of its marketing plan? Patient catchment areas are easily defined from the hospital discharge system, indicating complementary service areas, overlapping areas of lack of coverage.

Physician Service and Location Analysis

A hospital discharge system which identifies the physicians admitting, consulting and treating patients can be used to define physician service areas. In W.A., several surgeons operated in eight or more hospitals, probably spending more time in the car than with their patients. When this was pointed out to the surgeons, they began to alter their practice patterns. Added to this was the statistical information obtained when doctors and other health professionals re-licensed annually. This made possible analysis of current and future physician/population ratios, training needs, etc.

Physician Training

In order to train good doctors of the future, they must see and have experience with diseases and conditions as students. This raises the question, "where are all the potential teaching cases?" Prior to 1980, few medical students in W.A. ever saw a patient with cancer of the breast or who had a hernia, because these conditions were most often treated in the private hospitals. Once the problem was identified, it was rectified by creating "teaching units" under the direction of Fellowship (board-certified), university medical school approved surgeons within the private hospitals.

INFECTIOUS AND NOTIFIABLE DISEASES

The field of public health has long been concerned with prevention and control of infectious diseases. The inclusion of notifiable disease data (including some non-infections conditions such as lead poisoning) in the statistical data base resulted in better reporting then under the usual under-reported "notifiable diseases" system. Having hospital data in the data base along with diseases notified in the usual manner, deaths, and some laboratory results, gave a more accurate indication of disease incidence and/or prevalence. (In the case of sexually transmitted diseases, there was no patient identifier in the data base.) Of course, statistical evidence must be interpreted properly. Data from one northern community showed a 40-fold increase in the incidence of syphilis during a three month period. What really happened was that the health departments' STD screening team moved into the area for that period; interest was high, and so were notifications. After the screening team moved out, reporting again decreased. It would be nice to think the problem was solved "once and for all"; but that is rather wishful thinking!

Obstetric Services

Now that maternal mortality rates have dropped to a low level, many communities are striving for the reduction of infant and perinatal mortality. Using the W.A. data base to study 120,000 consecutive births, it was found that hospitals with fewer than ten maternity beds had three times the perinatal mortality and morbidity rates than hospitals which had ten or more maternity beds. This lead planners to regionalization of obstetric services, and closing almost all maternity units with fewer than ten beds!

Trauma Prevention

As in the USA, Australia has a high rate of injury in children and in males of all ages. Using the data base, several studies of trauma were carried out with far-reaching effect. One studied the types of injury and where they occurred for all injured children hospitalized or dying over a ten-year period. Injury rates for the under one-year old were quite low. The two to five year old, however, had a high rate of poisoning accidents, and the child six and over most often suffered from falls. Results of this study were instrumental in achieving legislation requiring a brown "ribbed" bottle for sales of liquids such as kerosene, cleaning fluids, etc. While this did not prevent the family members from putting such substances into other types of bottles, it did mean all such substances when purchased were in the special bottle, which had a unique size, shape, and feel, identifiable even in total darkness.

Likewise a study of ten years of bicycle accidents resulted in a concerted community-wide consortium-type of effort to make bicycling safer. This involved (1) education for the bicyclists along with periodic follow-up, (2) making people aware of safe equipment (condition of the bike and clothing, helmets of the rider) and (3) the establishment of separate, off-road bicycle-ways. The health department was assisted in this effort by the police department, local governments, education department, National Safety Council, Parents and Citizens groups (PTA), and the media; with a reduction in the number of severe bicycle accidents requiring hospitalization and/or resulting in death.

Ad Hoc Studies

In addition to the above studies carried out mainly by use of ongoing data systems, ad hoc surveys and studies could be added to the system.

In one semi-rural community, a study was carried out to ascertain the percent of doctors' office visits resulting in prescriptions written, by the patients age, sex, and reason for visit.

Pre- and post-fluoridation studies carried out by the state health department's Dental Health Services indicated that not only was fluoridated water of great value in preventing carries, but a study of pre- and post-natal fluoride showed a very statistically significant number of caries-free six year old children whose mothers took fluoride tablets or drank fluoridated water while pregnant.

Other Uses

In addition to the above noted examples, this data base was used by committees working to improve perinatal care, for quality of care and epidemiological studies (such as cancer, health status, health risks), in the setting of private health insurance rates under "Medibank I", and for improving and/or modifying political decision making. As knowledge of the statistical system grew, the use of the data base increased, and likewise its quality. The more a data system or database is used, the more vested interest data suppliers and users have in its quality!

SUMMARY

This paper superficially surveyed a state Health Information Service in a country whose culture & health care system are very similar to that of the USA. The keys to its effectiveness were: uniform data definitions, a minimum data set, and visions of the data managers to not only collect, manipulate & process data, but be able to properly interpret that data based on a wider knowledge of public health. This methodology will produce data which can be used to identify health problems, healthy ways of living, and to improve the quality of life.

Author's note: Photocopies of prints of the 20 slides used in the presentation of this paper at the "Conference on Records and Statistics", and further details of any of the above noted studies are available at no charge upon request from the author. Please send a self-addressed large envelope (minimum 8 1/2" x 11") or an address label with your request.

THE ILLINOIS PUBLIC HEALTH SURVEILLANCE SYSTEM

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Introduction

The Institute of Medicine's report "The Future of Public Health" states that one of the three core functions of public health agencies is assessment. In discussing assessment, the IOM contends that every public health agency should "regularly and systematically collect, assemble, analyze, and make available information on the health of the community, including statistics on health status, community health needs, and epidemiologic and other studies of health problems" (IOM, 1988, p. 7). From this it follows that for public health agencies to successfully carry out the assessment function, (1) data needs to have been collected on health status (such as health outcomes and risk factors), as well as health resources and health systems (2) this data must be accessible by those involved in policy development and program planning and implementation and (3) there needs to exist individuals with sufficient technical expertise to be able to interpret the data.

Although more data on health status and health systems is badly needed, particularly at the local level, much data are already collected by public health agencies which could be used better for policy development and program planning if it were more accessible to potential users.

As a result of this need to make agency data more accessible and to streamline the surveillance process, the Illinois Department of Public Health, in cooperation with other state agencies, is developing a computerized surveillance system comprised of integrated data from various state agencies and various programs within the Department of Public Health. We believe that this system, referred to as IPHSS, is structured in such a way that it can serve as a model for how to enhance state and local health departments abilities to conduct surveillance.

Purpose

The overall purpose of IPHSS is to make the state's data more accessible to a wider audience, particularly local health departments and staff in program and policy areas, so that health assessment can more easily be conducted. Some specific purposes are:
(1) to automate the process of retrieving commonly requested information;
(2) to facilitate morbidity and mortality surveillance of chronic diseases, perinatal outcomes and injuries;
(3) to facilitate the assessment of existing health services;
(4) to facilitate the assessment of the prevalence of risk factors and preventive behaviors;
(5) to assist in the evaluation of the effectiveness of program interventions;
(6) to make available to local health departments state-collected data about their areas; and
(7) to make data available for research purposes.

Data Components of IPHSS

Systems of surveillance already exist in Illinois for the major communicable diseases. However, with the exception of certain disease registries (such as cancer, occupational and birth defect registries) no such systems exist for other categories such as the chronic diseases, injuries and perinatal outcomes as well as for risk factors, preventive behaviors, or health resources, services and facilities. An automated surveillance system needed to be designed to contain data elements which would allow for surveillance of this broader range of health conditions and services.

IPHSS is designed to contain data from the following areas:
(1) Diseases and other health outcomes including:
  - chronic diseases (including those chronic diseases that are the major causes of mortality and morbidity and those which are considered preventable like breast, cervical and colo-rectal cancer);
  - injuries; and
  - perinatal outcomes.

Where available, both mortality and morbidity data will be incorporated into the system.
(2) Risk factors and preventive behaviors including:
  - demographics (e.g., age, race/ethnicity and sex as well as information on socioeconomic status, public aid status, employment statistics, educational levels, insurance status and housing);
  - behaviors (e.g., smoking, alcohol consumption, drug use and diet);
  - predisposing health conditions (e.g., hypertension and cholesterol levels); and
  - environmental factors (e.g.,

(3) Health systems including:
  - inpatient facilities (e.g., hospitals and long-term care facilities, with information on services, bed capacity, occupancy levels, etc.);
  - ASTCs and primary care clinics (with information on number of visits, procedures by speciality, etc.);
  - physicians by speciality; and
  - local public health grantees (including local health departments).

(4) Health utilization data including:
  - patient origin and destination data;
  - inpatient discharge diagnoses; and
  - procedures (surgery rates, inpatient use rates, etc.).

Source Data Systems

Having laid out what types of data we would like in the surveillance system, it is necessary to determine where the data can be obtained. The following source data systems have been identified as containing data elements needed for IPHSS. Each is followed by a list in parenthesis of the types of data that can be obtained.

(1) Vital records (mortality, perinatal outcomes, some risk factor information and some health systems data);
(2) Hospital discharge database (morbidity and mortality data on all health outcomes and some health systems data);
(3) Registries (morbidity data on cancers, perinatal outcomes and occupational diseases);
(4) Population surveys (risk factors, predisposing conditions, morbidity, and utilization data from surveys such as the Behavioral Risk Factor Survey and the National Health Interview Survey);
(5) Census and annual Current Population Surveys (demographics, socioeconomic status, housing);
(6) Health facility inventories (licensure, certificate of need); and
(7) Health related data from other state agencies (such as motor vehicle crash data from Department of Transportation, Medicaid data from Department of Public Aid).

Integration of Data from Different Sources

IPHSS is designed so that data from the above mentioned data sources can be combined into one database. This is an essential part of the system in that it makes possible the reporting of data from varied sources and thereby enhances the surveillance potential of the system considerably.

To achieve this integration, the following technical aspects of the database design were considered:

(1) Data on individuals need to be aggregated into data on groups of individuals.

From a planning and policy perspective, data on individuals is seldom useful. What is needed is summary data on groups of individuals (such as age groups, racial and ethnic groups and groupings by geographic region like county) so that generalizations can be made about the relative health status of one population sub-group as compared to another population sub-group. The grouping allows for the production of health statistics, such as group-specific mortality or morbidity rates.

Aggregation also means that there will be protection of confidentiality. It is important that a surveillance system such as this one, which is intended to be distributed to, among others, individuals outside the Department, not contain any individual-specific data. <u>All</u> data in the system will be aggregate level data.

(2) Fields common to all data sources needed to be identified and used as the basis for the aggregation and linking.

In order to integrate the different data sources into one database, the data sources must have common fields by which they can be linked. All health systems data to go into the system will have as their common field the facility. Data on individuals will have as their common fields geography (community or county of residence or occurrence, depending on the data source), year of occurrence of the health event, age, race/ethnicity and sex. These five fields were selected as the basis for the aggregation and linking as they provide information on the basic epidemiologic data of person, place and time. It is precisely these data elements that are used when conducting surveillance, planning and policy development. An important feature of the system is that if a particular data source does not contain data on all five fields then it can still be integrated, so long as it has data on at least one field. This will not be as useful, however, since data will be lacking for more specific groupings.

(3) The data needed to be stored in a relational database.

Relational databases are ideally suited for the storage of data from different sources. They provide for the construction of multiple "tables" of data. In IPHSS, each table contains data from one data source. The different tables can then be linked by their common "key" fields, either facility or the five fields on person place, or time. Relational databases have the ability to rapidly retrieve data from different tables so long as the tables have these common keys fields.

Improving Accessibility

Improving accessibility to state health agency data is one of the major reasons for the development of IPHSS. Surveillance, planning and policy formulation are difficult to carry out when the data needed for these activities is spread out among different databases and different agencies and when considerable technical expertise is required, in both computer science and statistics, in order to access and correctly interpret the data. Three aspects of IPHSS make for improved accessibility.

(1) Integration of the different data sources.

People with the technical expertise in computer science and statistics will generate the computer files which will be integrated into IPHSS, thus removing this responsibility from the less technically proficient "end user" of the data, namely those conducting surveillance and program and policy development. These end users will have easier access to a wide variety of data sources.

(2) Selection of pertinent variables for surveillance by knowledgeable people.

Most sources have data on many more variables than is actually needed for surveillance and the variables are not necessarily coded in a manner useful for surveillance. To select out the relevant variables and to do the recoding, the individuals proficient in computer science need to be informed by an epidemiologist and/or program staff. Together, they can come up with a design and plan for transforming each data source from its raw form to a more refined and useful form. This can be a time consuming process, but it is necessary if relevant data is to be made more accessible to users.

(3) Implement IPHSS on microcomputers.

To make the state's health data truly accessible, it is essential that the data be moved from the mainframe environment to the microcomputer. Microcomputers have become so widespread and have become powerful enough that it is technically feasible to place aggregate level data from many different data sources in the hands of "end-users". Most local health departments and divisions within state agencies have microcomputers with hard disks and thus can access the data in IPHSS. Updates to the data can be conveniently and inexpensively distributed via floppy disk or downloaded from state-run bulletin board systems.

(4) Provide a menu-driven "front end" to the database.

Relational databases are becoming easier to use each year. However, they still require considerable expertise in order to extract meaningful data from them. For this reason, IPHSS provides a menuing system as the primary means for accessing the data. The user can select such things as the geographic region and year of interest, as well as what statistics to display and what report format to use for the display (such as trend analysis or detailed age and race break-outs). In essence, the menu system further automates the query and report generation features of a relational database thereby making it more accessible to a wider audience.

Turning Data into Information

The points made so far have to do with making existing data more accessible to professionals involved in surveillance, program planning and evaluation, and policy development. However, more can be done to make the data more directly useful by these individuals. We commonly refer to data as being in raw form, at one extreme, to being highly refined, at the other extreme. Data will be more useful if we can transform it as much as possible from its raw form to its more refined form. For example, knowing how many deaths there were in 1987 to people in County X is data in a raw form. This data could be made much more useful by reporting, for example, the age-adjusted death rate by race and sex for County X along with comparable rates for the State as a whole and for past years. One could then see if County X is relatively high when compared to the state average or whether mortality rates have been getting better or worse. The system should ultimately be able to provide the results of statistical tests of significance, cause-specific mortality, national rates, the target goal for the years 1990 or 2000, as well as displaying information from other data sources (such as risk factors or health systems data) which the individual might find useful in interpreting the results.

Some steps that we have already taken in making the data more informative are:

(1) Data is reported as commonly used rates, rather than just number of events. These can be produced as specifically as the values in the five key fields (i.e., geographic, year, age, race and sex-specific rates can be produced).

(2) Adjusted rates can be produced (e.g., age-adjusted for mortality and birthweight adjusted for infant mortality). The user can select which standard

to use for adjustment (the default is the state) and whether to do direct or indirect standardization.

(3) Comparison groups are displayed along side of the data on the requested group (e.g., State of Illinois and Chicago data is presented for comparison purposes). Tests of significance with these comparison groups can be conducted.

(4) Trend analysis can be requested. The data in the system currently goes back to 1980, thereby allowing for an eight year trend analysis. Tests of trend can be performed with significance levels reported.

(5) Data can be aggregated into larger units (e.g., combining several years or several counties). This is useful in situations where the data is sparse and the user wishes to produce more stable rates and also when program planning and evaluation covers these larger units (e.g., a health department which spans several counties).

(6) Ability to export data and the results from queries so that the data can be used in other software applications such as graphics and mapping packages.

In addition, we are currently experimenting with knowledge-based, or expert system, software in order to determine its applicability to a surveillance system.

Some Examples

Some examples of report formats are shown in Tables 1, 2 and 3. Table 1 shows birth statistics from vital records by ethnicity (traditional race classification is also available) for Illinois (the same report for any geographic region or hospital) for the combined years of 1985 and 1986 (a single year or more years could have been selected). The statistics included in the report are meant to be the most common ones requested, although the user has control over which ones to include in the report. This report format is especially useful for comparisons of ethnic groups.

Table 2 shows a format which combines a trend analysis with a three year summary analysis, useful when rates need to be more stable. In addition, Chicago and Illinois data is presented along side to facilitate comparison and interpretation. The particular unit shown is one of the ten perinatal networks in Illinois. The system has these networks precoded so that it knows which hospitals to combine in order to produce this report. As with Table 1, the user can select what region or hospital to report on and which years. The same report can also be produced for specific racial or ethnic groups and for selected maternal age groupings (e.g., teen mothers).

Table 3 is a trend analysis, again structured in a way that is meant to contrast ethnic groups. Although not shown here, the results of tests of trend can be reported.

Conclusion

To accomplish the Year 2000 objectives, public health agencies at all levels of government will need to be able to assess the health status of the population on a continual basis and on a wide variety of health conditions. The ideal tool to do this assessment might be the survey. Such as survey would contain extensive demographic and health status information and be conducted annually. However, given fiscal constraints, it is clear that few such surveys will be developed. Instead, public health agencies will need to develop innovative ways to make use of existing data sources.

What has been described here is one model of how statewide surveillance might be conducted using existing data sources. Our work to date in Illinois on this system is encouraging that this may turn out to be an effective means for conducting surveillance.

TABLE 1

ILLINOIS 1985-1986	ALL GROUPS	ASIAN	BLACK	MEXICAN	PUERTO RICAN	WHITE	ALL HISP
Live birth	357224	5435	76616	23159	5896	240145	34411
Teens	12.5%	2.1%	26.3%	13.4%	21.3%	8.0%	15.1%
Not Married	26.4%	4.4%	72.3%	23.1%	50.0%	11.9%	29.2%
Not HS Grad	22.5%	12.0%	35.7%	71.1%	50.9%	12.8%	63.2%
Inadeq Care	22.0%	23.3%	35.4%	32.9%	25.5%	16.3%	31.5%
VLBW	1.4%	0.9%	3.1%	1.1%	1.5%	0.9%	1.2%
LBW	7.3%	6.4%	13.9%	5.2%	8.6%	5.4%	6.0%
Neo. Dth	7.9	5.0	14.1	7.4	8.6	6.0	7.6
Post-neo	3.8	2.2	8.0	2.9	3.9	2.6	3.0
Infant Dth	11.6	7.2	21.9	10.3	12.6	8.6	10.6
Adj. Neo.	7.2	6.6	7.3	8.4	7.1	7.6	8.0
Adj Post-ND	4.0	2.4	6.7	3.6	4.0	3.0	3.4
Adj Infant	10.9	8.9	13.7	11.6	10.9	10.4	11.2

TABLE 2

PERINATAL NETWORK #1	1985	1986	1987	Combined 1985-87	Chicago 1987	Illinois 1987
I. Live Births	17705	17627	19030	54362	55216	180441
II. Demographics/Factors						
% Asian	0.8	0.8	0.9	0.8	3.3	2.3
% Black	61.7	62.9	65.2	63.3	48.6	22.2
% Hispanic	4.4	4.4	4.3	4.4	22.5	10.0
% White	33.0	31.8	29.5	31.4	25.3	65.3
% teens	18.4	18.0	18.8	18.4	18.5	12.4
% >= 35 years old	6.0	6.6	6.6	6.4	7.4	7.7
% not married	50.8	52.0	53.8	52.3	50.4	28.0
% >=20 with < HS educ	19.9	18.8	18.9	19.2	29.9	15.8
% no prenatal care	1.6	2.1	2.0	1.9	2.2	1.6
% adequate pren. care	53.7	52.3	50.5	52.1	54.0	68.3
III. Birthweight Distrib.						
% 0-499 grams	0.3	0.5	0.3	0.3	0.3	0.2
% 500-1499 grams	1.9	2.3	2.0	2.1	1.9	1.2
% 1500-2499 grams	8.7	9.2	9.1	9.0	8.3	6.0
% >= 2500 grams	89.1	88.0	88.6	88.6	89.5	92.6
IV. Mortality Rates						
Fetal	11.4	10.8	11.2	11.2	9.1	7.7
Neonatal	12.2	12.7	N/A	12.5	10.3	7.9
Post-Neonatal	4.7	6.9	N/A	5.8	5.7	3.8
Infant	16.9	19.5	N/A	18.2	16.0	11.7

TABLE 3

	ALL GROUPS	ASIAN	BLACK	MEXICAN	PUERTO RICAN	WHITE	ALL HISP
Infant Dth							
1980	14.0	14.1	25.2	10.7	13.4	10.6	11.9
1981	13.6	11.9	23.8	11.5	13.6	10.6	12.0
1982	13.2	9.8	25.2	7.9	15.5	10.1	9.6
1983	12.0	7.9	22.2	9.2	13.3	9.1	10.7
1984	11.6	7.7	21.3	9.7	12.7	8.8	10.5
1985	11.5	6.4	21.8	10.6	14.4	8.5	10.8
1986	11.7	8.0	22.0	10.0	10.8	8.6	10.4

WIDE-RANGING ON-LINE DATA FOR EPIDEMIOLOGIC RESEARCH (WONDER)

Andrew M. Friede, M.D.
Centers for Disease Control

(Not available for publication)

ASSIST: A DATA ACCESS AND ANALYSIS SYSTEM

Marcus J. Sanchez, National Center for Health Statistics

INTRODUCTION

ASSIST (Automated System for Survey Information Statistical Tools) is a user-friendly automated data access and analysis system. This paper presents the motivation and projects that have lead to the development of ASSIST, a description of what it does, its current status, an illustration of how ASSIST functions, and finally, the plans for future improvements to the ASSIST system.

MOTIVATION AND BACKGROUND

ASSIST is designed to overcome barriers to easy data access. These barriers are inherent in the size and complex design of Center's surveys, the amount and highly technical nature of documentation required to negotiate the Center's computer system, the existence of multiple file formats and storage media, and the need for skills and training in specific computer languages and systems.

At present, it is difficult to access and analyze National Center for Health Statistics' (NCHS or Center) data for several reasons. To select a data system containing needed health data, it is usually necessary to read a great many pages of documentation pertaining to the survey mechanism used to gather the health information. The documentation describes the survey design, defines the data items collected by the survey, describes the target population, etc. NCHS has many data systems that conduct multiple health surveys. Sorting through the documentation pertaining to these surveys can take days or, in some cases, weeks.

Once users identify the health data of interest, they are confronted with the problem of data retrieval and analysis. If currently proficient in computer programming, users need to obtain information about the data files, computer software, and the computer operating system in order to make computer runs. Several runs to perfect programs and to retrieve and analyze the data are usually required. On the other hand, users may not have the time or the inclination to learn programming. In this case, they are dependent on others to program the computer. Regardless of the means by which the information is obtained, a considerable amount of time and effort will be spent on mastering the computer expertise required for data access and analysis. Frequently, due to the overwhelming volume and complexity of computer operations, little time is left for the critical and creative thinking that is central to competent data analysis.

ASSIST is the product of a continuing three part effort to improve access to and analysis of the NCHS health data. As a first step, the Center funded an evaluation of its current data access methods in two of the Center's four major data systems: Vital Statistics and Health Examination Statistics. During the evaluation a prototype automated data access system (ASSIST) was developed to address the problems identified in the evaluation and assess the prototype system's advantages and disadvantages compared to the current methods.

To further improve access to the Center's health data, a second evaluation was conducted. The work plan for the second phase was similar to that of the first; however, access methods for data from the Health Interview Statistics and Health Care Statistics systems were evaluated. During the second phase, ASSIST was broadened, enhanced and redefined to address the access problems identified during the second evaluation, and modified to accommodate selected data from the Health Care and Health Interview data systems. Work on the second phase will be completed at the end of September of 1989.

The third phase, concerned with evaluating the automated analysis of the Center's health data, will begin in October of 1989. This project will evaluate the Center's present analytical methods and develop a prototype automated analytical system to address problems identified in the evaluation. Then the prototype analytical system's advantages and disadvantages compared to the current methods will be assessed. During the third phase, ASSIST will be modified to contain and/or access the analytical tools developed for this project.

WHAT ASSIST DOES

ASSIST is a prototype software system for the mainframe computer that is used to access and analyze complex survey and other health data from the Center's data systems. ASSIST improves access to and analysis of the Center's health data regardless of storage media or format. Whether the data set is resident on a computer disk or tape, or in a SAS, M204, OS etc. format, ASSIST can access the data in a user-friendly and efficient manner.

ASSIST improves data access and analysis by automating the process by which an analyst: 1), selects health data for analysis; 2), selects computer software to perform the analysis; and 3), communicates these selections to the computer's operating system for execution

Almost anyone can use **ASSIST**. It is menu driven and user friendly. The user need not know a computer language, such as JCL, TSO, MODEL 204, WYLBUR, SAS, BMDP, SPSS, etc., to obtain information from **ASSIST**. All that is required is that the user be able to read simple screens and menus written in English. Although easy to learn and use, one of **ASSIST's** strengths in that its use is not limited to computer novices. **ASSIST** can help all NCHS data users regardless of computing sophistication:

skilled NCHS computer users can use **ASSIST** to quickly gain familiarity with and apply their skills to expanded numbers and types of data,

analysts unfamiliar with computer operating system languages, but skilled with analytic software, can use **ASSIST** to access and analyze data with the software of their choice, and

researchers with analytical skills who are unfamiliar with both operating system and analytic software can use **ASSIST** to obtain information by the application of menu selected analytical tools.

ASSIST is not limited to analytical applications. The **ASSIST** architecture was designed to facilitate any type of computer operation. For example, the prototype has a special purpose feature to allow subject matter specialists in the Division of Health Examination Statistics (regardless of their level of computer sophistication) to edit NHANES III data as it arrives from the field.

CURRENT STATUS

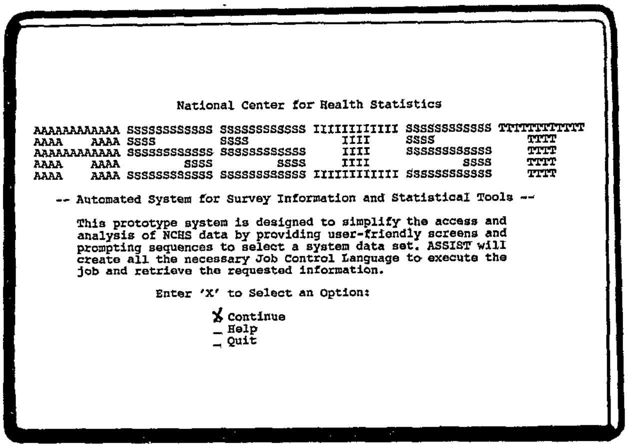
ASSIST is currently a prototype system that has been developed over the last two years. During this time, the prototype has proven that the system concept and architecture are efficient; easy to extend, adapt, manage, and maintain; flexible with regard to user sophistication; designed to easily access new data and tools; secure; and easy to use. Data sets from several NCHS data systems have been made available to **ASSIST** users for the purpose of this evaluation.

ASSIST DEMONSTRATION

This section illustrates the screens and menus that a user would observe when accessing and analyzing data in the **ASSIST** prototype system. Note that the screens and menus are easy to understand and use. To facilitate the use of **ASSIST**, a HELP option is available on every screen and menu. The HELP option clarifies each selection available to the user.

This illustration assumes that the user is interested in investigating the relationship between height and weight as obtained by physical examination.

The first screen tells the user a little about **ASSIST** and what it does. The user interacts with **ASSIST** by using the tab key to move the cursor to the appropriate choice, entering an X (or other character as instructed), and pressing return.



```
                    National Center for Health Statistics

AAAAAAAAAAAA SSSSSSSSSSSS SSSSSSSSSSSS IIIIIIIIIIII SSSSSSSSSSSS TTTTTTTTTTTT
AAAA    AAAA SSSS         SSSS             IIII     SSSS             TTTT
AAAAAAAAAAAA SSSSSSSSSSSS SSSSSSSSSSSS     IIII     SSSSSSSSSSSS     TTTT
AAAA    AAAA         SSSS         SSSS     IIII             SSSS     TTTT
AAAA    AAAA SSSSSSSSSSSS SSSSSSSSSSSS IIIIIIIIIIII SSSSSSSSSSSS     TTTT

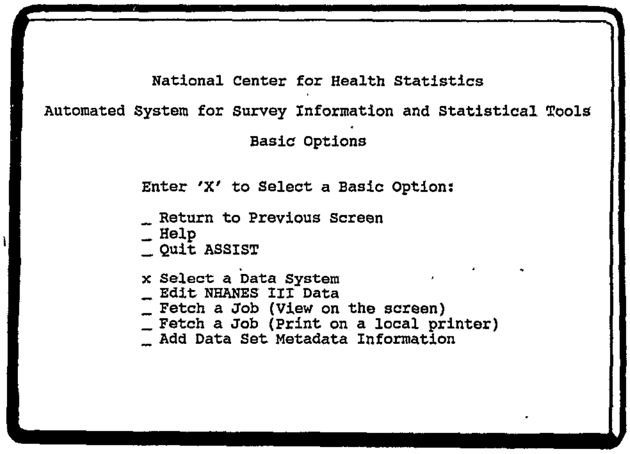
   -- Automated System for Survey Information and Statistical Tools --

      This prototype system is designed to simplify the access and
      analysis of NCHS data by providing user-friendly screens and
      prompting sequences to select a system data set. ASSIST will
      create all the necessary Job Control Language to execute the
      job and retrieve the requested information.

                 Enter 'X' to Select an Option:

                        X Continue
                        _ Help
                        _ Quit
```

The Basic Options screen allows the user to select a data system, edit a data set (HANES III is the only data set available for the edit function), fetch the output from a computer run to the screen, print the output from a computer run, or add information about a new data set. In order to investigate the relationship between height and weight data, we select the Data System option.



```
              National Center for Health Statistics

 Automated System for Survey Information and Statistical Tools

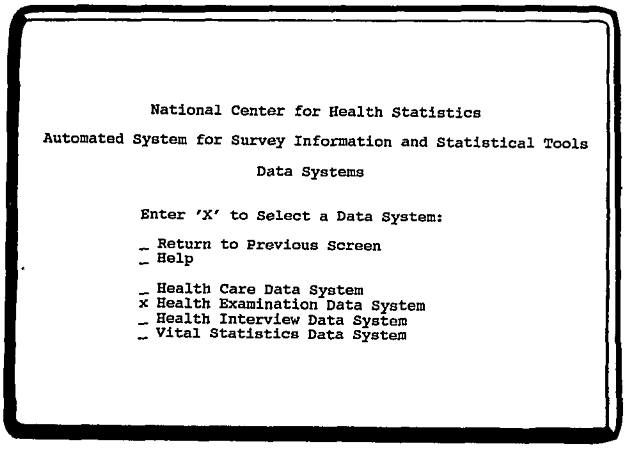
                          Basic Options

            Enter 'X' to Select a Basic Option:

            _ Return to Previous Screen
            _ Help
            _ Quit ASSIST

            x Select a Data System
            _ Edit NHANES III Data
            _ Fetch a Job (View on the screen)
            _ Fetch a Job (Print on a local printer)
            _ Add Data Set Metadata Information
```

Next we select the Health Examination option as we are interested in a relationship among data obtained by physical examination.



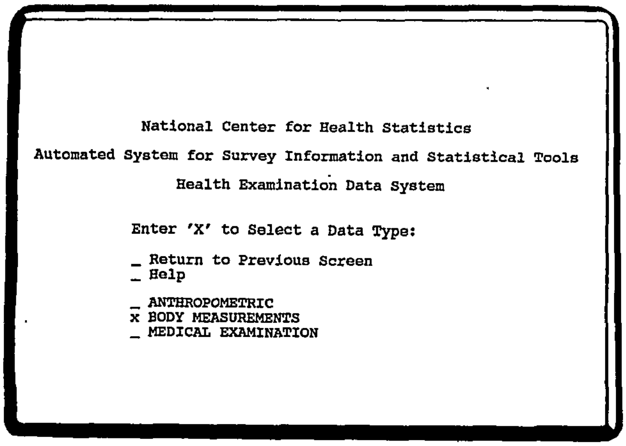
```
             National Center for Health Statistics
Automated System for Survey Information and Statistical Tools
                        Data Systems

            Enter 'X' to Select a Data System:

            _ Return to Previous Screen
            _ Help

            _ Health Care Data System
            x Health Examination Data System
            _ Health Interview Data System
            _ Vital Statistics Data System
```

As height and weight are body attributes, we select the Body Measurement option.



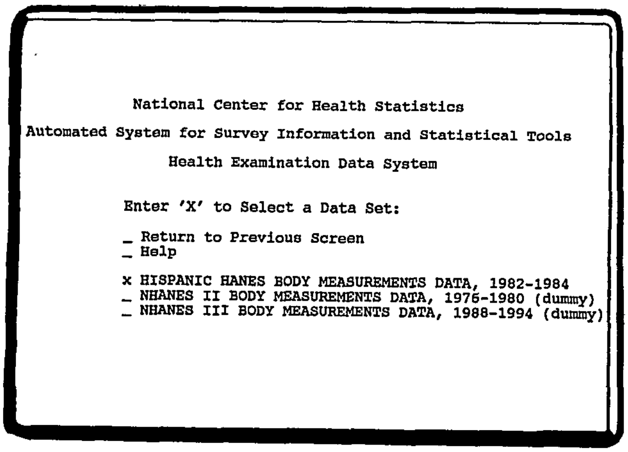
```
             National Center for Health Statistics
Automated System for Survey Information and Statistical Tools
               Health Examination Data System

            Enter 'X' to Select a Data Type:

            _ Return to Previous Screen
            _ Help

            _ ANTHROPOMETRIC
            x BODY MEASUREMENTS
            _ MEDICAL EXAMINATION
```

For this illustration we select the Hispanic HANES option.



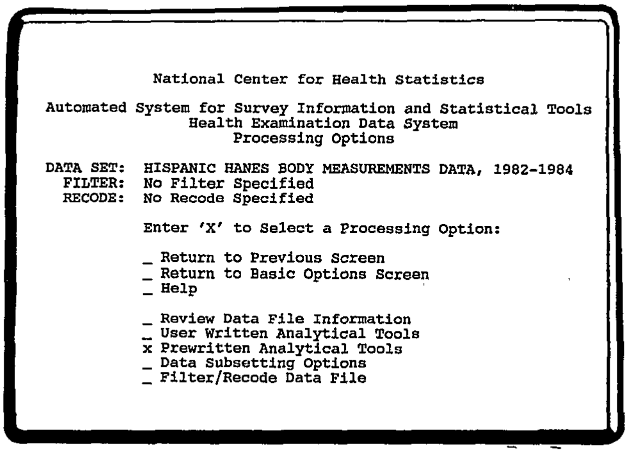
```
             National Center for Health Statistics
Automated System for Survey Information and Statistical Tools
               Health Examination Data System

            Enter 'X' to Select a Data Set:

            _ Return to Previous Screen
            _ Help

            x HISPANIC HANES BODY MEASUREMENTS DATA, 1982-1984
            _ NHANES II BODY MEASUREMENTS DATA, 1976-1980 (dummy)
            _ NHANES III BODY MEASUREMENTS DATA, 1988-1994 (dummy)
```

The first selection in the Processing Options screen allows the user to gain in-depth information about the contents of the data set and the survey that collected the information: the target population, survey description, sample design, type of data collected, etc. The other selections allow the user to write or execute his own pre-written computer program (in the software of his choice), actuate analytical tools that have been written for the user, create a new data set by subsetting the selected data, or exclude or recode information contained in the selected data set. As we are interested in illustrating how easy **ASSIST** is to use, a pre-written tool to obtain the relationship between height and weight is selected in this demonstration.



```
             National Center for Health Statistics
Automated System for Survey Information and Statistical Tools
               Health Examination Data System
                     Processing Options

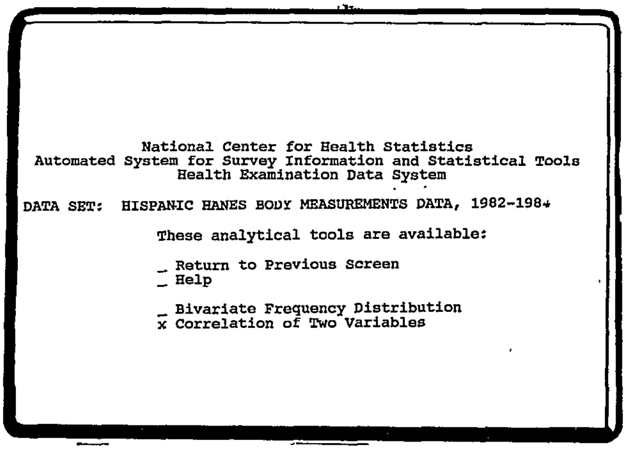
DATA SET:  HISPANIC HANES BODY MEASUREMENTS DATA, 1982-1984
  FILTER:  No Filter Specified
  RECODE:  No Recode Specified

           Enter 'X' to Select a Processing Option:

           _ Return to Previous Screen
           _ Return to Basic Options Screen
           _ Help

           _ Review Data File Information
           _ User Written Analytical Tools
           x Prewritten Analytical Tools
           _ Data Subsetting Options
           _ Filter/Recode Data File
```

As we are interested in measuring the association between two variables, we select the Correlation of Two Variables option.



```
             National Center for Health Statistics
Automated System for Survey Information and Statistical Tools
               Health Examination Data System

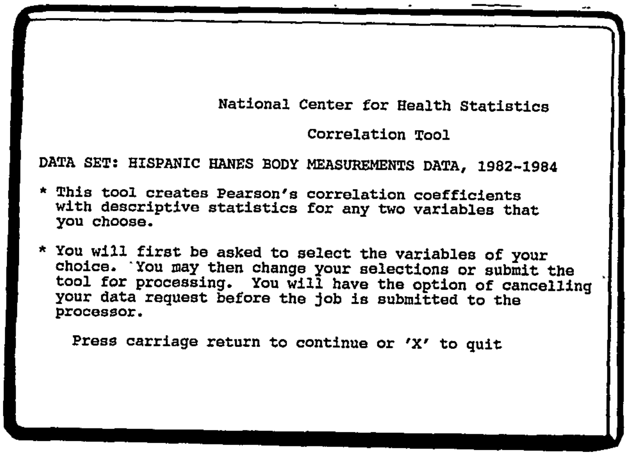
DATA SET:  HISPANIC HANES BODY MEASUREMENTS DATA, 1982-1984

           These analytical tools are available:

           _ Return to Previous Screen
           _ Help

           _ Bivariate Frequency Distribution
           x Correlation of Two Variables
```

What follows is an information screen. The user is told that he has selected the Pearson's correlation and what is required to use the tool.



```
             National Center for Health Statistics
                      Correlation Tool

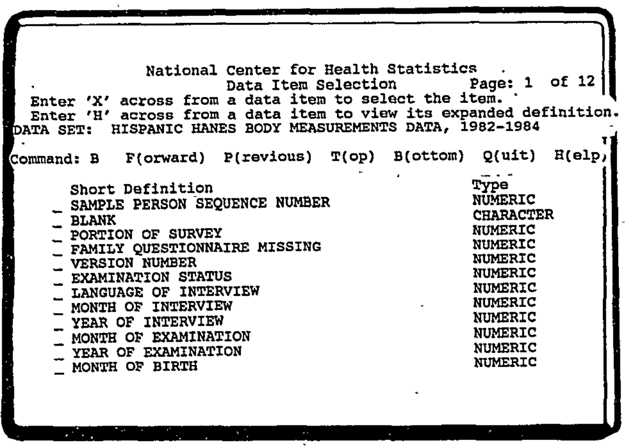
DATA SET: HISPANIC HANES BODY MEASUREMENTS DATA, 1982-1984

* This tool creates Pearson's correlation coefficients
  with descriptive statistics for any two variables that
  you choose.

* You will first be asked to select the variables of your
  choice.  You may then change your selections or submit the
  tool for processing.  You will have the option of cancelling
  your data request before the job is submitted to the
  processor.

  Press carriage return to continue or 'X' to quit
```

The next screen displays all of the fields in the selected data set. Any two fields may be chosen for the correlation. All of the fields may be viewed by placing the letter F in the command line. Height and weight are located near the end of the listing. The letter B is placed in the command line so that we view the information at the bottom or end of the data set.

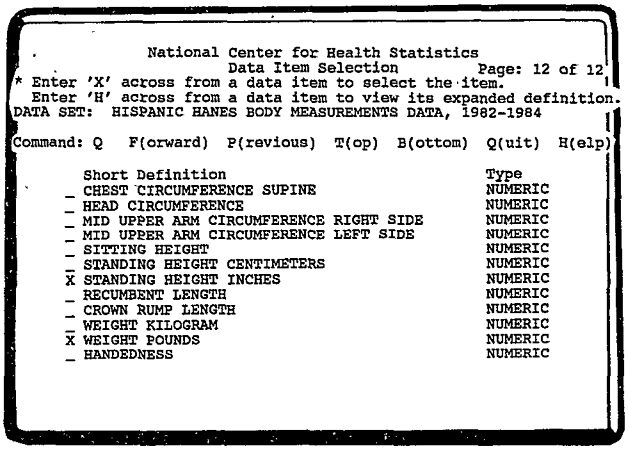


```
                National Center for Health Statistics
                          Data Item Selection          Page: 1  of 12
 Enter 'X' across from a data item to select the item.
 Enter 'H' across from a data item to view its expanded definition.
DATA SET:  HISPANIC HANES BODY MEASUREMENTS DATA, 1982-1984

Command: B   F(orward)  P(revious)  T(op)  B(ottom)  Q(uit)  H(elp)

       Short Definition                                Type
     _ SAMPLE PERSON SEQUENCE NUMBER                   NUMERIC
     _ BLANK                                           CHARACTER
     _ PORTION OF SURVEY                               NUMERIC
     _ FAMILY QUESTIONNAIRE MISSING                    NUMERIC
     _ VERSION NUMBER                                  NUMERIC
     _ EXAMINATION STATUS                              NUMERIC
     _ LANGUAGE OF INTERVIEW                           NUMERIC
     _ MONTH OF INTERVIEW                              NUMERIC
     _ YEAR OF INTERVIEW                               NUMERIC
     _ MONTH OF EXAMINATION                            NUMERIC
     _ YEAR OF EXAMINATION                             NUMERIC
     _ MONTH OF BIRTH                                  NUMERIC
```

As we are interested in the relationship between height and weight, the letter X is placed beside the fields labeled STANDING HEIGHT INCHES and WEIGHT POUNDS. To exit, Q for quit is placed in the Command line.

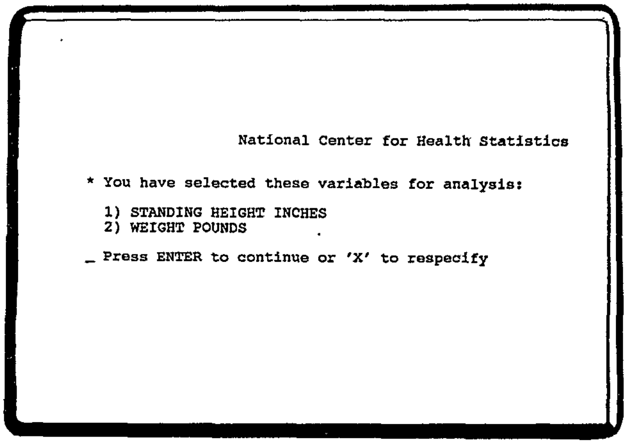


```
                National Center for Health Statistics
                          Data Item Selection          Page: 12 of 12
* Enter 'X' across from a data item to select the item.
  Enter 'H' across from a data item to view its expanded definition.
DATA SET:  HISPANIC HANES BODY MEASUREMENTS DATA, 1982-1984

Command: Q   F(orward)  P(revious)  T(op)  B(ottom)  Q(uit)  H(elp)

       Short Definition                                Type
     _ CHEST CIRCUMFERENCE SUPINE                      NUMERIC
     _ HEAD CIRCUMFERENCE                              NUMERIC
     _ MID UPPER ARM CIRCUMFERENCE RIGHT SIDE          NUMERIC
     _ MID UPPER ARM CIRCUMFERENCE LEFT SIDE           NUMERIC
     _ SITTING HEIGHT                                  NUMERIC
     _ STANDING HEIGHT CENTIMETERS                     NUMERIC
     X STANDING HEIGHT INCHES                          NUMERIC
     _ RECUMBENT LENGTH                                NUMERIC
     _ CROWN RUMP LENGTH                               NUMERIC
     _ WEIGHT KILOGRAM                                 NUMERIC
     X WEIGHT POUNDS                                   NUMERIC
     _ HANDEDNESS                                      NUMERIC
```

Now **ASSIST** confirms the selection of the height and weight fields and gives you an opportunity to change your selection. ENTER is pressed to continue.



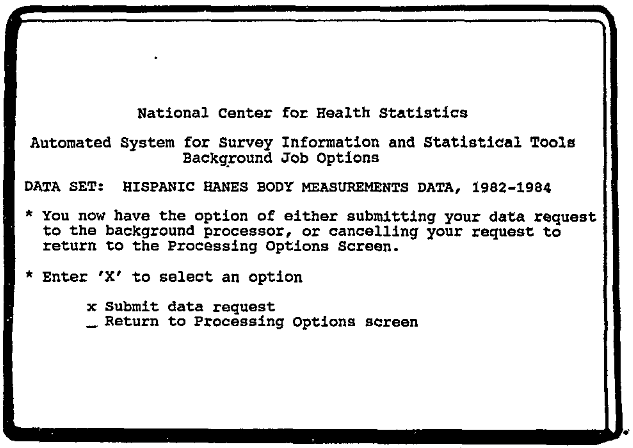
```
                National Center for Health Statistics

  * You have selected these variables for analysis:

    1) STANDING HEIGHT INCHES
    2) WEIGHT POUNDS

  _ Press ENTER to continue or 'X' to respecify
```

The next screen allows the user to have the correlation executed or not. The job is submitted for execution.



```
                National Center for Health Statistics

Automated System for Survey Information and Statistical Tools
                     Background Job Options

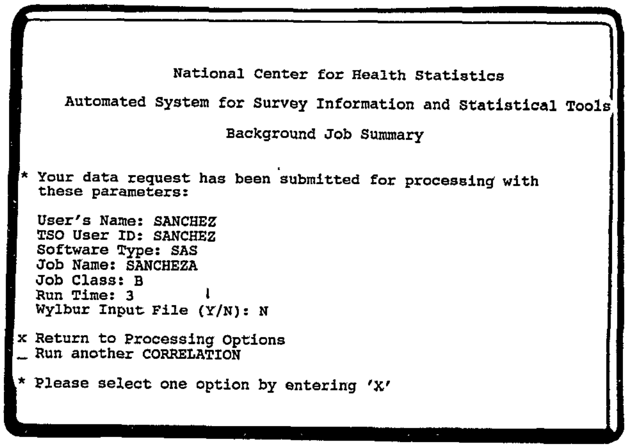
DATA SET:  HISPANIC HANES BODY MEASUREMENTS DATA, 1982-1984

* You now have the option of either submitting your data request
  to the background processor, or cancelling your request to
  return to the Processing Options Screen.

* Enter 'X' to select an option

      x Submit data request
      _ Return to Processing Options screen
```

Here **ASSIST** summarizes the attributes of the correlation job just submitted: Programmer's name, class of job, estimated run time, etc. The user is also given the option of executing another correlation.



```
                National Center for Health Statistics

   Automated System for Survey Information and Statistical Tools

                     Background Job Summary

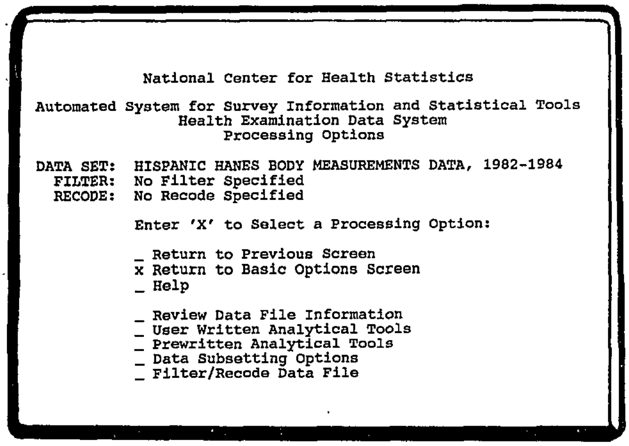
* Your data request has been submitted for processing with
  these parameters:

  User's Name: SANCHEZ
  TSO User ID: SANCHEZ
  Software Type: SAS
  Job Name: SANCHEZA
  Job Class: B
  Run Time: 3
  Wylbur Input File (Y/N): N

x Return to Processing Options
_ Run another CORRELATION

* Please select one option by entering 'X'
```

To view the output of the correlation run, it is necessary to return to the Basic Options Screen.



```
                 National Center for Health Statistics

      Automated System for Survey Information and Statistical Tools
                       Health Examination Data System
                            Processing Options

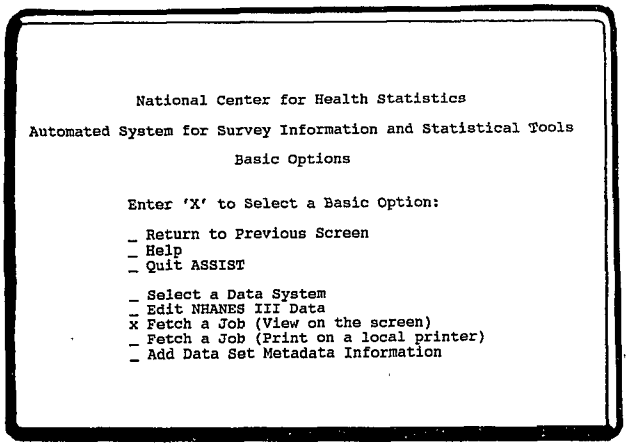
      DATA SET:  HISPANIC HANES BODY MEASUREMENTS DATA, 1982-1984
        FILTER:  No Filter Specified
        RECODE:  No Recode Specified

                 Enter 'X' to Select a Processing Option:

                 _ Return to Previous Screen
                 x Return to Basic Options Screen
                 _ Help

                 _ Review Data File Information
                 _ User Written Analytical Tools
                 _ Prewritten Analytical Tools
                 _ Data Subsetting Options
                 _ Filter/Recode Data File
```

Here we choose to fetch the output and view it on the screen.



```
                 National Center for Health Statistics

      Automated System for Survey Information and Statistical Tools

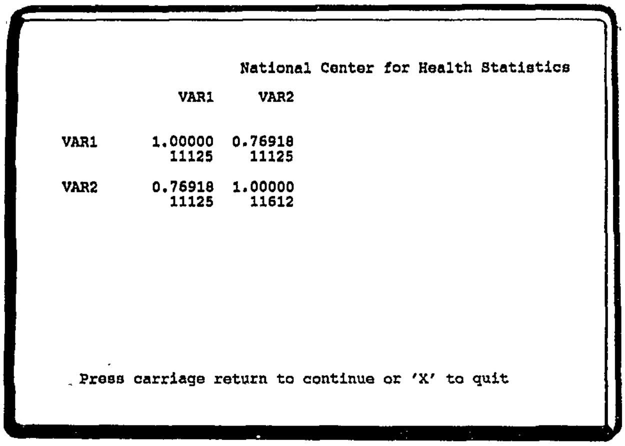
                            Basic Options

                 Enter 'X' to Select a Basic Option:

                 _ Return to Previous Screen
                 _ Help
                 _ Quit ASSIST

                 _ Select a Data System
                 _ Edit NHANES III Data
                 x Fetch a Job (View on the screen)
                 _ Fetch a Job (Print on a local printer)
                 _ Add Data Set Metadata Information
```

The output from the correlation run shows a correlation of approximately .77 between height and weight.



```
                          National Center for Health Statistics

                VAR1      VAR2


      VAR1     1.00000   0.76918
                 11125     11125

      VAR2     0.76918   1.00000
                 11125     11612

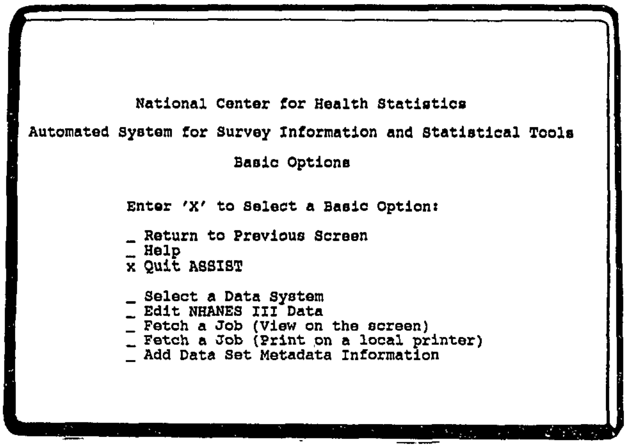







   Press carriage return to continue or 'X' to quit
```

Now the user would simply exit ASSIST.



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                 National Center for Health Statistics

      Automated System for Survey Information and Statistical Tools

                            Basic Options

                 Enter 'X' to Select a Basic Option:

                 _ Return to Previous Screen
                 _ Help
                 x Quit ASSIST

                 _ Select a Data System
                 _ Edit NHANES III Data
                 _ Fetch a Job (View on the screen)
                 _ Fetch a Job (Print on a local printer)
                 _ Add Data Set Metadata Information
```

This simple illustration clearly illustrates that ASSIST is designed to allow data access and analysis in a very straightforward and friendly fashion.

FUTURE DEVELOPMENTS

Plans call for ASSIST to help with additional data processing needs beyond basic access and analysis when fully implemented. ASSIST architecture is easily extendable to include creating of new data sets, combining old data sets, editing data sets, creating new data processing tools with the user's choice of language, and many other features. Some of the functions and features not currently in the prototype system that are being worked on or are in the planning phase are:

A) A menu-driven feature to write, develop, edit, and submit source code software (e.g., SAS, PL/1, C, Fortran, SPSS, etc.) through ASSIST. With this tool, users could create, save, delete, retrieve, and modify software.

B) A menu-driven tool to construct appropriate weighted estimates and variance-covariance estimates for sample survey data. This would be accomplished through a link to special purpose analytical software now nearing completion.

C) Menu-driven tools for frequently used analytic procedures such as regression, cohort analysis, logistic regression, relative risk analysis, categorical data analysis through selected general linear models, ANOVA, ANCOVA, time series analysis, longitudinal analysis, etc.

D) Menu-driven tools for subsetting and merging appropriate data sets and their documentation for output (including down-loading to the PC or NCHS Integrated Office Automation System environment).

E) Tools to allow appropriate subject matter specialists to edit NCHS data after it is collected or during the construction of final data sets.

F) A menu-driven browsing tool to allow users to quickly search across multiple data systems for user specified variables.

Session N

Mortality Surveillance

PHCRS

Vital Statistics Field Efforts and Reported Suicides in Wisconsin

R. D. Nashold and P. L. Peterson, Wisconsin Center for Health Statistics

As with other socially stigmatizing events, there have been persistent problems with completeness of reporting of suicide. Because of the subjective nature of suicide, it is often not detectable. Suicide information may also be suppressed by relatives or friends. This might include the removal of evidence by survivors or the unwillingness of local officials to pursue investigation into the cause of the death. The impingement of social factors on the accurate reporting of suicide has been widely discussed.[1] It has also been shown that the rules and methods for ascertaining whether deaths are due to suicide may not be uniformly applied.[2,3]

Suicide rates are subject to large annual variation for unclear reasons. If there is a national increase or decrease, we are inclined to look for economic or social variables that might be associated with the change. The very high rates in the early 1930s are associated with the economic crash of 1929. The large wartime decline in 1943, is attributed to social phenomena concerning war -- perhaps a new interest, or an opportunity to die with approval rather than disapproval. Wisconsin data clearly reflected these events (Table 1).

Table 1
Suicide Trends
Wisconsin, 1928-1988

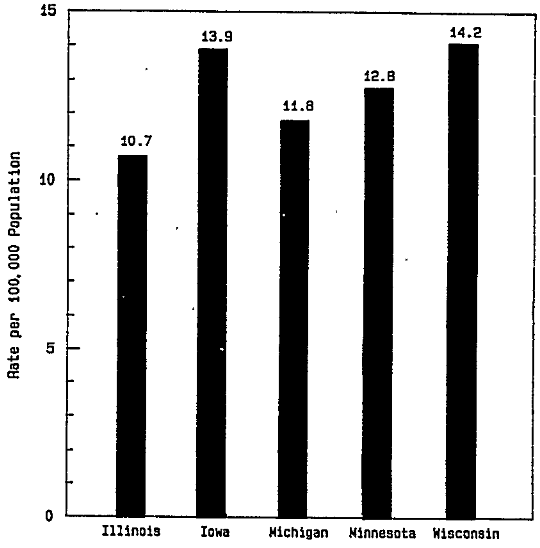
1928	409	14.1
1929	451	15.4
1930	553	18.8
1931	579	19.5
1932	564	18.9
1933	506	16.8
1934	498	16.4
1935	477	15.7
1936	464	15.1
1937	524	17.0
1938	513	16.6
1939	464	14.9
1940	470	15.0
1941	423	13.5
1942	502	16.4
1943	352	11.7
1944	383	12.9
1945	416	14.0
1946	416	13.1
1947	468	14.4
1948	404	12.2
1949	413	12.2
1950	426	12.4
1951	359	10.4
1952	388	11.2
1953	408	11.7
1954	417	11.6
1955	417	11.4
1956	433	11.6
1957	415	10.9
1958	450	11.6
1959	427	10.9
1960	429	10.8
1961	450	11.3
1962	423	10.5
1963	453	11.1
1964	403	9.8
1965	470	11.3
1966	427	10.2
1967	460	11.0
1968	437	10.4
1969	534	12.3
1970	497	11.2
1971	528	11.8
1972	558	12.4
1973	522	11.5
1974	531	11.6
1975	546	11.9
1976	598	13.0
1977	591	12.7
1978	582	12.4
1979	593	12.7
1980	552	11.7
1981	585	12.4
1982	583	12.3
1983	616	13.0
1984	606	12.7
1985	609	12.5
1986	594	12.4
1987	680	14.2
1988	647	13.5

States generally follow national trends. However, at the state level, particularly when a given state differs substantially from surrounding states, it is useful to explore random variation or the possibility of statistical or reporting artifacts. Such is the focus of this paper.

In 1987, the Wisconsin suicide rate was higher than that of the surrounding contiguous states of Illinois, Michigan and Minnesota and similar to Iowa (Figure 1). Between 1986 and 1987 suicide rates for Illinois and Michigan decreased, Minnesota remained the same and Iowa increased. Wisconsin had a numeric increase of 86 (594 to 680) and the rate rose from 12.4 to 14.1, more than can be accounted for by random statistical variation at the .05 level. The increase in Iowa was not significant at the .05 level of probability.

Figure 1

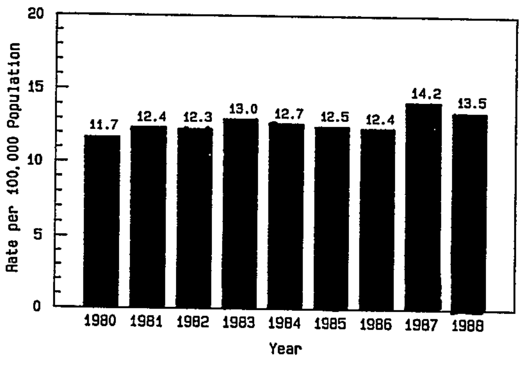
Suicide Rates in Five Contiguous Midwest States
1987



The crude suicide rate of 14.2 per 100,000 population for Wisconsin in 1987 was the highest rate that had occurred in Wisconsin since post-World War II (Table 1). The rate for 1987 clearly stands out as the highest for the decade (Figure 2).

Figure 2

Wisconsin Suicide Rates
1980–1988



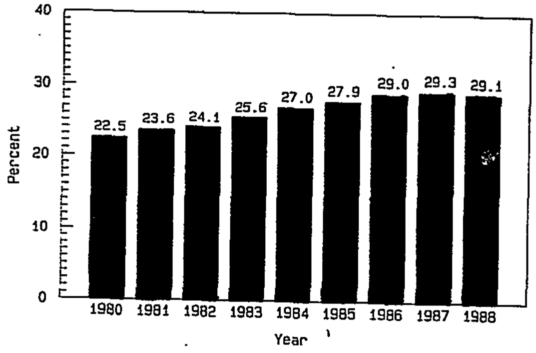
The most obvious prior event in Wisconsin with a likelihood of association with increased suicides was a major revision of Wisconsin's vital statistics statutes[4] that went into effect in November, 1986. However, in analyzing the statutory changes no provision was found that would directly affect the reporting of suicide. Following implementation of the new statute coroners began to comment about an increase workload which they attributed to statutory change. Based on this perceived extra workload, coroners in some counties asked their county boards to increase the budget of the coroner's office. Data available from 1980 through 1988 show a rather constant rise in the workload of the coroner and medical examiner offices (Table 2, Figure 3). The revised statute made the duties of the office more explicit, i.e., the need to sign all death certificates where the death requires involvement of the coroner or medical examiner by statute, the need to view a body prior to cremation, the need to investigate home deaths and the deaths of the elderly that involve trauma regardless of where the death occurs. Such points were stressed in the training that accompanied the introduction of the new statute.

Table 2
Coroner and Medical Examiner Deaths
Wisconsin 1980-1988
(Occurrence Data)

Year	Total Deaths	Coroner /ME Deaths	Percent
1988	43,106	12,554	29.1
1987	42,151	12,340	29.3
1986	42,046	12,204	29.0
1985	41,450	11,573	27.9
1984	40,954	11,061	27.0
1983	40,968	10,487	25.6
1982	40,153	9,685	24.1
1981	40,414	9,547	23.6
1980	40,839	9,169	22.5

Figure 3

Percent of Coroner and Medical Examiner Deaths
Wisconsin, 1980–1988



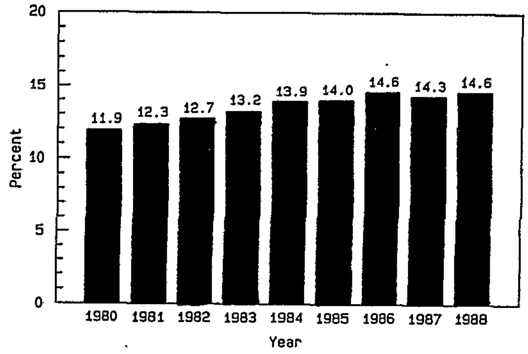
Thirteen training sessions were held throughout the state with 1,142 coroners, medical examiners and funeral directors in attendance. These sessions strongly reinforced the long-standing statutory provisions requiring home investigations under specified circumstances. At subsequent regional and statewide meetings, the vital statistics field representative and other staff of vital statistics raised questions about affects of the statutory change and it was the overwhelming consensus of the coroners and medical examiners that more home investigations were being conducted. It appears that it was not so much the new statute as the additional training which caused an increase in investigations of home deaths. It should also be noted that from 1980 to the present, there has been an increase in the proportion of deaths occurring at home (Table 3, Figure 4).

Table 3
Deaths At Home
Wisconsin 1980-1988
(Occurrence Data)

Year	Total Deaths	Home Deaths	Percent
1988	43,106	6,280	14.6
1987	42,151	6,042	14.3
1986	42,046	6,122	14.6
1985	41,450	5,803	14.0
1984	40,954	5,711	13.9
1983	40,968	5,413	13.2
1982	40,153	5,102	12.7
1981	40,414	4,971	12.3
1980	40,839	4,854	11.9

Figure 4

Percent of Deaths at Home
Wisconsin, 1980–1988

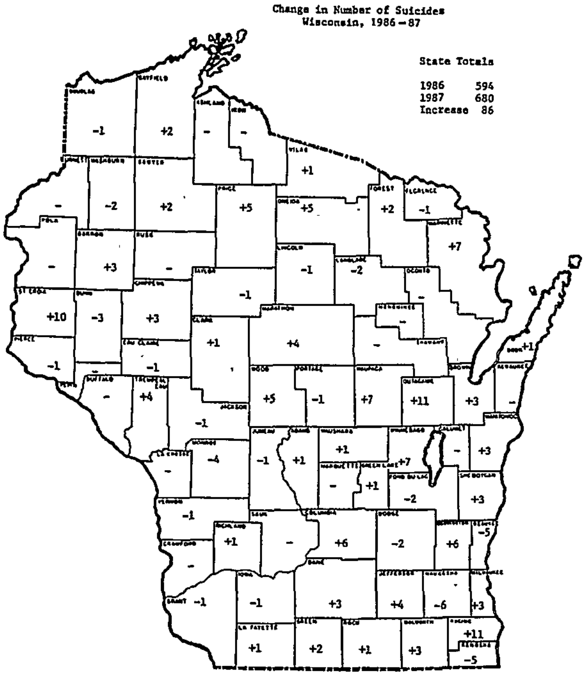


To further explore an increase in investigations of home deaths, a survey was conducted using a single page questionnaire which asked for the total number of home investigations and the number of home investigations that involved suicide reported in 1986, 1987 and 1988 and for additional comments (see Appendix A).

After two mailings and phone reminders, the response was disappointing. Of the 72 coroners and medical examiners' replies were received from 48, but of these only 33 were useable. This probably attests to the lack of continuity in record keeping which may be due to lack of staff and the lack of automation of records in these local offices. It may also be partially explained by turnover among the 61 elected coroners in a state where these elections occur every two years. Of the 33 useable responses, a net increase of 190 home investigations were reported. If the non-reporting counties followed this pattern it could account for an overall increase of more than 400 home investigations. This, along with possible random variation and perhaps some additional actual increase, could account for the increase of 86 suicides in Wisconsin from 1986 to 1987.

By county, between 1986 and 1987, there are 32 which show a numeric increase in suicides, 24 which show a decrease and 16 which remain the same (Figure 5). The average increase is four and the average decrease is two. Two large counties showed an increase of 11 each, and one moderate size county an increase of 10. After discussions with the coroners in these counties, no events having socio-economic consequences and no changes in the coroner/medical examiner system that might have contributed to the increase could be identified. Between 1986 and 1987, the percent of elderly suicides (age 75+) more than doubled (2.9% to 7.6%) in these three counties. In Racine County the coroner reported an increased number of home investigations; however, in the other two counties information on the number of home investigations was not available. The other possible explanation for at least part of the increase is that 1987 was a randomly high year for suicides in these three counties. Trend data supports this possibility particularly in the two larger counties.

Figure 5



The age distributions of suicide in Wisconsin for 1986 and 1987 provides further information for analysis. Between 1986 and 1987 suicide rates in Wisconsin increased or remained nearly stable for all age groups (Table 4, Figure 6). The largest increase occurred for persons aged 20-29 and for age group 80 and over. The rate for the 20-29 year olds increased by 30 percent and for those aged 80 and over, the rate increased by over 94 percent. Without home investigations, it is more likely that the elderly would be assigned to a cause of death other than suicide because the elderly are afflicted with more serious conditions that could cause death. There are simply more conditions to choose from for the elderly population than there are for the younger population in assigning cause of death. Iowa showed increases for age groups 20-29 and 60-69. The other states surrounding Wisconsin did not show such increases by age.

All suicides should involve the coroner or medical examiner system. These systems vary widely between jurisdictions[5] (states and counties) and are subject to statutory change. Some of the differences are shown by the following questions:

- Are there coroners, medical examiners or both?
- Are coroners or medical examiners elected or appointed?
- If elected, how frequently?
- If appointed, by whom and how frequently?
- What are the necessary qualifications?
- What proportion of those serving have medical or health training?
- How many deputies are there?
- What are the qualifications of deputies?
- If coroners or deputies are physicians, can they review the deaths of the patients they attend?
- Is there a state medical examiner?
- What are the funding sources and adequacy of funding?
- Are autopsies encouraged or discouraged?
- Are laboratory tests encouraged?
- Are there training programs?
- Are there computerized data systems?

Coroners and medical examiners would probably list adequacy of funding as the most important factor influencing completeness of reporting because it limits so many other factors.

At the state or county level, changes in any of the above categories might affect the reporting of suicide either directly or indirectly. At the national level, there would be a greater likelihood of compensating changes, and therefore more stability in reporting.

Trend discussions of suicide are generally premised on an assumption that the completeness of suicide reporting from year to year is rather consistent. Therefore, changes in trends are more likely to be associated with changing socioeconomic or other conditions. This study is a reminder that at the state (or local) level there is likely to be more variability in the reporting systems, and therefore in the completeness of reporting.

Table 4
Suicide in Five Contiguous Midwest States
By Age, 1986 and 1987

Age Group	Rates* Illinois 1986	Illinois 1987	Iowa 1986	Iowa 1987	Michigan 1986	Michigan 1987	Minnesota 1986	Minnesota 1987	Wisconsin 1986	Wisconsin 1987
10-19	5.7	6.0	9.6	7.0	6.4	7.2	12.9	9.6	7.2	8.0
20-29	14.9	13.1	12.3	15.2	15.8	15.0	14.2	18.8	16.3	21.2
30-39	13.3	12.8	17.6	15.8	15.5	15.3	15.7	14.5	14.9	15.8
40-49	13.3	11.6	19.6	15.0	15.6	14.4	13.7	13.0	14.6	16.9
50-59	14.2	12.9	16.0	16.3	14.7	15.9	16.3	13.5	17.6	18.9
60-69	14.8	16.0	18.0	24.0	15.0	15.3	15.7	17.1	15.8	14.2
70-79	22.7	19.9	25.7	26.4	20.4	17.3	21.9	16.7	23.0	25.0
80+	22.1	20.7	19.7	20.3	27.1	14.9	13.1	19.2	12.2	22.6
Total**	11.4	10.7	12.8	13.9	12.2	11.8	12.7	12.8	12.4	14.1

* Rate per 100,000 population.

** Based on the total population in each state rather than on population aged 10 and over.

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2. Pescosolido BA, Mendelsohn R: Social Causation or Social Construction of Suicide? An Investigation Into the Social Organization of Official Rates, American Sociological Review 1986; 51:80-101.
3. WHO Chronicle, Suicide Statistics the Problem of Comparability 1975; 29:188-193.
4. Wisconsin Statutes, 1987-1988, 39th Edition, Vol. 2, Chapter 69, Subchapter 1: Vital Statistics.
5. Parrish RG, Ing R: Medical Examiner and Coroner Jurisdictions in the United States, American Academy of Forensic Science 1988.

Appendix A

SUICIDE QUESTIONNARE

Please answer as many of the following questions as possible. If you are unable to complete items 3 and/or 4 on the questionnaire, please specify the reason (example: newly-elected coroner with no information on past practices, etc.)

Thank you for your continued cooperation and assistance.

1. How many home deaths (pronouncement of death made at home) did your office investigate in the following years?

1986 ________ Is this number based on a tabulation? ____ or an estimate? ____
1987 ________ Is this number based on a tabulation? ____ or an estimate? ____
1988 ________ Is this number based on a tabulation? ____ or an estimate? ____

2. How many home deaths were ruled suicide? (Please note that this number would not include all suicide investigations in your county, but rather only those that involved home deaths.)

1986 ________ Is this number based on a tabulation? ____ or an estimate? ____
1987 ________ Is this number based on a tabulation? ____ or an estimate? ____
1988 ________ Is this number based on a tabulation? ____ or an estimate? ____

3. Has there been a change in your county (1986-1988) in the way the determination of suicide is made? Yes ____ No ____ If yes, please briefly describe:

4. Prior to November, 1986, were death certificates of suicides in your county signed by the attending physician rather than by the coroner?

____ Often ____ Sometimes ____ Rarely ____ Never

Please return this information to: Peggy Peterson, Center for Health Statistics,
P.O. Box 309, Madison WI 53701-0309

For additional information call: Peggy Peterson (608) 267-7812 or
Ray Nashold (608) 266-1334

(Signature of Coroner/M.E.) (County) (Date Signed)

TRENDS IN FIRE DEATHS, 1970 - 1986

Beatrice Harwood, U.S. Consumer Product Safety Commission

For some years a general consensus has existed within the fire community that most people who die in fires are killed by smoke inhalation rather than burns. However the supporting epidemiological evidence has been based on a few local studies with a relatively small number of cases and have provided no indication of whether the smoke inahalation problem is growing larger or smaller.

The purpose of this paper is to review the mortality data collected by NCHS as it relates to this important problem.

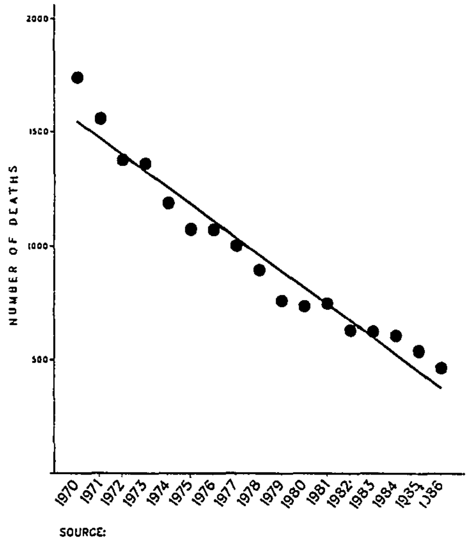
First let us examine the fire death trends from 1970 through 1986. The E-codes that designate accidental deaths from fires and flames are E 890-899. These codes include the majority, but not all of the accidental deaths caused by fires. They do not include those caused by suicide or homicide, nor deaths from vehicular fire deaths. We have divided these codes into 2 groups. E-codes 890 and 891 denote deaths that occurred in "structural conflagrations" while E-codes 892-898 denote deaths in fires that did not involve a structural conflagration; that is, outside fires like brush or trash fires, or deaths from flames that did not cause a structure to catch on fire, like the ignition of clothing or fires involving heating equipment, absent a general conflagration. The reason for the dichotomy is that structural conflagrations present a degree of smoke inhalation hazard that one would not expect to encounter in fires that did not result in a structural conflagration.

Let us first look at the trend since 1970 in fire deaths that did not involve a structural conflagration. Both the actual data and a linear regression line are shown. The trend is sharply down over the entire period, a drop of some 73 percent. The differences between these rates of change are profound. In 1970 1,738 such deaths were recorded. By 1986 that number stood at 466.

The second chart shows the trend in deaths from structural conflagrations, (that is E-codes 890-891). This graph is quite different from the first. There is no pronounced trend, and the linear regression is not a very good fit. In fact, during the 1970's the number of deaths actually went up slightly. A modest decline has occurred during the 1980's, but overall the percentage change during the entire 16 year period has been only minus 8 percent. Note also that this is where the bulk of fire deaths occur, in structural conflagrations. In 1970 4,450 such deaths occurred. By 1986 the number was 4,112.

FIRE DEATHS FROM NON-STRUCTURAL CONFLAGRATIONS
OR FLAMES WITHOUT CONFLAGRATION

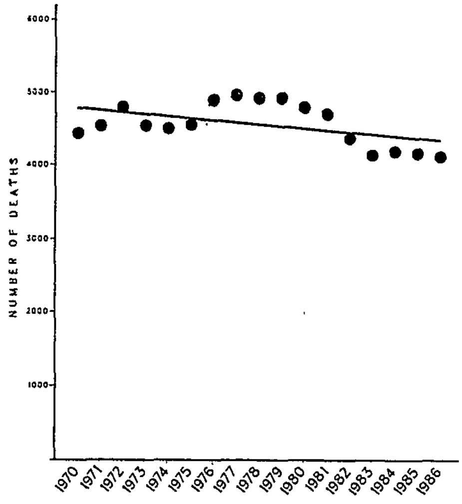
E-codes 892 - 898



SOURCE:
U.S. Consumer Product Safety Commission/EPHA
National Center for Health Statistics

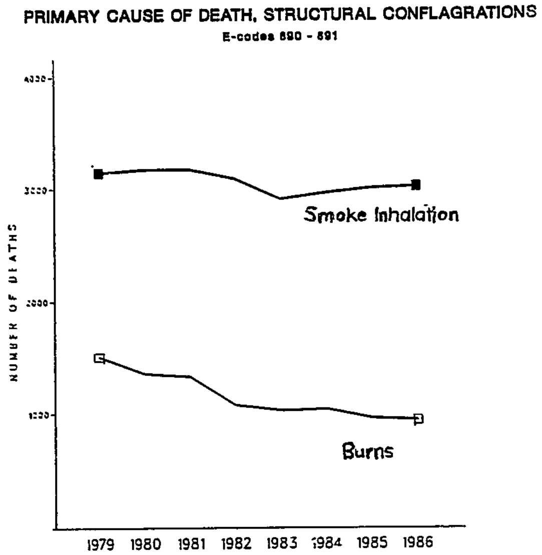
FIRE DEATHS FROM STRUCTURAL CONFLAGRATIONS

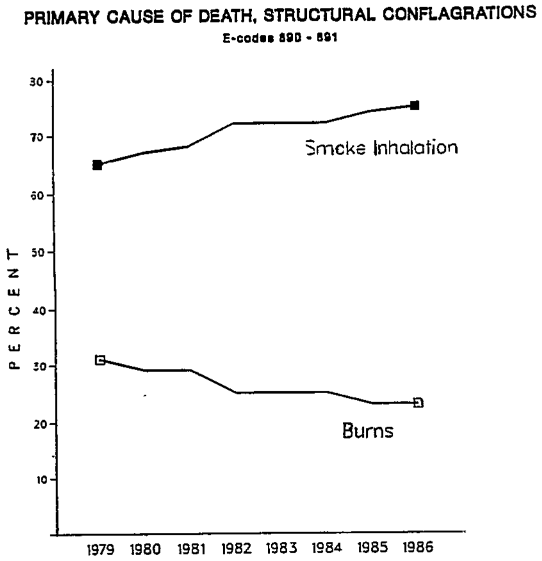
E-codes 890 - 891



SOURCE:
U S. Consumer Product Safety Commission/EPHA
National Center for Health Statistics

As mentioned earlier, structural fires are those most likely to present a smoke inhalation hazard. Undoubtedly because of that, the ninth revisions to the E-codes provided, for structural conflagrations only, a differentiation between smoke inhalation and burns as the primary nature of injury causing death. The next chart shows how these data have changed since 1979, when the new codes became effective. In all years, smoke inhalation was a more important cause of death than burns, and the rate of change was different for the two causes. From 1979 through 1986, smoke inhalation deaths (in structural conflagrations) declined by only 4 percent, burns by 37 percent.

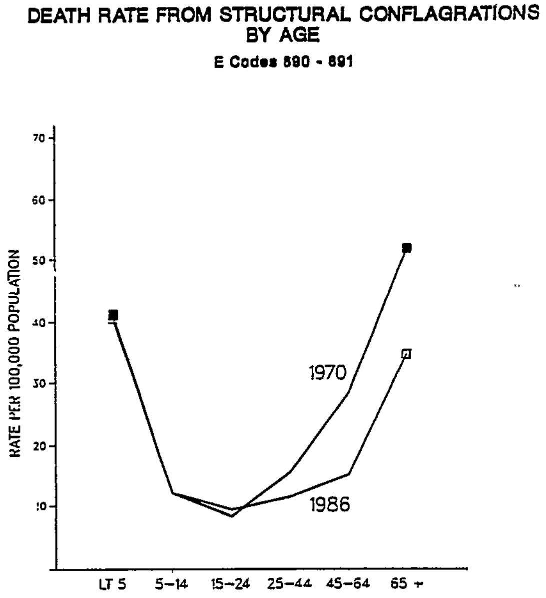

PRIMARY CAUSE OF DEATH, STRUCTURAL CONFLAGRATIONS
E-codes 890 - 891


PRIMARY CAUSE OF DEATH, STRUCTURAL CONFLAGRATIONS
E-codes 890 - 891

SOURCE:
U.S. Consumer Product Safety Commission/EPHA
National Center for Health Statistics

The next graph shows the same data but in terms of the percentage share for each cause. In 1979 the ratio of smoke inhalation deaths to burn deaths was about 2:1; by 1986 it was 3:1.

Since the age distribution of the population has shifted significantly during the last 16 years, and since we know that age is an important factor in the risk of fire death, we examined trends since 1970 in fire death rates by age - again, for structural fires only.


DEATH RATE FROM STRUCTURAL CONFLAGRATIONS BY AGE
E Codes 890 - 891

SOURCE:
U.S. Consumer Product Safety Commission/EPHA
National Center for Health Statistics

The U-shaped curve that is familiar to fire service professionals can easily be seen. The very young and the old are at particularly high risk of dying in a fire. However, one can see that the most substantial reduction in death rates has occurred among middle-age adults and the elderly, the least reductions among children and young people.

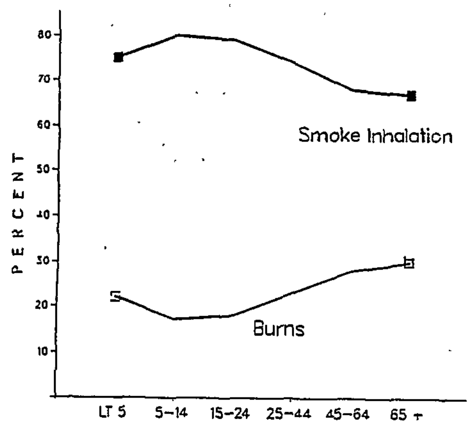
The table below shows the actual computed rates, and the percentage change from 1970 - 1986. The per capita (fire death) rates have declined more rapidly than actual frequencies. This, of course, is because the U.S. population increased by an estimated 17 percent during that time period. Therefore, while actual frequencies decreased by only 8 percent during the 16 year period, per capita rates decreased by 23 percent. Again, one can see that virtually all of this decrease can be attributed to a reduction in risk for middle age and older adults.

DEATH RATE FROM STRUCTURAL CONFLAGRATIONS
by AGE
E-Codes 890 - 891

	Rate Per 100,000 Population			PERCENT CHANGE
Age	1970	1980	1986	'70-86'
All Ages	21.9	21.2	16.9	-23%
Less Than 5	41.1	48.9	40.5	- 2%
5-14	12.0	13.1	12.0	+ 0%
15-24	8.2	12.1	9.3	+13%
25-44	15.5	13.6	11.4	-26%
45-64	28.2	22.4	15.1	-46%
65+	51.7	45.8	34.6	-33%

Those differences in per capita risk by age raise questions about the influence of age on the likelihood of death from smoke inhalation vs. burns. The next chart shows those differences, with data aggregated over 3 years. Except for the very youngest age group the percentage of burn deaths varied directly with age,
while the percentage of smoke inhalation deaths was inversely related. Thus, in general, the persons who were shown to have registered the least reduction in risk of fire death over time, children and young adults, were also those generally more likely to die of smoke inhalation rather than burns.

DEATHS IN STRUCTURAL CONFLAGRATIONS
BY AGE AND NATURE OF INJURY
1983 - 1985



SOURCE:
U.S. Consumer Product Safety Commission/EPHA
National Center for Health Statistics

To summarize, these data have demonstrated that:

- Fire deaths attributed to smoke inhalation are several times more frequent than deaths attributed to burns and going down more slowly.
- Rates for young people are declining more slowly than those for adults and the elderly.
- Young people are more apt to die of smoke inhalation instead of burns than older people are.

There are some caveats to the NCHS data that should be mentioned. The cause of any accidental death is determined by a local coroner or health examiner. This person may be, but is not necessarily, a physician. An autopsy may or may not have been performed. Thus, varying degrees of certainty may attach to the attribution of burns or smoke inhalation as the primary cause of death, particularly when both of these conditions were present. Information from the fire services indicates that most victims have suffered both smoke inhalation and burns. It is possible that changes in perception or certain other coding artifacts have affected cause of fire death classification over time.

On the other hand, the differences shown here are pronounced, not minor, and the trends are consistent over time. The data strongly suggest that smoke inhalation represents an increasingly large proportion of the fire problem.

The reasons for this are not self-evident. However, the results are consistent with a reported increase in the presence of furnishings and materials in American homes that may present a greater risk of toxic smoke generation in the event of a fire. It is also possible that more advanced methods of treating serious burn injuries have resulted in the survival of patients who might have died years ago, leading to a more pronounced decline in burn deaths than in smoke inhalation deaths.

In any case, these results highlight the need to keep in mind, when designing strategies to prevent fire deaths, that smoke inhalation appears to be the larger hazard, and account for an increasing proportion of the total.

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SURVEILLANCE OF INTENTIONAL AND UNINTENTIONAL INJURIES THROUGH OCCUPATIONAL MORTALITY STUDIES

Jay S. Buechner, Rhode Island Department of Health
David M. Gute, Tufts University

Introduction. Much research in the field of occupational health begins with the analysis of mortality patterns of workers in different occupations and industries as compared to the experience of the general population. The primary purpose of these studies is to detect statistical associations from which cause-and-effect relationships may be proposed. Such hypothesized relationships may then be examined using more definitive epidemiologic methods, examination of exposures in the workplace, and other techniques. The ultimate purpose of such efforts is to identify workplace risks and reduce or eliminate them.

The study reported here concerns the application of occupational mortality analysis to the problem of injury mortality that results from personal risk patterns. Although worksite injuries have been a principal concern in occupational health, injuries of other kinds may vary among different occupations if some occupational circumstances lead to elevated rates of alcohol or drug use, of risk-taking behavior, or of other predictors of high injury rates. In this study, then, occupation has been used as a proxy measure for patterns of personal behavior. The value of the occupational approach is that it helps identify target groups for injury control efforts and encourages the use of the worksite as a locale for interventions in the same way it has been used for other health promotion activities. An additional benefit is that such studies may illuminate the causes of injuries and suggest methods to prevent them.

Background. The Rhode Island Department of Health has previously performed occupational mortality analyses for four different time periods covering the years 1968-84.[1-4] These studies have given rise to a number of detailed investigations of particular elevations in mortality rates that are of suspected occupational origin. The elevated mortality rates investigated have included malignant melanoma in the printing industry,[5] a variety of causes of death among jewelry workers,[6] a variety of causes of death among textile workers,[7] suicide among social workers,[8] and heart disease among policemen.[9] Occupational surveillance efforts in Rhode Island have also been cited in publications describing the results of programs sponsored by the National Institute for Occupational Safety and Health (NIOSH) in the areas of occupational mortality[10] and sentinel health events.[11]

Methods. The Rhode Island death certificate requests the "usual occupation" of the decedent, defined as the "kind of work done during most of working life, even if retired." Beginning with 1968 deaths, these entries have been coded for all Rhode Island residents who were 15 years of age or older at the time of their death. The coding system used for death certificates for 1979 onward was that used in the 1980 United States Census.[12] Underlying cause of death was coded using the International Classification of Diseases, Ninth Revision (ICD-9), for the same time period. For analysis, the codes for occupation and cause of death were combined into logical groups so that the analytic results are based on larger numbers of cases, thereby increasing their stability. The cause of death groupings employed for injuries appear in Table 1. Occupational groupings follow the category headings appearing in the Bureau of the Census coding guide; there were 58 major and minor categories employed in the analysis.

Table 1: Definition of Cause of Death Code Groups for Injuries

Cause of Death	Code Range*
Injuries and Adverse Effects	800-999
Unintentional Injuries	800-949
Motor Vehicle	810-825
Poisonings	850-869
Falls	880-888
Fires	890-899
Drownings	830,832,910
Firearms	922
Intentional Injuries	950-978
Suicide	950-959
Homicide and Legal Intervention	960-978

*ICD-9 (External Causes of Injury and Poisoning)

The method of analysis employed was the proportionate mortality rate (PMR). The PMR is determined from the ratio of two proportions: the numerator is the proportion of persons dying during a chosen time period from a particular cause of disease in the occupational category of interest; the denominator is the proportion of persons in the general population dying from that cause during the same time period. The resulting ratio is multiplied by 100, so that a PMR of greater than 100 states that a higher proportion of persons in the indicated occupational group died from the indicated cause than did so in the general population. PMR's were calculated separately for race-sex groups and for three age groups (15-54 years, 15-64 years, and 65 years or older). PMR's based on four or more deaths due to a specified cause in an occupational group were subjected to a test for statistical significance using the Mantel-Haenszel chi-square statistic.[13] A discussion of the PMR method as used here is presented in the original Rhode Island study.[1]

Results. There were 54,065 deaths of Rhode Island residents age 15 or older during the period 1979-84; these were distributed by race and sex as shown in Table 2. It is clear from the table that the number of non-white deaths in Rhode Island during this period is insufficient to support analysis at this level of detail. All further discussion will center on the results for the white population, therefore.

Table 2: Deaths of Residents Ages 15 and Older, by Race and Sex, Rhode Island, 1979-84

Race/Sex	Number of Deaths
White Male	26,976
White Female	25,730
Non-white Male	731
Non-white Female	628

Table 3 presents the numbers of deaths during the six years studied among white males and white females age 15 or older, by cause of death, including the injury categories listed in Table 1. Overall, 5.9% of white male deaths were due to injuries; for white females the figure was 3.1%. Among those age 15-54, the proportion dying from injuries was 31.7% among white males and 20.4% among white females. The numbers of deaths in several of the specific injury categories are seen to be very small despite the aggregation of six years of data; such small numbers imply that elevated mortality rates for those causes of death will be difficult to detect with any level of statistical significance.

Table 3: Deaths of White Residents Ages 15 and Older, by Cause of Death and Sex, Rhode Island, 1979-84

Cause of Death	Number of Deaths Male	Number of Deaths Female
Non-Injuries	25,380	24,943
Injuries and Adverse Effects	1,596	787
Unintentional Injuries	968	553
Motor Vehicle	457	199
Poisonings	65	25
Falls	184	186
Fires	36	37
Drownings	80	12
Firearms	5	0
Intentional Injuries	595	218
Suicide	457	156
Homicide and Legal Intervention	138	62

Selected instances of elevated PMR's for occupational groups are presented in Table 4 (white males) and Table 5 (white females). The selection has been made on the basis of a number of considerations, including the extent of elevation as indicated by the PMR, the number of apparent excess deaths, the level of statistical significance, the suggestion of patterns for occupational groups, and other public health considerations.

Of greatest interest in Tables 4 and 5 is the extent to which occupational groups are found to have elevated PMR's for more than one type of injury, indicating an overall pattern of injury-prone behavior among workers in those occupations. Among male workers in the construction trades, including the subcategories of carpenters and painters, mortality rates are elevated for accidental poisonings, falls, fires, drownings, and suicide. Male laborers of various kinds exhibit excess mortality from accidental poisonings and falls, as well as unintentional injuries in general. Machine operators, both male and female, show excess mortality in several categories of injury, including falls (males only), fires (males and females), and homicide (females only). Female teachers have high PMR's for motor vehicle-related deaths and falls, although these elevations are limited to the elderly.

Specific findings of note in Tables 4 and 5 have been investigated in further detail. The very high PMR for drownings among males in the forestry, fishing, and hunting occupations is an instance of true occupational risk; all eight deaths resulted from boating accidents to commercial fishermen. This group had elevated mortality rates for unintentional injuries in general beyond those due to drownings, but the numbers of deaths were small and the elevations were not statistically significant. The elevated suicide rate among male protective service workers, including policemen, firemen, and private security guards, may also be related to occupational circumstances. Of the 16 deaths, 14 were due to firearms, suggesting that access to firearms in the course of their duties increased the risk of suicide among these workers. This finding has not been reported in other studies.

Homicides were an elevated cause of death among both males and females in the precision metal and woodworking occupations during this period. In all cases, the victims were workers in the jewelry industry, and a majority fell into the specific occupational category of precious stones and metals workers. The possibility of robbery as a motive for these homicides can only be tested with additional data.

The finding of elevated numbers of suicides among females in the health diagnosis and treatment occupations (including physicians and registered nurses), echoes earlier findings from British data.[14] Five of the eight suicides were accomplished by poisoning due to prescription drugs or other medications, possibly reflecting the ease of access to such drugs among these workers.

Cause-specific mortality rates among white female teachers, especially those age 65 or older, were elevated in an interesting pattern. Table 6 presents selected PMRs for this group for both injuries and selected other causes of death. Cancers of the

Table 4: Occupational Groups with Elevated Proportionate Mortality Rates (PMR), by Cause of Death, White Males, Rhode Island, 1979-84.

Cause of Death/Occupational Group	Age	PMR	Deaths
Unintentional Injuries			
Forestry, Fishing, and Hunting Occupations	All Ages	184	25 ($p<0.01$)
Construction Trades	All Ages	131	88 ($p<0.01$)
Handlers, Equipment Cleaners, Helpers, and Laborers	All Ages	140	78 ($p<0.01$)
Motor Vehicle			
Farming and Other Agriculture	65+	492	5 ($p<0.01$)
Poisonings			
Construction Trades	15-54	195	8 ($p<0.05$)
Laborers (Non-Construction)	15-64	331	5 ($p<0.01$)
Falls			
Technicians and Related Support Occupations	All Ages	371	7 ($p<0.01$)
Carpenters and Apprentices	15-64	380	4 ($p<0.01$)
Machine Operators (Assorted Materials)	15-54	311	5 ($p<0.01$)
Handlers, Equipment Cleaners, Helpers, and Laborers	All Ages	212	16 ($p<0.01$)
Fires			
Construction Trades	15-64	261	5 ($p<0.05$)
Machine Operators and Tenders (Except Precision)	15-64	220	6 ($p<0.05$)
Drownings			
Forestry, Fishing, and Hunting Occupations	15-64	649	8 ($p<0.01$)
Construction Trades	15-64	211	9 ($p<0.01$)
Suicide			
Protective Service Occupations	15-64	186	16 ($p<0.01$)
Painters (Construction and Maintenance)	15-64	233	9 ($p<0.01$)
Homicide			
Farming and Other Agriculture	All Ages	352	7 ($p<0.01$)
Precision Metal and Woodworking Occupations	15-64	190	10 ($p<0.05$)

Table 5: Occupational Groups with Elevated Proportionate Mortality Rates (PMR), by Cause of Death, White Females, Rhode Island, 1979-84

Cause of Death/Occupational Group	Age	PMR	Deaths
Unintentional Injuries			
Professional Specialty Occupations	All Ages	144	53 ($p<0.01$)
Teachers	65+	227	22 ($p<0.01$)
Motor Vehicle			
Teachers	65+	427	7 ($p<0.01$)
Food Preparation and Service Occupations	15-64	233	10 ($p<0.01$)
Falls			
Teachers	65+	263	14 ($p<0.01$)
Fires			
Machine Operators (Assorted Materials)	All Ages	494	5 ($p<0.01$)
Suicide			
Health Diagnosis and Treatment	15-64	210	8 ($p<0.05$)
Homicide			
Precision Metal and Woodworking Occupations	All Ages	284	6 ($p<0.01$)
Textile, Apparel and Furnishings Machine Operators	15-54	504	4 ($p<0.01$)

Table 6: Cause of Death Groups with Elevated Proportionate Mortality Rates (PMR) among White Female Teachers, Rhode Island, 1979-84.

Cause of Death	Age	PMR	Deaths
Unintentional Injuries	65+	227	22 ($p<0.01$)
Motor Vehicle	65+	427	7 ($p<0.01$)
Falls	65+	263	14 ($p<0.01$)
Malignant Neoplasms of the Esophagus	65+	315	6 ($p<0.01$)
Chronic Liver Disease and Cirrhosis	65+	205	7 ($p<0.05$)

esophagus, chronic liver disease, and accidents are all elevated and share a common risk factor, alcohol consumption. Alcohol consumption rates are known to vary with occupation, and rates among professional women are higher than among other women.[15] Although teachers are not normally thought to be at risk for alcohol abuse, the findings of this study warrant further attention to the personal risk factors affecting this group, their possible occupational origins, and potential preventive measures.

Discussion. This report presents selected associations between elevated injury mortality rates and occupation in Rhode Island during 1979-84. Most of these elevations do not represent true occupational exposures; they more likely reflect differing patterns of health-related behavior. As an example of health-related behavior that varies with occupation, a 1985 sample survey of the Rhode Island population revealed that cigarette smoking rates varied from a low of 23 percent among those in managerial or professional occupations to a high of 42 percent among those in service occupations.[16] An association from the 1979-84 Rhode Island study that may reflect personal risk factors is the pattern of mortality among white female teachers, if these patterns are indeed related to alcohol consumption.

The results presented here are for the most part suggestive and not conclusive, and further information would be needed to establish associations between mortality patterns and personal risk factors for specific groups. Nevertheless, this study has been useful in several ways. First, it has demonstrated that some occupations exhibit patterns of elevated injury mortality that are not related to the workplace. Second, in employing occupation as a proxy for social and economic factors in personal health behavior, it has extended the scope of occupational mortality analysis. Third, it has provided an additional source of information, and potentially an aditional intervention locale, for injury control efforts. Finally, it has expanded the usefulness of occupational information that is expensive to code and keypunch by employing it in an innovative way that can be adopted wherever these data are available.

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AN ASSESSMENT OF SURVEILLANCE AND VITAL STATISTICS FOR MONITORING TETANUS MORTALITY, 1979-84

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Session O

State Epidemiology and Statistics

PHCRS

A FULLY AUTOMATED VITAL REGISTRATION SYSTEM:A MEANS FOR MORE ACCURATE, TIMELY AND COMPLETE HEALTH STATISTICS

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KEY WORDS: vital records, automation

Scope of the problem

The New Hampshire Bureau of Vital Records & Health Statistics (NHBVRHS) registers and maintains legal/statistical copies of major individual life events: birth, marriage, divorce and death. The Bureau is also the State's Health Statistics Center, charged with collecting and analyzing health data. The Bureau and other agencies use birth and death certificate data to identify the health needs of New Hampshire residents and make the best use of health resources. Information from these certificates can help identify potential health hazards in the environment, workplace or home. Such health risk information may include industry/occupation of a decedent or of a newborn's parents, maternal smoking status and pregnancy history.

The State of New Hampshire's small geographical area and population size gives us unique opportunities to innovate in the arena of vitals registration. Approximately 17,000 births occur annually, 98% in 27 hospitals and over 90% in 18 of these, Exhibit 1. However NH lacks county health departments; instead of contact with ten counties, our Bureau must deal regularly with 234 town clerks who occupy one step in vital events registration.

Since John Graunt's Bills of Mortality in 1603 London, data quality and timeliness problems have plagued vital registration. From paper, pens, typewriters and xerography to microcomputers, each technological advance has brought more improvement, but problems remain, particularly when those doing the work do it as a peripheral duty rather than as their principal task. In July of 1988 New Hampshire began implementation of an Automated Birth Certificate (ABC) system in order to overcome difficulties experienced with the previous paper trail manual system.

The New Hampshire ABC is an integrated microcomputer system for the collection, management and reporting of vital records. ABC uses modern interactive methods of data acquisition, storage, retrieval and reporting. Networks of microcomputers are coupled with a common relational data base manager software package.

Exhibit 2 compares paper and automated systems task by task. The paper system obviously takes more time, more care, more steps and offers more chance for errors and omissions. These difficulties derive from the fact that each additional entry or change must pass from a human mind onto a page and back again. Paper forms cannot respond to missing or inappropriate entries. Nor does the paper move to the next step with minimal human intervention.

By establishing a common interface between public and private institutions concerned with the delivery of good health care services, ABC expedites the vital registration process. Computerization of birth records as close as possible to the health service event thus bypasses many time-consuming, redundant, and error-prone intermediate steps now part of present public health data systems.

The concept most fundamental in an automated system is to reduce redundant effort and to eliminate data errors by automating routine paper records (forms) as close as possible to the original sources of information. ABC enables hospital personnel to type birth certificate data into a microcomputer terminal and have these data instantly edited for completeness and correctness. By capturing information directly in the hospital, chances of error decrease while data transfer speed increases. Two products are created: a printed paper record and a computer data record. A modem connecting the hospital by regular phone line transmits data to the State Bureau of Vital Records, or a floppy diskette is sent to update State files.

From a public health users' standpoint, an automated vitals system has several advantages. It lends itself to applications formerly impossible such as immediate surveillance and follow-up of high risk infants, and it can help to identify future children at risk. Any ad hoc or periodic reports can be abstracted in a timelier and more accurate fashion than paper/manual systems allow.

The NH Division of Public Health has identified automating the vitals process as an item of high priority. Previously vital event registration was an essentially manual system in which data were handled by a mixture of over twenty fragmented programs. The new automated system allows prompt registration of more accurate vitals information, checked at the source during capture. Vital record certificates or data files thus can be available within hours of the respective vital event. Such timeliness better meets requestors' needs, be they a legal copy of a birth certificate or immediate notification of all newborns having birth defects. This system also reduces the time involved and the errors that occur during manual coding of certificates because nearly all the coding of medical and demographic items is done by the computer program (see Exhibit 3, Worksheet for Preparing Certificate of Live Birth); for example, race, education, and maternal use of tobacco and alcohol use computer-coded entries.

After review of automated systems in California (AVSS), Rhode Island, Massachusetts and those on the proprietary software market, we developed the NH ABC program using a commercial data base management software package. We supply hospitals with a copy of the compiled ABC program on a floppy diskette. This diskette can be loaded to the hard disk of any IBM-compatible microcomputer. The program is menu-driven, user-friendly and runs directly from the DOS level with no other support. The end-user needs no knowledge of programming. A basic understanding of microcomputer operation is helpful but not necessary.

ABC was introduced on a pilot basis in two participating hospitals and the state central office. After testing, our goal was to get the eighteen largest hospitals on the system and thus cover in excess of 90% of the births in the state.

Results

During an in-house pretest phase, ABC worked so well that we began using it for all birth certificate data entry January 1, 1988. For the pilot test phase, we then engaged the two cooperating hospitals asterisked in Exhibit 1.

Once the pilot hospitals gave us the benefit of their experience an upgraded ABC version was released. By mid-1989 we had expanded, on a voluntary basis, to 16 hospitals with 3 additional hospitals scheduled to begin in August reaching 93% of NH births. Because the tail of our birthing hospital distribution has six sites with fewer than 100 births/year/site, we cannot expect full Statewide automation within an exact time frame, although several of the very small birthing centers have shown interest. ABC complete with software and technical assistance will be offered by mutual agreement to all centers able and willing to support it.

ABC has a significant impact on reducing the number of queries and data lag time. In examining the number of queries by ABC hospitals before and after automation. Queries dropped by over 90%. Adhearnce to the state 10 day time reporting requirement increased by 30%. Hospitals were able to reduce their data lag time from weeks to days.

Obtaining social security numbers shortly after birth and adding them to the birth file enhance the potential for use of additional information and linkage with other datasets. For example children's mortality data from death certificates may be associated with parental risk information obtained from birth certificates, such as smoking status or occupation.

Although other sites may not fare as well, we expect to save five person-days per week, four in-house and the other divided among participating hospital birth centers. The reduced querying speaks well for increased quality of data, both as fewer omissions and more accurate entry. ABC has changed the very philosophical basis involved in the origination of vital records information; keeping the entire recording process among medical records personnel frees clinical care providers from duties many saw as onerous and thus increases accuracy and timeliness.

The estimated state-level costs include 0.5 person-year of programming, approximately $500 travel, $300 communication, $5000 hardware, and $600 in software. Site costs vary widely depending on availability of existing microcomputers.

System Design Characteristics

The NHBVRHS ABC project team agreed upon six required system design features:

1) -interactive, fast, easy use by hospital personnel without prior computer experience;

2) -security safeguards;

3) -accurate on-line edit capabilities;

4) -ease of transport;

5) -flexible potential for growth;

6) -cost effectiveness.

The ABC program was developed using the industry standard data base management software package, dBase III+ and then compiled with Clipper, a dBASE compiler, to increase speed and efficiency . An interpretive language, dBase reads and executes one line of code at a time. The interpreter steps through each line of code and, if no errors are detected, converts the line into machine-language code. While an interpreter works well for learning or developing programs, it tends to operate too slowly for actual program use. A compiled program runs many times faster than the original source form and no longer requires the interpreter, the compiler, or the original program . It also protects authors' copyright interests in the code, as a compiled program is practically unreadable and difficult to alter. Clipper translates a dBase program into native code, an (-.EXE) file executed directly from the DOS level. No runtime modules, runtime or royalty fees are involved in distributing the compiled program. Kermit software is used for online communications with hospitals. Three hospitals representing 24% of the birth records began transmitting their records via modem in May of 1988 (see timeline, Exhibit 4).

ABC was designed to reduce repetitive or unnecessary keystrokes. ABC reduces the average number of keystrokes required to complete a birth certificate by about 200 (38%). This was done by programming computer-filled entries based on initial responses to key items. For instance, once the hospital has indicated that the birth occurred in their facility, the city and county of birth are computer-filled. In addition, the hospital clerk need only enter the first few letters of the birth attendant's last name, and the program searches the file for a match, prompts the data entry person for verification, and then fills the attendant's full name, title and address. ABC also performs interactive edits and validity checks to detect errors the moment they are entered (cf. Exhibit 5). In all ABC performs up to 30 interactive edits (44%), 34 checks on range or validity (50%), 5 program defaults (1%), 27 computer filled responses (40%) a total of 57 assisted items (84%) with some overlap among 68 items.

Birth Certificate Processing: Legal versus Statistical Information

For each NH live birth, the hospital must file a birth certificate with the city or town clerk where the birth occurred within 6 working days. After the town clerk reviews and signs the certificate, the original legal copy is sent to NHBVRHS, and one copy is kept at the town level. Hospitals have 10 days to send statistical copies to the NHBVRHS; with ABC, these copies are sent on a single diskette or via modem.

After a diskette is received from the hospital it is appended to the state statistical file. When a hospital file is uploaded to the state file the system date is computer-filled into the date-received field. All data are backed up daily to Bernoulli Box cartridges.

All non-ABC hospital certificates are entered into an adapted state version of ABC and added to the statistical file. A report is generated for all automated records with items containing codes for blanks or unacceptable entries, and these certificates are flagged for query. Once a statistical record is complete and all queries answered, birth records are ready for upload to the master file on the mainframe computer system. After a record has been uploaded to the master file it is removed from the PC statistical file.

State legal copies are processed weekly and issued state certificate numbers upon receipt from town clerks. Legal copies are then entered into the mainframe system and matched against the uploaded PC statistical file. Error reports and lists of unmatched certificates are produced and records corrected and updated as appropriate. A 10% sample of electronic certificates is checked manually against the paper worksheets. Master files are then created from all corrected or verified records. In the unusual case that future analysis should suspect or discover inappropriate data items, a copy of the certificate worksheet can be retrieved from the patient's permanent medical record at the hospital.

Future Plans: Additional Record Types

Beginning with birth certificates, our ultimate goal is a paperless system, with all vital records fully automated, including deaths, marriages and divorces. All vital events will be entered into a modified version of the Automated Birth Certificate program. A separate record-generating state mainframe file, subject to soon to be proposed legislation, will also enable local online issuance of certified copies of all vital events. Inclusion of social security numbers will further facilitate record linkages. We also plan to automate coding of industry and occupation classifications.

An automated death certificate program will be developed following successful ABC operation in the hospitals. The death program will be installed in the same manner as the birth certificate on a voluntary basis and will be either hospital or funeral home based or a combination thereof. Funeral directors would benefit from this type of automated system by enabling them to produce their own burial permit, presently required before making a burial. Depending on volume and hospital needs the same microcomputer could be used for processing both certificates. The system will then be extended for use by non-birthing hospitals, nursing homes and town clerks. As noted, in an additional phrase, marriage and divorce data will be entered by town clerks and clerks of court and transmitted to the state vital registry.

Principles of the ABC system apply reasonably well to any record system using a standard form. Thus not only vital events but also emergency medical system (ambulance) run reports, hospital discharges, motor vehicle crashes, workers' compensation, social security, insurance, retirement, WIC or other systems may be automated using this type of approach. As other systems become automated record linkage is enhanced and therefore adds value to these datasets. Analogous benefits may be expected; obviously appropriate safeguards need to be developed which will assure confidentiality and protection of the vital information from unauthorized access, use or abuse.

Items under long-term consideration include the use of an optical disk data base system to perform document image processing. Among additional required pieces of equipment are an optical scanner, IBM-compatible microcomputer, optical disk storage medium, optical disk data base software and a laser printer. With this type of system existing certificates would be processed without need for any human data entry. Certified copies thus generated have a better appearance than the original certificate.

Conclusion

Replacing diverse and changing individual and distractible minds with a standardized, hierarchical system able to prompt data entry clerks and to refuse inappropriate entries assures higher quality data. The ability to program repeated items to be entered with a single keystroke rather than typing whole phrases relieves all concerned parties from the tedium of filling out forms. The public gets a higher quality document sooner. Statistical research acquires more complete and accurate data with less lag time. Health care providers relieved of paperwork can concentrate on their patients. The entire ABC process reduces the costs of a vital government function while it helps to promote public health and that is what we are all about!

Exhibit 1: LEADING NEW HAMPSHIRE RESIDENT HOSPITAL BIRTH FREQUENCIES, 1988

Hospital	Births	Percent	Cum. births	Cum. %
Nashua*	2123	12.4	2123	12.4
Elliot*	1964	11.5	4087	23.9
Concord**	**1647**	**9.7**	**5734**	**33.6**
M H M C*	1069	6.3	6803	39.9
Wentworth*	995	5.8	7798	45.7
Exeter*	937	5.5	8735	51.2
Portsmouth*	877	5.1	9612	56.3
St Joseph*	832	4.9	10444	61.2
Catholic*	774	4.5	11218	65.7
Lakes*	768	4.5	11986	70.2
Cheshire*	662	3.9	12648	74.1
Parkland*	640	3.8	13288	77.9
Frisbie*	571	3.3	13859	81.2
USAF/Pease*	460	2.7	14319	83.9
Monadnock *	423	2.5	14742	86.4
Valley Reg**	**374**	**2.2**	**15116**	**88.6**
Littleton*	304	1.8	15420	90.4
Memorial*	303	1.8	15723	92.2
A Peck Day	260	1.5	15983	93.7
Franklin	189	1.1	16172	94.8
Androscoggin	178	1.0	16350	95.8
At-home int	166	1.0	16516	96.8
Weeks*	130	0.8	16646	97.6
Speare	106	0.6	16752	98.2
Up Cn Valley	71	0.4	16823	98.6
Fam Birthing	68	0.4	16891	99.0
Huggins	49	0.3	16940	99.3
New London	47	0.3	16987	99.6
Cottage	42	0.3	17029	99.9
At home unint	15	0.1	17044	99.9
All other	9	0.1	17053	100.0

**** 1988 ABC pilot sites.** *** ABC hospitals**

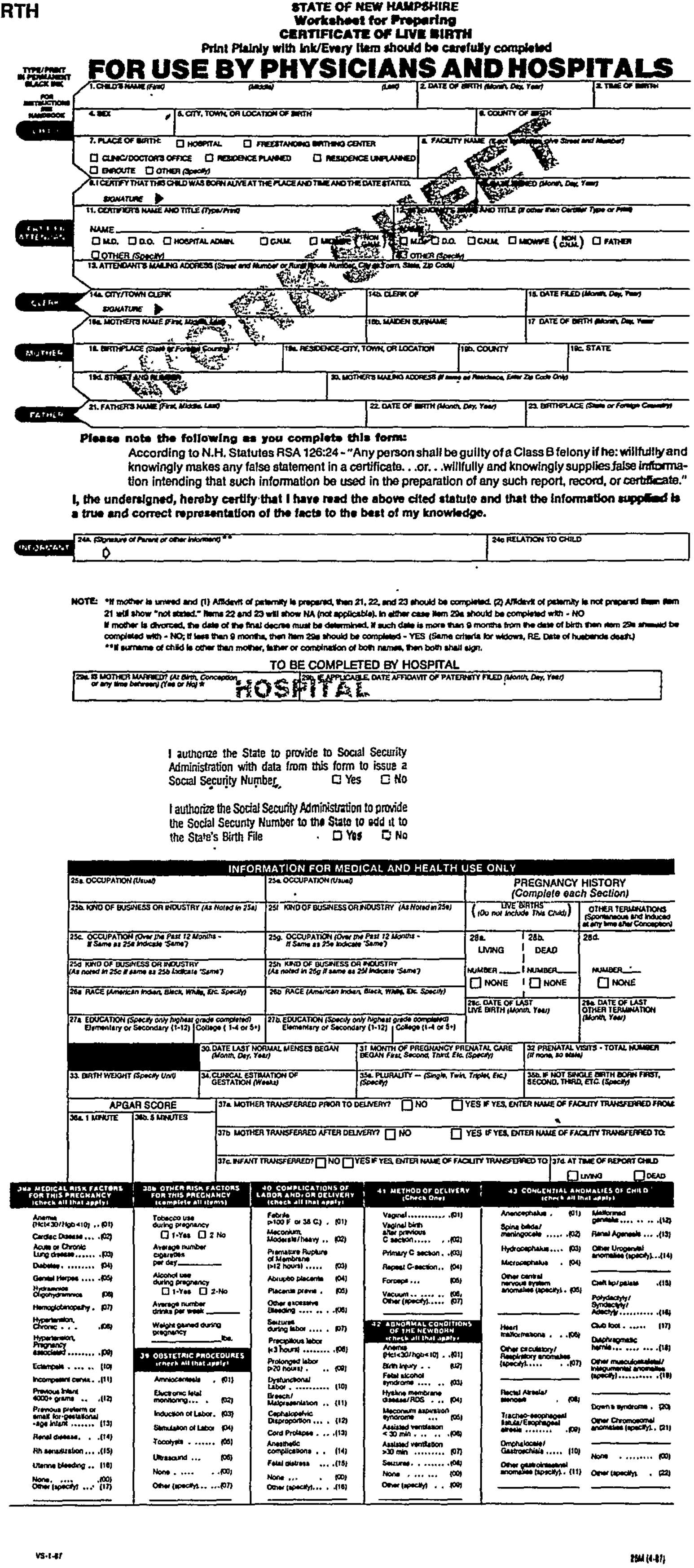
Exhibit 2: NH AUTOMATED BIRTH CERTIFICATE PROJECT (ABC) Fact Sheet

ABC automates birth event data processing interactively at the data source. Appropriate hospital personnel can type birth certificate data into microcomputer workstation terminals with instant editing for completeness and correctness. Two products--a printed paper record and a computer data record are then created.

MAJOR DIFFERENCES BETWEEN PAPER SYSTEMS AND ABC

TASK:	PAPER SYSTEM	ABC
Type certificate	Type certificate on typewriter	Enter birth record data on computer terminal and print out when complete
Enter hospital 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 hospitals for follow-up	Computer record files created at time of data entry on terminal at hospital; minor data editing before loading to master file
Proportion of records requiring follow-up	10-15%; 1988 mean=38%; range=3-395%/hospital	Less than 1%
Time period to create master file	Approximately six months	Approximately seven weeks

Exhibit 3: WORKSHEET FOR PREPARING CERTIFICATE OF LIVE BIRTH



STATE OF NEW HAMPSHIRE
Worksheet for Preparing
CERTIFICATE OF LIVE BIRTH
Print Plainly with Ink/Every Item should be carefully completed

FOR USE BY PHYSICIANS AND HOSPITALS

TYPE/PRINT IN PERMANENT BLACK INK

FOR INSTRUCTIONS SEE HANDBOOK

WORKSHEET

CHILD

1. CHILD'S NAME *(First)* *(Middle)* *(Last)*
2. DATE OF BIRTH *(Month, Day, Year)*
3. TIME OF BIRTH
4. SEX
5. CITY, TOWN, OR LOCATION OF BIRTH
6. COUNTY OF BIRTH
7. PLACE OF BIRTH: ☐ HOSPITAL ☐ FREESTANDING BIRTHING CENTER ☐ CLINIC/DOCTOR'S OFFICE ☐ RESIDENCE PLANNED ☐ RESIDENCE UNPLANNED ☐ ENROUTE ☐ OTHER *(Specify)*
8. FACILITY NAME *(If not institution, give Street and Number)*
9. I CERTIFY THAT THIS CHILD WAS BORN ALIVE AT THE PLACE AND TIME AND THE DATE STATED. SIGNATURE ▶
10. DATE SIGNED *(Month, Day, Year)*

CERTIFIER ATTENDANT

11. CERTIFIER'S NAME AND TITLE *(Type/Print)* NAME ☐ M.D. ☐ D.O. ☐ HOSPITAL ADMIN. ☐ C.N.M. ☐ MIDWIFE (NON C.N.M.) ☐ OTHER *(Specify)*
12. ATTENDANT'S NAME AND TITLE *(If other than Certifier Type or Print)* NAME ☐ M.D. ☐ D.O. ☐ C.N.M. ☐ MIDWIFE (NON C.N.M.) ☐ FATHER ☐ OTHER *(Specify)*
13. ATTENDANT'S MAILING ADDRESS *(Street and Number or Rural Route Number, City or Town, State, Zip Code)*

CLERK

14a. CITY/TOWN CLERK SIGNATURE ▶
14b. CLERK OF
15. DATE FILED *(Month, Day, Year)*

MOTHER

16a. MOTHER'S NAME *(First, Middle, Last)*
16b. MAIDEN SURNAME
17. DATE OF BIRTH *(Month, Day, Year)*
18. BIRTHPLACE *(State or Foreign Country)*
19a. RESIDENCE-CITY, TOWN, OR LOCATION
19b. COUNTY
19c. STATE
19d. STREET AND NUMBER
20. MOTHER'S MAILING ADDRESS *(If same as Residence, Enter Zip Code Only)*

FATHER

21. FATHER'S NAME *(First, Middle, Last)*
22. DATE OF BIRTH *(Month, Day, Year)*
23. BIRTHPLACE *(State or Foreign Country)*

Please note the following as you complete this form:

According to N.H. Statutes RSA 126:24 - "Any person shall be guilty of a Class B felony if he: willfully and knowingly makes any false statement in a certificate. . .or. . .willfully and knowingly supplies false information intending that such information be used in the preparation of any such report, record, or certificate."

I, the undersigned, hereby certify that I have read the above cited statute and that the information supplied is a true and correct representation of the facts to the best of my knowledge.

INFORMANT

24A. *(Signature of Parent or other Informant)* **
24c RELATION TO CHILD

NOTE: *If mother is unwed and (1) Affidavit of paternity is prepared, then 21, 22, and 23 should be completed. (2) Affidavit of paternity is not prepared then item 21 will show "not stated." Items 22 and 23 will show NA (not applicable). In either case item 29a should be completed with - NO
If mother is divorced, the date of the final decree must be determined. If such date is more than 9 months from the date of birth then item 29a should be completed with - NO; if less than 9 months, then item 29a should be completed - YES (Same criteria for widows, RE. Date of husbands death.)
**If surname of child is other than mother, father or combination of both names, then both shall sign.

TO BE COMPLETED BY HOSPITAL

HOSPITAL

29a. IS MOTHER MARRIED? *(At Birth, Conception or any time between) (Yes or No)* *
29b. IF APPLICABLE, DATE AFFIDAVIT OF PATERNITY FILED *(Month, Day, Year)*

I authorize the State to provide to Social Security Administration with data from this form to issue a Social Security Number ☐ Yes ☐ No

I authorize the Social Security Administration to provide the Social Security Number to the State to add it to the State's Birth File ☐ Yes ☐ No

INFORMATION FOR MEDICAL AND HEALTH USE ONLY

25a. OCCUPATION *(Usual)*
25b. KIND OF BUSINESS OR INDUSTRY *(As Noted in 25a)*
25c. OCCUPATION *(Over the Past 12 Months - If Same as 25a Indicate 'Same')*
25d KIND OF BUSINESS OR INDUSTRY *(As noted in 25c if same as 25b Indicate 'Same')*
25e. OCCUPATION *(Usual)*
25f KIND OF BUSINESS OR INDUSTRY *(As Noted in 25e)*
25g. OCCUPATION *(Over the Past 12 Months - If Same as 25e Indicate 'Same')*
25h KIND OF BUSINESS OR INDUSTRY *(As noted in 25g if same as 25f Indicate 'Same')*
26a RACE *(American Indian, Black, White, Etc. Specify)*
26b RACE *(American Indian, Black, White, Etc. Specify)*
27a EDUCATION *(Specify only highest grade completed)* Elementary or Secondary (1-12) | College (1-4 or 5+)
27b EDUCATION *(Specify only highest grade completed)* Elementary or Secondary (1-12) | College (1-4 or 5+)

PREGNANCY HISTORY
(Complete each Section)

LIVE BIRTHS *(Do not include This Child)*
28a. LIVING NUMBER ___ ☐ NONE
28b. DEAD NUMBER ___ ☐ NONE
28c. DATE OF LAST LIVE BIRTH *(Month, Year)*

OTHER TERMINATIONS *(Spontaneous and Induced at any time after Conception)*
28d. NUMBER ___ ☐ NONE
28e. DATE OF LAST OTHER TERMINATION *(Month, Year)*

30. DATE LAST NORMAL MENSES BEGAN *(Month, Day, Year)*
31 MONTH OF PREGNANCY PRENATAL CARE BEGAN First, Second, Third, Etc. *(Specify)*
32 PRENATAL VISITS - TOTAL NUMBER *(If none, so state)*
33. BIRTH WEIGHT *(Specify Unit)*
34. CLINICAL ESTIMATION OF GESTATION *(Weeks)*
35a. PLURALITY — *(Single, Twin, Triplet, Etc.) (Specify)*
35b. IF NOT SINGLE BIRTH BORN FIRST, SECOND, THIRD, ETC. *(Specify)*

APGAR SCORE
36a. 1 MINUTE
36b. 5 MINUTES

37a. MOTHER TRANSFERRED PRIOR TO DELIVERY? ☐ NO ☐ YES IF YES, ENTER NAME OF FACILITY TRANSFERRED FROM:
37b MOTHER TRANSFERRED AFTER DELIVERY? ☐ NO ☐ YES IF YES, ENTER NAME OF FACILITY TRANSFERRED TO:
37c. INFANT TRANSFERRED? ☐ NO ☐ YES IF YES, ENTER NAME OF FACILITY TRANSFERRED TO
37d. AT TIME OF REPORT CHILD ☐ LIVING ☐ DEAD

38a MEDICAL RISK FACTORS FOR THIS PREGNANCY *(check all that apply)*
- Anemia (Hct<30/Hgb<10) .. (01)
- Cardiac Disease .... (02)
- Acute or Chronic Lung disease ...... (03)
- Diabetes .... (04)
- Genital Herpes .... (05)
- Hydramnios Oligohydramnios (06)
- Hemoglobinopathy . (07)
- Hypertension, Chronic . . . (08)
- Hypertension, Pregnancy associated .... (09)
- Eclampsia . ... .. (10)
- Incompetent cervix . (11)
- Previous Infant 4000+ grams .. (12)
- Previous preterm or small-for-gestational-age infant .... (13)
- Renal disease. . (14)
- Rh sensitization .... (15)
- Uterine bleeding .. (16)
- None. .... (00)
- Other (specify) ... (17)

38b OTHER RISK FACTORS FOR THIS PREGNANCY *(complete all items)*
- Tobacco use during pregnancy ☐ 1-Yes ☐ 2 No
- Average number cigarettes per day ______
- Alcohol use during pregnancy ☐ 1-Yes ☐ 2-No
- Average number drinks per week ______
- Weight gained during pregnancy ______ lbs.

39 OBSTETRIC PROCEDURES *(check all that apply)*
- Amniocentesis . (01)
- Electronic fetal monitoring.... . (02)
- Induction of Labor. (03)
- Stimulation of Labor (04)
- Tocolysis . ... (05)
- Ultrasound ... (06)
- None . .... . (00)
- Other (specify)... ...(07)

40 COMPLICATIONS OF LABOR AND/OR DELIVERY *(check all that apply)*
- Febrile (>100 F or 38 C.) . (01)
- Meconium, Moderate/heavy .. (02)
- Premature Rupture of Membrane (>12 hours) ..... (03)
- Abruptio placenta (04)
- Placenta previa . (05)
- Other excessive Bleeding ....(06)
- Seizures during labor .... . (07)
- Precipitous labor (<3 hours) .... (08)
- Prolonged labor (>20 hours) . .. (09)
- Dysfunctional Labor . ... (10)
- Breech/ Malpresentation .. (11)
- Cephalopelvic Disproportion .... . (12)
- Cord Prolapse . .. .(13)
- Anesthetic complications . . (14)
- Fetal distress ... .(15)
- None ... . (00)
- Other (specify)... . .(16)

41 METHOD OF DELIVERY *(Check One)*
- Vaginal ....(01)
- Vaginal birth after previous C section..... . .(02)
- Primary C section . .(03)
- Repeat C-section .. (04)
- Forceps ... (05)
- Vacuum .. .. (06)
- Other (specify)..... (07)

42 ABNORMAL CONDITIONS OF THE NEWBORN *(check all that apply)*
- Anemia (Hct<30/hgb<10) . .(01)
- Birth injury . . (02)
- Fetal alcohol syndrome .... .. (03)
- Hyaline membrane disease/RDS . .. (04)
- Meconium aspiration syndrome ... (05)
- Assisted ventilation < 30 min . .. .. .(06)
- Assisted ventilation >30 min .... (07)
- Seizures . . ..(08)
- None . ... (00)
- Other (specify) . . (09)

43 CONGENITAL ANOMALIES OF CHILD *(check all that apply)*
- Anencephalus . (01)
- Spina bifida/ meningocele ..... .(02)
- Hydrocephalus .... (03)
- Microcephalus . (04)
- Other central nervous system anomalies (specify) . (05)
- Heart malformations . . .(06)
- Other circulatory/ Respiratory anomalies (specify).... . .(07)
- Rectal Atresia/ stenosis . (08)
- Tracheo-esophageal fistula/Esophageal atresia ....(09)
- Omphalocele/ Gastroschisis ..... (10)
- Other gastrointestinal anomalies (specify) . . (11)
- Malformed genitalia ....(12)
- Renal Agenesis ... .(13)
- Other Urogenital anomalies (specify)...(14)
- Cleft lip/palate .(15)
- Polydactyly/ Syndactyly/ Adactyly ....(16)
- Club foot . ..... (17)
- Diaphragmatic hernia ... .(18)
- Other musculoskeletal/ integumental anomalies (specify) ....(19)
- Down's syndrome . (20)
- Other Chromosomal anomalies (specify) . . (21)
- None . ... (00)
- Other (specify) . (22)

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25M (4-87)

Exhibit 4: TIMELINE

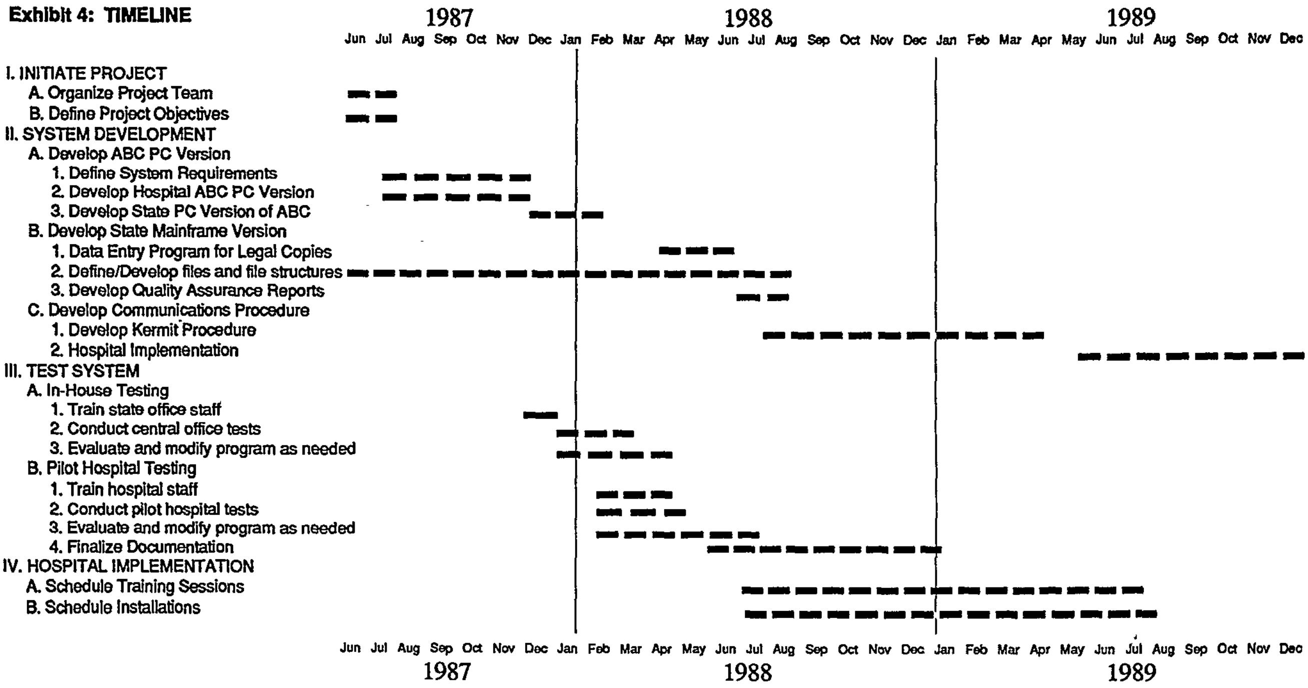

Exhibit 5: BIRTH WORKSHEET ITEMS BY TYPE OF ABC ASSISTANCE

	Worksheet Item	Type of Assistance
1.	CHILD'S NAME	*
2.	DATE OF BIRTH	*#
3.	TIME OF BIRTH	#
4.	SEX	#
Did Birth Occur at This Facility?		
5.	CITY,TOWN, OR LOCATION OF BIRTH	+#
6.	COUNTY OF BIRTH	+
7.	PLACE OF BIRTH	+
8.	FACILITY NAME	+
Is the Attendant also the Certifier?		
11.	CERTIFIER NAME AND TITLE	+*
12.	ATTENDANT'S NAME AND TITLE	+*
13.	ATTENDANT'S MAILING ADDRESS	+
16a.	MOTHER'S NAME	*
16b.	MAIDEN SURNAME	*
17.	MOTHER'S DATE OF BIRTH	*#
18.	MOTHER'S BIRTHPLACE	*#
Is Mother a Resident of NH?		
19a.	MOTHER'S RESIDENCE-CITY,TOWN OR LOCATION	*#
19b.	MOTHER'S RESIDENCE COUNTY	+
19c.	MOTHER'S RESIDENCE STATE	+#
19d.	MOTHER'S RESIDENCE ADDRESS	
20.	MOTHER'S MAILING ADDRESS OR ZIP CODE	+
21.	FATHER'S NAME	*
22.	FATHER'S DATE OF BIRTH	*#
23.	FATHER'S BIRTHPLACE	*#
24c.	INFORMANT'S RELATIONSHIP TO CHILD	@
29a.	IS MOTHER MARRIED	
29b.	DATE AFFIDAVIT OF PATERNITY FILED	
25a-d.	MOTHER'S INDUSTRY/OCCUPATION	
25e-h.	FATHER'S INDUSTRY/OCCUPATION	
26a.	MOTHER'S RACE	@
26b.	FATHER'S RACE	@
27a.	MOTHER'S EDUCATION	*#
27b.	FATHER'S EDUCATION	*#

Worksheet Item	Type of Assistance
Has Mother has any previous live births or terminations?	
28a. NUMBER OF LIVE BIRTHS NOW LIVING	*+#
28b. NUMBER OF LIVE BIRTHS NOW DEAD	*+#
28c. DATE OF LAST LIVE BIRTH	*+#
28d. OTHER TERMINATIONS	*+#
28e. DATE OF LAST OTHER TERMINATION	*+#
30. DATE LAST NORMAL MENSES BEGAN	*#
31. MONTH OF PREGNANCY PRENATAL CARE BEGAN	#
32. PRENTAL VISITS-TOTAL NUMBER	#
33. BIRTH WEIGHT	#
34. CLINICAL ESTIMATION OF GESTATION	#
35a. PLURALITY	@
35b. BORN FIRST,SECOND,THIRD,ETC.	+#
36a. APGAR SCORE (1 MINUTE)	#
36b. APGAR SCORE (5 MINUTES)	#
Was Mother or Infant Transferred Prior to or After delivery?	
37a. MOTHER TRANSFERRED PRIOR TO DELIVERY	+
Name of Facility Transferred From	+*
37b. MOTHER TRANSFERRED AFTER DELIVERY	+
Name of Facility Transferred To	+*
37c. INFANT TRANSFERRED	+
Name of Facility Transferred To	+*
37d. AT TIME OF THIS REPORT CHILD LIVING OR DEAD	*@
38a. MEDICAL RISKS FACTORS FOR THIS PREGNANCY	*+#
38b. OTHER RISK FACTORS FOR THIS PREGNANCY	
Tobacco Use During Pregnancy	
Average Number Cigarettes per day	#
Alcohol use during pregnancy	
Average number drinks per week	#
Weight gained during pregnancy	#
39. OBSTETRIC PROCEDURES	*+#
40. COMPLICATIONS OF LABOR AND/OR DELIVERY	*+#
41. METHOD OF DELIVERY	*#
42. ABNORMAL CONDITIONS OF THE NEWBORN	*+#
43. CONGENITAL ANOMALIES OF CHILD	*+#

TOTAL NUMBER OF WORKSHEET ITEMS 68

	Number of Items with Assistance	Percent With ABC Assistance
*	30 Interactive Edits	44%
#	34 Range or Validity Check	50%
@	5 Program Defaults	1%
+	27 Computer Filled Responses	40%
TOTAL	57 Assisted Items	84%

THE USE OF A CANCER REGISTRY IN OCCUPATIONAL CANCER SURVEILLANCE

Ross C. Brownson (Missouri Department of Health), Shelia Hoar Zahm, Jian C. Chang, James R. Davis

ABSTRACT

The Missouri Cancer Registry (MCR) is a statewide, central registry. It is one of the few registries that routinely collects information on occupation and smoking status at the time of cancer diagnosis. This risk factor information is abstracted from the hospital medical record. The uses and limitations of these data for occupational cancer surveillance are discussed in the context of three previous registry-based studies.

The first study evaluated the relationship between various occupations and histologic types of lung cancer, while adjusting for cigarette smoking. This study confirmed some previously reported associations and suggested possible new etiologic hypotheses, most notably the association between occupational exposure to wood dust and adenocarcinoma of the lung.

The second project was conducted to investigate occupational risks for colon cancer, including analysis by anatomic subsite within the colon. Elevated risks were identified for workers in several occupations and industries including printers, food manufacturers, telephone workers, and men employed in petroleum product trade. Analysis by anatomic subsite showed that excess risk for an occupational group was usually confined to a single subsite suggesting some specificity of effect. In addition, industrial hygiene ratings of occupational physical activity associated with various jobs showed an inverse relationship between occupational physical activity and risk of colon cancer.

The third study examined the accuracy of smoking and occupational information collected by the registry. Interviews were conducted for 441 cancer patients to compare registry-collected information with that obtained by interview. These data indicated that ever- versus never-smoking status was accurate for 85% of the records and exact three-digit agreement for occupation was 72%. These results are useful in assessing the source and magnitude of potential bias in studies based on cancer registry data such as those of the MCR.

These studies suggest that cancer registries that collect risk factor data may be valuable, cost-effective tools for occupational cancer epidemiology in the 1990's and beyond.

INTRODUCTION

Although 54 of 81 cancer registries in the world and 11 of 32 U.S. registries record occupational histories (1, 2), these data are not fully utilized (3). Studies from Denmark suggest that occupational information collected in conjunction with cancer registration is useful in identifying high risk occupational groups (3-5). Similarly, the New Zealand Cancer Registry collects employment information and has been useful in identifying excess cancer risk among agricultural workers (6, 7). However, a study conducted in the Detroit area found that reporting of occupation as a part of cancer incidence reporting was infeasible, primarily due to the high proportion of missing information on employment (8).

It has been suggested that if cancer registries can obtain occupational information as well as smoking histories, they would offer a suitable instrument for occupational cancer surveillance (9). Registries that collect employment histories may be especially useful for cancers with high fatality rates where next-of-kin interviews may be invalid or difficult to obtain. If registry-collected data are to be utilized in etiologic studies, careful attention must be paid to accuracy and potential bias.

The Missouri Cancer Registry (MCR) is a statewide registry that routinely obtains data on occupational history, smoking, and alcohol consumption. This information is collected from medical records by hospital registrars and subsequently reported to the MCR. This paper reviews and discusses three recent studies based on the MCR data. Two of the studies were etiologic studies that examined occupational risks for lung cancer (10) and colon cancer (11). The third study involved an assessment of the validity of the MCR data based on a comparison with interview information (12).

METHODS

Subject Selection

Subjects for the three studies were identified through the MCR, maintained by the Missouri Department of Health. The Registry began collecting data on cancer cases in 1972, however, reporting became mandatory only in 1984. Mandatory reporting includes exposure variables such as occupation, smoking history, and alcohol use.

Occupation and Tobacco Information

Occupation at the time of diagnosis of cancer has been abstracted from medical records by MCR since 1980. Occupation and industry are coded by trained medical records technicians on the MCR staff according to three-digit U.S. Census codes (13).

Information on use of tobacco products at the time of cancer diagnosis is recorded for all cancer patients according to the following categories: 0) None, never smoked, 1) former smoker, 2) light smoker (<1 pack per day), 3) moderate smoker (1-2 packs per day), 4) heavy smoker (>2 packs per day), 5) smoker--amount unknown, 6) uses other form of tobacco, such as cigars, snuff, etc., and 9) unknown tobacco history.

Lung Cancer Study

Cases were all white male Missouri residents who were diagnosed with histologically-confirmed lung cancer (International Classification of Diseases for Oncology [ICD-O] site code 162) (14) from

January 1980 through November 1985. Case selection was limited to white males due to the small numbers of nonwhites and the lack of occupational diversity among females. Six men with unknown histology were excluded. The remaining 4,431 cases were characterized by histologic type and grade as recorded on the Cancer Registry record. Lung cancers were classified as squamous cell, small cell, adenocarcinoma, and other or mixed, according to the definitions given in Dodds et al. (15). Less than 10% of the records contained vague histologic types, such as "malignant neoplasm" or "carcinomas, not otherwise specified."

Controls were all white male Missouri residents diagnosed with cancer, excluding cancers of the lip, oral cavity, esophagus, lung, bladder, ill-defined sites, and unknown sites (ICD-O site codes 140-141, 143-145, 150, 162, 188, 195, 199), from January 1980 through November 1985. These cancers were excluded to avoid confounding by etiologic factors shared with lung cancer, such as cigarette smoking and certain occupational exposures (16-19). The control group included 736 skin cancers. The controls numbered 11,326.

While it was possible to compare histologic types of the lung cancer cases without using any control series, inclusion of controls allowed calculation of ORs for known lung cancer risk factors (e.g., cigarette smoking, asbestos worker, pipe fitter) which indicated the generalizability and epidemiologic value of the MCR data base.

The measure of association between occupation and lung cancer was the odds ratio (OR). The reference category for each occupation was all other occupations. Effect estimates were adjusted for age (0-59 years, 60-69 years, 70 or more years) and cigarette smoking. Maximum likelihood estimates of the overall risk and 95% confidence intervals (CI) were computed by Gart's method (20).

Colon Cancer Study

The case group consisted of white males diagnosed with histologically-confirmed colon cancer (International Classification of Diseases for Oncology [ICD-O] code 153) (14) between January 1984, and June 1987. Selection was limited to white males due to the small number of nonwhites and the lack of occupational diversity among females.

A frequency-matched sample of controls was chosen from all other white male patients in the registry for the same time period, excluding ill-defined and unknown primary sites (ICD-O codes 195 and 199). For each case, five controls were randomly selected within each of seven age strata. The analyses included a total of 1,993 cases and 9,965 controls.

Two control groups were used in the colon cancer study. Control group 1 consisted of all controls, whereas control group 2 excluded subjects with leukemia and cancers of the peritoneum, nasal cavity, lung, pleura, and bladder (sites for which occupational hazards are thought to contribute to 10 per cent or more of cancer deaths among males (21)). We felt that the second control group was necessary because a control group containing cancers with known occupational links may over-represent some high risk occupations and bias some ORs toward the null.

The classification scheme of Garabrant et al. (22) was used to categorize occupations according to the level of physical activity. Individual occupations were classified according to whether physical activity is required more than 80 per cent of the time (high activity), 20-80 per cent of the time (moderate activity), or less than 20 per cent of the time (low activity).

The odds ratio (OR) was the measure of association between occupation and colon cancer. Gart's method (20) was used to calculate maximum likelihood estimates of the OR and corresponding 95 per cent confidence intervals (CI). For each occupation and industry with four or more cases, age-adjusted ORs were computed based on each of two control groups. The reference category consisted of all persons not in the occupation of interest.

For the ORs associated with occupational physical activity, the highest level of activity was used as the reference category since that level was hypothesized as having the lowest risk of colon cancer.

Subsite-specific ORs were calculated for the transverse colon (ICD-O code 153.1), descending colon (ICD-O code 153.2), sigmoid colon (ICD-O code 153.3), cecum (ICD-O code 153.4), ascending colon (ICD-O code 153.6), and other subsites within the colon (ICD-O codes 153.0, 153.5, 153.7, 153.8, 153.9).

Validation Study

A random sample of subjects, stratified by sex, was drawn from the MCR. The study group was limited to patients who were 21 years and older and diagnosed between June 1986 and May 1987. Males were oversampled at an approximate 3:1 ratio in order to increase the occupational diversity of responses. More recently diagnosed patients were chosen in an attempt to decrease the necessity for next-of-kin interviews. Only patients whose records had complete information on the three major variables of interest (i.e., occupation, smoking status, and alcohol consumption) were eligible for selection. When the study was initiated, a total of 6,366 patients, ages 21 years and older, had been reported to the registry for the study period. Of these, 85 per cent had codable information on smoking history, 75 per cent for alcohol consumption, 66 per cent for industry, and 64 per cent for occupation. For 51 per cent of the total subjects, complete information was available for all of the variables. No subjects had "retired" listed as their occupation on the registry.

Interviews were completed for 441 (85 per cent) of the 522 eligible subjects chosen in the original random selection. The participation rate among those contacted was 93 per cent. The majority of the interviews were conducted with the patients themselves (63 per cent). Proxy interviews were completed primarily with the spouse (71 per cent) or with a child (9 per cent), sibling (6 per cent), or other relative (6 per cent) of the patient.

Two trained interviewers administered a

relatively brief, standardized questionnaire by telephone. The interviewers had no knowledge of the type of cancer or risk factor information reported for each subject. Questions on occupation, smoking habits, and alcohol consumption followed the format by which data are reported to the Missouri Cancer Registry as closely as possible.

Data collected by interview were coded, checked, and entered by the same staff members who routinely process data for the registry. Data on occupation, smoking, and alcohol use were coded without knowledge of the existing registry data. In all analyses, the interview information was taken as the "true" measure.

Since the registry obtains information from medical records, we were concerned that reporting on a particular risk factor may be more accurate for tumors known to be associated with that factor. For example, patients with lung cancer may have a more detailed and accurate smoking history than those with colon cancer. Thus, for each variable of interest, sites were grouped and accuracies were calculated separately for cancers related to the risk factor of interest and for all other sites. The accuracies of occupational histories were analyzed separately for those sites in which occupational hazards are thought to contribute to 10 per cent or more of cancer deaths among males and five per cent or more among females (21). The sites considered occupationally-related included leukemia and cancers of peritoneum, nasal cavity, lung, pleura, and bladder. The smoking-related grouping included cancers of the oral cavity, esophagus, larynx, and lung (23). Cancers of the mouth, pharynx, esophagus, liver, and larynx were included in the alcohol-related site grouping (21). The programs of the Statistical Analysis System (24, 25) were used in all analyses.

RESULTS

This paper reports only major findings for each of the three studies. Detailed results have been reported previously (10-12). For the lung and colon cancer studies, ORs are presented that were statistically significant or were greater than or equal to 2.0.

Lung Cancer Study

Table 1 presents the lung cancer risk estimates according to job category. Significantly elevated ORs were identified for police, firemen, and protective services (OR=1.6), food services (OR=1.8), mechanics and repairers (OR=1.3), carpenters (OR=1.3), painters, paper hangers, and plasterers (OR=2.0), and motor vehicle drivers (OR=1.5). Nonsignificantly elevated risks were noted for insulation workers (OR=6.0), roofers (OR=2.1), and boilermakers (OR=2.7). A deficit of lung cancer was observed among teachers (OR=0.5; 95% CI=0.3,0.8), sales workers (OR=0.8; 95% CI=0.7,1.0), and farmers (OR=0.9; 95% CI=0.7,1.0).

Adenocarcinoma of the lung was elevated among carpenters (OR=1.6; 95% CI=1.0,2.5) and cabinet and furniture makers (OR=2.0; 95% CI=0.4,8.1). Adenocarcinomas were also elevated among plumbers (OR=2.0; 95% CI=1.0,3.8) and printers (OR=1.8; 95% CI=0.7,4.2). Electricians were at slightly increased risk for adenocarcinoma (OR=1.5; 95% CI=0.7,2.8), and other or mixed cell types of lung cancer (OR=1.5; 95% CI=0.8,2.9), but at decreased risk for small cell (OR=0.8; 95% CI=0.3,2.0) and squamous cell (OR=0.8; 95% CI=0.4,1.6) tumors. Among welders, adenocarcinoma (OR=1.7; 95% CI=0.7,3.8) and squamous cell (OR=1.7; 95% CI=0.9,3.3) cancers were elevated, but small cell and "other" lung cancers were not.

TABLE 1. Number of Lung Cancer Cases and Odds Ratios, Adjusted for Age and Cigarette Smoking

Job Category	No. of Cases	OR (95% CI)
Police, firemen, protective services	60	1.6 (1.1,2.3)
Food services	24	1.8 (1.0,3.5)
Mechanics, repairers	106	1.3 (1.0,1.7)
Carpenters	92	1.3 (1.0,1.7)
Painters, paper hangers, plasterers	37	2.0 (1.2,3.3)
Insulation workers	5	6.0 (0.7,137.8)
Roofers	6	2.1 (0.6,8.2)
Boilermakers	2	2.7 (0.2,75.3)
Motor vehicle drivers	186	1.5 (1.2,1.8)

Colon Cancer Study

The ORs based on control group 1 and control group 2 were generally of similar magnitude. Because of this similarity, only ORs based on control group 1 are shown in the table. Odds ratios based on control group 2 are presented only when the magnitude of the second comparison was substantially increased or decreased.

The colon cancer risk estimates associated with various occupations and industries are shown in Table 2. Among job categories with low potential for exposure to occupational carcinogens, significantly elevated risk was noted for managers, administrators, and executives (OR=1.3), sales workers (OR=1.5), workers in finance, insurance, and real estate (OR=1.5), school workers (OR=1.4), and men employed in executive and government offices (OR=1.7). Other significant risk estimates were noted for artists, entertainers, and athletes (OR=1.9), printing machine operators (OR=1.9), food manufacturers (OR=1.6), communications workers (OR=1.8), and petroleum product trade workers (OR=2.7). Job categories with nonsignificantly elevated ORs $\geq$ 2.0 included bakery workers (OR=2.9), men employed in shoe stores (OR=2.9) and membership organizations (OR=2.3), horticulture workers (OR=2.5), and workers in machinery trade (OR=2.2) and petroleum product trade (OR=2.7).

Elevated risk (OR=1.4; 95% CI=1.0,2.0) was also suggested for precision production workers such as tool and die makers and sheet metal workers, based on a comparison with control group 2. For dwelling and building repair workers, the OR increased from 1.6 (95% CI=0.5,4.6) to 3.7 (95% CI=0.9,16.5) when compared with control groups 1 and 2, respectively.

TABLE 2. Number of Colon Cancer Cases and Odds Ratios, Adjusted for Age

Job Category	No. of Cases	OR (95% CI)
Managers, admins., executives	158	1.3 (1.1,1.6)
Sales workers	121	1.5 (1.2,1.8)
Bakeries	7	2.2 (0.8,5.7)
Shoe stores	4	2.9 (0.7,10.9)
Finance, insurance, real estate	48	1.5 (1.1,2.1)
Schools	42	1.4 (1.0,2.0)
Membership organizations	5	2.3 (0.7,7.1)
Executive/government offices	26	1.7 (1.1,2.8)
Artists, entertnrs., athletes	14	1.9 (1.0,3.6)
Printing machine operators	18	1.9 (1.0,3.3)
Horticultural services	4	2.5 (0.6,9.1)
Food manufacturing	54	1.6 (1.2,2.2)
Communications	21	1.8 (1.1,3.1)
Machinery trade	6	2.2 (0.7,6.0)
Petroleum product trade	7	2.7 (1.0,7.2)

The subsite-specific risk patterns are presented in detail elsewhere (11). The general patterns of risk suggested that among job categories with significantly elevated risk, the excess was often confined to one subsite within the colon. In addition, one-half of the elevated ORs for manufacturing job categories (Census codes 100-392) occurred for cancer of the cecum.

The risk of colon cancer was examined according to the level of occupational activity. An increasing trend (p=0.02) in risk was observed across the physical activity levels of high, medium, and low. Significantly elevated risk was observed for the low activity level (OR=1.4; 95% CI=1.0,1.9). The strongest gradient in risk by occupational physical activity category was observed for cancer of the cecum, although all subsites except the sigmoid colon had elevated ORs in the low activity category.

Validation Study

Table 3 presents summary findings for the study of the accuracy of MCR risk factor information. The overall exact agreement for occupation was 70%, compared with 72% for industry. Agreement was slightly higher for males than for females for both occupation and industry. Little difference in occupational agreement was observed between occupationally-related cancer sites and other sites.

Agreement on dichotomous smoking status for all subjects was 83%. Agreement was higher for females (89%) than for males (81%). Smoking status among smoking-related cancers was more accurately described than that among other cancers, with agreements of 96% and 80%, respectively.

Information on previous alcohol consumption (nondrinker versus drinker) showed an overall concordance of 65%. Agreement on alcohol consumption showed little difference when analyzed separately by sex. Among alcohol-related cancers, the agreement rate was 88%, compared with 65% for other sites.

TABLE 3. Levels of Agreement for Cancer Registry and Interview Data for Selected Variables

Variable	Agreement (%)
Occupation*	70
Industry*	72
Dichotomous smoking history	83
Smoking-related cancers	96
Other cancer sites	80
Dichotomous alcohol consumption	65
Alcohol-related cancers	88
Other cancer sites	65

*Exact agreement at the three-digit level.

DISCUSSION

The two etiologic studies of cancer of the lung and colon confirmed some associations for *a priori* suspected high risk occupations and suggested some additional occupational groups that may be worthy of future investigation. The study of the validity of MCR-collected risk factor information was useful in assessing the direction and magnitude of misclassification for occupational, smoking, and alcohol information.

The lung cancer study confirmed the previously reported associations between lung cancer and employment in insulation work, boilermaking, firefighting and other protective services, food services, and various construction trades (18, 26-29).

Men employed as carpenters and cabinet and furniture makers, occupations with some common exposures including wood dust, had 1.3-fold excess risk of lung cancer. This is consistent with reports of excess lung cancer among wood-exposed workers (30, 31). The excess adenocarcinoma among carpenters and cabinet and furniture makers in Missouri is interesting because of previous links between adenocarcinoma and wood exposure. Morton and Treyve (32) reported excess adenocarcinoma of the lung among wood and paper mill workers and excess small cell lung cancers among carpenters. Adenocarcinoma has also been associated with wood exposure at other sites including nasal (33, 34), colon (35, 36), and stomach (9, 30, 31, 37).

The colon cancer study confirmed several previously reported occupational associations for both potentially high-risk occupations and for level of occupational physical activity.

The elevated risk among printers is consistent with three previous proportionate mortality studies (38, 39) and with a study of mortality patterns among US veterans that found a slight excess risk among pressmen and printing plant workers (40), although no excess was seen in another study (41). In our data, this association was strongest for the cecum and sigmoid colon.

The excess risk among metal workers such as tool and die makers, machinists, and sheet metal workers has been previously reported by Berg and Howell (42) and Williams et al. (28). As with printers, the association was strongest for the cecum. Spiegelman et al. (43), using data from the Third National Cancer Survey to evaluate the associations with workplace exposures, found excess colon cancer among males with exposure to solvents, abrasives, and fuel oils. The excess risk that we observed among printers and metal workers may be partially due to these types of exposures.

As in two previous studies (28, 44), we found a significantly elevated risk for males employed in food manufacturing, particularly for the transverse and sigmoid colon. The excess risk for males employed in petroleum industries, particularly in the cecum, agrees with the previous finding by Hoar et al. (44). An OR of 3.7, based on a control group 2 comparison, was observed for building and dwelling repair workers, who are potentially asbestos-exposed.

Several occupations of higher socioeconomic status were at increased risk of colon cancer, as reported by others. These included managers, administrators, and executives (44), sales workers (28), and males employed in finance, insurance, and real estate (42). The elevated risks for these occupations remained statistically significant based on control group 2 comparisons.

Our findings add to the growing body of evidence suggesting that a low level of physical activity increases the risk of colon cancer. We found that males in sedentary jobs had 1.4 times the colon cancer risk of those in high activity jobs with a significant gradient in risk from high to low activity levels. Garabrant et al. (22) first reported this association and found a 1.6-fold risk. Subsequent studies of various designs and populations have corroborated the relationship (45-49). Paffenbarger et al. (50), however, found little effect of physical activity on colon cancer mortality among longshoremen and college alumni.

The analyses of job activity and risk of colon cancer by anatomic subsite were in general agreement with two previous studies (46, 47). The strongest gradient in risk was identified for cancer of the cecum.

In the validation study, we observed overall exact agreement for occupation of about 70%. This finding is in general agreement with nine previous studies that have assessed the accuracy of occupational information on death certificates, although a wide range of accuracies has been reported (8, 51-58). These researchers have reported a range of overall agreement from 51% to 80%, with an average agreement rate across the studies of 71%. We found little difference in level of occupational concordance between occupationally-related cancer sites and other sites.

We found agreement rates over 80 per cent between registry and interview data on smoking status (never versus ever). The rate of concordance was higher for smoking-related sites than for other sites, suggesting that differential misclassification was present.

Concordance on dichotomous alcohol consumption (65%) was relatively low in this study, primarily due to the number of registry-reported nondrinkers who were classified by interview as ex-drinkers and light drinkers.

CONCLUSION

If reasonably accurate data on occupation can be recorded as part of cancer registration it would offer several advantages over death certificate studies for occupational surveillance of cancer. Hospital-diagnosed tumors provide a more accurate classification of disease than that provided by death certificates. In a study that compared the underlying cause of death as coded on the death certificate with that based on hospital diagnosis, Percy et al. (59) found only 65% of the cancer deaths met their criteria for accuracy. Cancers reported by hospitals include information on histologic type of cancer, anatomic subsite of cancer, and method of diagnosis. In addition, the high survival rates for some tumors make those cancers unsuitable for study by death certificates.

Cancer registries that record information on risk factors, such as the MCR, can be appropriate sources of data for cost-effective pilot studies. Registries may be most useful for occupational surveillance of cancer since they allow accurate classification of disease and may include information on smoking. Even though registry-based occupational studies lack information on duration of employment and short-term occupational pursuits, they are suitable for preliminary investigation of potentially hazardous occupations and provide a basis for more detailed and sophisticated studies.

In addition, the availability of cancer risk factor information, even in relatively crude form, may decrease the cost of other large-scale studies. For example, we are currently conducting a case-control study of residential radon exposure and lung cancer in nonsmoking women. The MCR is being used to identify nonsmoking female lung cancer cases, thus eliminating the costly initial step of contacting all female lung cancer patients.

We encourage other tumor registries, especially those involved in implementation of mandatory reporting, to examine the feasibility of collecting cancer risk factor information in conjunction with incidence reporting.

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ASSESSMENT OF THE PREVALENCE OF INJURIES IN MINNESOTA: A TELEPHONE SURVEY APPROACH

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Recently, there has been increased attention to the prevention and control of injuries. This is evident by the establishment of the Center for Environmental Health and Injury Control, within the Centers for Disease Control. Injury was one of the major public health problems in 1985 and accounted for 3.6 million potential years of life lost before age 65. Moreover, injury is the leading cause of death between ages one and 44 resulting in a larger impact on the population in terms of years of potential life lost, than cancer and heart disease.

In terms of characterizing this problem, death certificates are used to classify injuries that resulted in death. But death from injuries represents the tip of the iceberg in relation to the magnitude of the injury problem. It is estimated that injury is the leading cause of physician contacts and represents over 25 percent of hospital emergency room visits. Hospital discharge data, workers' compensation reports, emergency medical services data bases, motor vehicle crash reporting and trauma registries have been considered primary sources for estimating the prevalence of injuries. Each of these data sources has limitations, including data collection cost and coverage. Issues related to the severity of injuries (e.g. injuries requiring hospitalization) and the definition of trauma (e.g. injuries requiring surgical intervention) have set limits on understanding the scope as well as the etiology of injuries. Planning for injury prevention requires detailed information on the host, agent, and environment in which injuries do occur.

In this paper we report on exploring the use of statewide household telephone surveys as part of the Behavioral Risk Factor Surveillance System (BRFSS) to measure the perceived exposure to risk of injuries on the job in 1987 and to assess the prevalence of injuries among adults in 1988. Finally we examine the reliability and validity of the use of the Behavioral Risk Factor Surveillance System as a means of assessing injury prevalence in Minnesota.

The Behavioral Risk Factor Surveillance System

The Behavioral Risk Factor Surveillance System (BRFSS) is a monthly telephone survey which has been in continuous operation since January 1984. Currently, 285 interviews of Minnesota adults are completed each month, which yield about 3,420 interviews a year. The BRFSS questionnaire contains questions related to health risk behaviors (e.g. smoking, drinking, exercise, weight control, use of seatbelts), chronic disease conditions, preventive health practices and demographics. Over the years, the Minnesota Center for Health Statistics added questions related to general health status and disability, utilization of health care resources, health insurance coverage, and more recently the incidence of household injury.

The sampling objective for the telephone interview is to select a probability sample which accurately reflects the population in Minnesota. Respondent households are selected randomly from non-institutionalized civilian residents with a telephone. The sample is selected using a multistage cluster design procedure based on the Waksberg method (1978). The universe of all possible first eight digits of the ten digits in telephone numbers (i.e. area codes, prefixes, and the first two digits of suffixes) is constructed. These are the primary sampling units. A random sample of the primary sampling units and the last two digits of the suffix is selected for screening to determine whether they are residential, business or unassigned. If the dialed number is non-residential, the entire cluster of 100 numbers in the primary sampling unit is discarded. On the other hand, if the dialed number is residential, the primary sampling unit is retained in the sample and additional third and fourth digits of the suffix for the primary sample units are selected at random until three interviews from each cluster are completed.

After reaching a household, the interviewers randomly select an adult 18 years of age or older from all the adults in the household using a selection algorithm built into the computer-assisted telephone interviewing system. Interviewers usually make at least five attempts on different occasions to contact a number in case of no answer and at least once in case of initial refusal before substituting it with the next number. Interviews are made between the hours of 3:00 P.M. and 9:00 P.M. Monday through Friday and on the weekend during the day and early afternoon.

The Behavioral Risk Factor Surveillance System is not void of bias. Telephone non-coverage, response rate in comparison to in-person interviewing, and self reporting of the data are major sources of bias. In Minnesota, non-coverage is about four percent, therefore it is unlikely that non-coverage will have a significant effect on estimates of behavioral risk in the state population as a whole. The response rate for the state based on the completion of 3,400 interviews per year has been about 87 percent. But this upper bound response rate accounts only for refusals and terminations. The response rate based on the formula developed by the Council of American Survey Research Organization (CASRO) is about 73 percent. This response rate is based on the ratio of completed interviews to the sum of completed interviews, refusals, and a standard fraction of numbers which work but resulted in ring-no-answer or busy after several attempts to contact. The sex distribution in the sample is 45 percent males and 55 percent females. In general, the sample is a good approximation of the demographic characteristics of the Minnesota population.

Exposure to Risk of Injuries On the Job

Effective injury prevention and control programs in the workplace require an understanding of the circumstances surrounding exposure to job hazards as well as estimates of level of exposure to risk of injuries on the job. The 1985 National Health Interview Survey included a supplement on health promotion and disease prevention. This supplement contained a module related to occupational safety and health. One question specifically addressed the issue of exposure to risk of injury on the job as follows: In your present job are you exposed to any risk of accidents or injuries? The Minnesota Center for Health Statistics utilized the same module of occupational safety and health in the behavioral risk factor telephone survey in 1987. The questions were asked only of those who indicated that their employment status was employed for wages or self-employed.

Weighted estimates from the Minnesota Behavioral Risk Factor Surveillance (Table 1) of adults exposed to risk of accidents or injuries on their present job was 41.8 percent which is in close agreement with 40 percent estimated by the National Health Interview survey. However, the estimate varied by sex between Minnesota (57 percent for men and 23.5 percent for women) and the national household interview survey (51 percent for men and 26 percent for women).

Table 1
Percent Exposed to Risk of Accidents or Injuries On the Job by Selected Demographics
Minnesota, 1987

	Men	Women	Total
Age Group			
18 and over	57.0	23.5	41.8
18 - 24	69.4	21.9	45.6
25 - 34	62.1	26.3	45.7
35 - 44	49.3	22.0	37.0
45 - 54	48.1	18.8	35.4
55 - 64	58.5	30.5	47.2
65 and over	42.6	20.4	31.6
Educational Attainment			
<12 years	61.2	32.3	53.0
High School Graduate	66.1	22.0	44.9
Some College	62.9	27.3	46.4
College Graduate	36.7	19.4	28.7
Occupation			
Managers, Professionals	31.6	21.4	26.6
Technical, Sales, Clerks	42.7	16.6	26.4
Service	61.1	30.9	41.3
Farming	82.0	*	
Crafts	73.0	*	
Operators, Laborers	76.2	51.7	69.2
Sample Size	1059	932	1991

* Sample too small for analysis

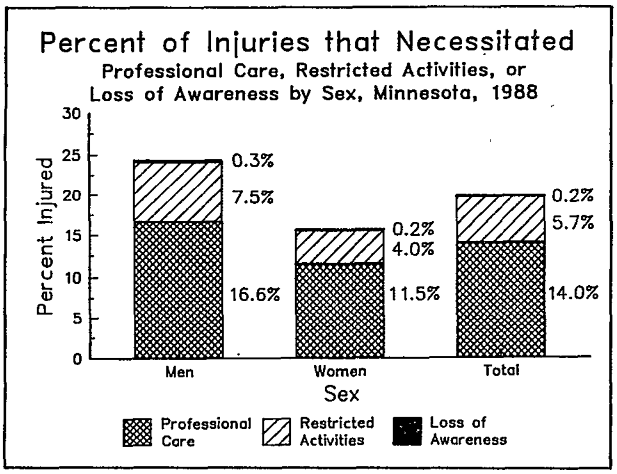
The majority of young working men perceived themselves to be exposed to risk of injuries on the job (69.4 percent for workers in age group 18-24) in comparison to older workers (48.1 percent for workers in age group 45-54). There is no obvious pattern to the relationship between age of women and perceived exposure to risk of injuries. College graduates are less likely to report that they are exposed to risk of injury (29 percent), presumably because the majority of them may have held white collar jobs. Variations in educational attainment below college graduate level seems to have less influence on the perception of risk of injuries on the job.

Agriculture is one of the most hazardous occupations. The large majority of farmers (82 percent) confirmed this fact. Operators and laborers is the next occupational group where both men and women employed in these occupations thought that they are at risk of injury on the job. Women employed in service occupations are more likely to perceive exposure to risk of injury (31 percent) than women employed in technical, sales and clerical occupations (16.6 percent).

The Prevalence of Injuries in Minnesota

The successful assessment of exposure to risk of injury in the workplace through a telephone survey has provided an impetus for use of the Behavioral Risk Factor Surveillance in 1988 to estimate the prevalence of injuries among adults in Minnesota. We have adopted the National Health Interview Survey definitions of injury with very slight modification for the purpose of ease of interviewing by telephone. Figure 1 presents the findings of using the operational definition of injury through a telephone survey.

Figure 1



Respondents were asked first: During the past year, have you had an injury or accident that required professional care? If the answer was no, the next question was: During the past year, have you had an injury or accident that restricted normal activities for at least four hours? If the answer was no, the next question was: During the past year, have you had an injury or accident that resulted in loss of consciousness, loss of awareness, or amnesia for any length of time? If the answer was no, the interviewer proceeded with the next module in the questionnaire. In case of positive response to any of the above three questions, the respondent was asked: Where did the injury or accident take place?

Among the adults who sustained injuries during the past year from the date of interviewing, 70.4 percent identified their injury as one which required professional care. Nearly 29 percent associated their injury with restriction of normal activities for at least four hours. Only 1.0 percent of the injured reported that their injury resulted in loss of awareness for any length of time.

In order to derive an estimate of the prevalence of injuries, a new variable was created which combines the three operational definitions of injuries. The result of the weighted estimates is shown in Table 2. The weighting process accounts for variation in the number of adults in each household, number of completed interviews in each cluster, number of telephones that reach each household, and the age-sex group distribution in the population.

Table 2
Percent of Injuries by Selected Demographics
Minnesota, 1988

	Men	Women	Total
Age Group			
18 and over	23.1	15.2	19.0
18 - 24	36.8	21.6	29.3
25 - 34	28.8	16.8	22.8
35 - 44	20.2	15.0	17.6
45 - 54	20.2	13.4	16.7
55 - 64	15.9	10.7	13.2
65 and over	8.2	11.7	10.2
Educational Attainment			
<12 years	20.9	10.6	16.2
High School Graduate	20.1	15.3	17.4
Some College	28.9	16.8	22.5
College Graduate	20.9	15.3	18.2
Employment Status			
Employed	23.8	16.4	20.4
Unemployed	39.7	12.3	27.2
Homemaker	*	15.2	
Student	39.0	20.7	31.9
Retired	8.2	10.7	9.6
Marital Status			
Single	32.5	20.3	27.1
Married	19.3	13.3	16.3
Divorced	29.0	19.0	22.8
Widowed	9.9	13.3	12.6
Geographic Area			
Metropolitan	24.3	16.0	20.0
Non-Metropolitan	21.6	14.3	17.8
Sample Size	1527	1893	3240

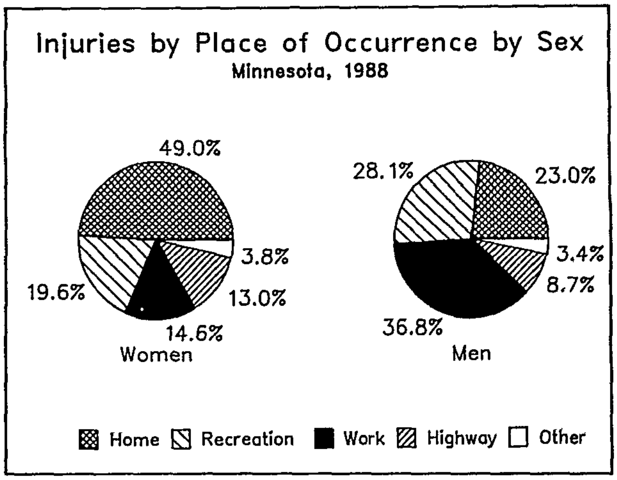
* Sample too small for analysis

Nineteen percent of Minnesota adults sustained injuries during the year preceding the date of interview. However, there was a marked difference between the proportion of men and women who reported injuries (23.1 percent for men vs. 15.2 percent for women). In both sexes the percentage of injured declined with age. Men in the 18-24 age group reported the highest incidence of injury (36.8 percent). Also, this age group was the one which exhibited the highest difference between men and women in terms of the prevalence of injury (36.8 percent for men vs. 21.6 percent for women). Overall, educational attainment level seems to have no relationship to the experience of injury. The higher percentage of injuries among those whose educational attainment category is some college (28.9 percent) may be due to the inclusion of those with vocational-technical education in this category. Persons with vocational-technical education are presumably employed in technical and crafts occupations where the incidence of injury is usually high. The highest incidence of injury among students may be related to their involvement with sports and recreational activities. Residents of the Minneapolis-St. Paul metropolitan area sustained a slightly higher proportion of injuries than residents of the remainder of the state.

Place of injury has implications in planning and designing educational programs that deal with prevention and control of injury. Homes in Minnesota ranked as the No. 1 place of injury (33.7 percent), followed by work sites (27.7 percent), places of recreation (24.6 percent), streets and highways (10.5), and the category "other" (3.6 percent).

As shown in Figure 2 the ranking of place of injury varies significantly by sex. Almost fifty percent of women experienced their injuries at home vs. only 23 percent of the men. Work site is the most common place of occurrence of injuries among men (36.8 percent) but it ranked No. 3 for women (14.6 percent). Highways and streets are the places of occurrence of

Figure 2



injuries to more women than men, 13.0 and 8.7 percent, respectively.

Reliability and Validity of Injury Estimates

Reliability of the estimate of injury was assessed by comparing the Behavioral Risk Factor Survey estimates of 1988 (N=3420) with that of the January-June 1989 survey (N=1710). Preliminary findings indicate a close agreement between the two estimates (19.0 percent in 1988 vs. 18.3 percent in 1989).

Data from Minnesota Motor Vehicle Crash Facts was utilized to assess the validity of the telephone survey data. It was estimated by the Minnesota Department of Public Safety, Office of Traffic Safety that approximately 30,600 adults were injured on the state highways and streets in 1987. This estimate is derived from accident reports submitted by citizens and law enforcement agencies for motor vehicle crashes involving personal injury. Based on data from the telephone survey it was estimated that about 38,700 adults were injured on the highway or street where motor vehicles were involved in the injuries. The difference between the two estimates is expected since not every injury on the highways is presumably reported to the Department of Public Safety.

The Minnesota Occupational Injuries and Illnesses survey conducted by the U.S. Department of Labor, Bureau of Labor Statistics provided another source of data to assess the validity of the telephone survey in estimating work-related injuries. Based on an incident rate of 7.6 percent injury, it was estimated that about 114,000 workers sustained injury in Minnesota. In the telephone survey, for persons who indicated their employment status was employed for wages, it was estimated that 117,000 workers had experienced work-related injuries. However, this very close agreement between the estimates from occupational injuries survey and the Minnesota Behavioral Risk Factor Survey may be overstated. In the occupational injuries survey the incident rate was based on 100 fulltime workers, while in the telephone survey the percentage of time worked was not assessed.

We conclude that the Behavioral Risk Factor Surveillance System is a good vehicle for gathering information pertaining to the prevalence of injuries. It provides valid as well as reliable estimates at a very modest cost. We plan to collect further information on the nature, sources, severity, etc., of injuries to take full advantage of telephone-based surveillance systems.

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Session P

Marriage and Divorce Statistics—Part I

PHCRS

MARRIAGE AND DIVORCE RATES AND THEIR IMPLICATIONS

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I am glad to be here to talk to you about the value of vital statistics on marriage and divorce. My first professional job was in vital statistics registration. In the early 1970's, I had the opportunity to work in the Demographic Analysis Section of the California Department of Public Health. It was a good job, but it was also a time of reorganization in California's health system, and a time when new leadership was being installed with the philosophy that what counted was management skills, not knowledge specific to what was managed. At one point, the Department's statistical services were reorganized into one unit, and a new manager from another part of state government was brought in to administer it. As a good manager, he reviewed the budget carefully, and at his first staff meeting he pressed his subordinates hard about spending priorities. Why, he wanted to know, did the Department of Public Health spend so much on finding the numbers of births, deaths, marriages, and divorces in the state when the banks published those figures every month? There was an awkward moment in the meeting until someone quietly explained that the banks got their figures from the Department of Public Health. Like many things, vital statistics are easily taken for granted and not appreciated until they are not available.

Information on marriage and divorce is particularly important today, as family patterns are changing as never before. The record high levels of divorce, the unprecedented increases in consensual unions, and the rising incidence of out-of-wedlock births point to an institutional revolution whose causes are not fully understood and whose future directions are still unknown. Will the individual eclipse the family? Will distinctions between men and women disappear, or will women occupy a different kind of subordinate role? Who will care for the children? It is already clear that marriage has lost its primacy, and that female headed households are the new locus of poverty.

I would very much like to tell you that the answer lies in better vital statistics. If only it were so. I do want to tell you that rates of marriage and divorce, derived from vital statistics, have played a significant role in understanding past changes in marriage and the family and have an important role to play in the future. In particular, rates based on a continuous, contemporaneous, and comprehensive system of registration provide unequalled measures of marriage and divorce behavior, can depict the life experiences of real (or hypothetical) groups, and can lead to a better understanding of marriage choice.

Let me begin by saying a word about rates. Conventional rates, which relate the number of times a specified event occurs to the population at risk of experiencing the event, are the basic measures of both public health and demography. Rates are implicitly dynamic, as they focus on change. Their time-specific nature makes rates ideal for following experience over age, and thus of reflecting experience over the life course. Furthermore, rates can be made specific to meaningful subgroups of the population, including those identified by race, ethnicity, education, and place of residence. The life course behavior of specific groups, or of persons in particular circumstances, can thus be analyzed.

An outstanding example is the study by Samuel H. Preston and John McDonald on "The Incidence of Divorce Within Cohorts of American Marriages Contracted Since the Civil War" (Preston and McDonald, 1979). They combined marriage and divorce registration data and, with some care and prudent assumptions, estimated the probability a marriage would end in divorce for cohorts marrying from 1867 through 1964. That work demonstrated clearly that there had been a steady and nearly exponential increase in American divorce for nearly a century. Preston and McDonald also showed that increases in longevity played only a small role. Their work demonstrated that divorce is hardly a post-World War II "fad", a phenomenon related to television, or a consequence of Dr. Benjamin Spock's teachings, as the rise in divorce started long before those developments could have had any influence. Those conclusions rest on a solid foundation of fact because of the existence of a long term, continuous system of vital records. [By the way, Preston and McDonald's study was updated and extended by James A. Weed in an NCHS "Rainbow Report" (Weed, 1980).]

There are many other examples of studies that could not have been done without vital statistics. In my own work, vital records were essential to two major projects that have occupied a good deal of my time over the past decade. The first project examined the marriage, divorce, and mortality experience of cohorts born since the late 1900's in the United States and four West European countries. That work required data on, among other things, the number of marriages by age, sex, and previous marital status, the number of divorces by age and sex, and the number of deaths by age, sex and marital status for at least 14 time points in 5 different countries. Those who worked on the project got to look at a lot of vital statistics and calculate more than a few rates.

The marital status life table, which follows a closed group of persons through life and through different marital statuses, provided the analytical framework for depicting the combined implications of those marriage, divorce, and death rates. In fact, by reconstructing the whole of cohort experience, the marital status life tables allowed the calculation of such summary measures as the life expectancy of a marriage, the probability a marriage would end in divorce, and the likelihood of remarriage, measures that are not readily available from censuses, surveys, or other data sources.

The results for the United States provided extensive information on male and female cohorts born from 1888 to 1950 (Schoen, Urton, Woodrow, and Baj, 1985). Let me give you some examples. The proportion ever marrying of those surviving to age 15 reached a maximum for cohorts born during 1938-42, when 96% of males and 97% of females married. The average age at first marriage was then 23.3 years for males and 21.1 for females. The life expectancy of a marriage reached a peak for women born 1928-32, but even then it was only 31.1 years. The average duration of a female widowhood remained virtually unchanged. It went from 15.2 years for women born 1888-1892 to 15.0 years for women born 1948-50. The likelihood of remarriage from divorce was high for both sexes, varying between 79-83% for males and 72-78% for females. In contrast, recent period experience is quite different. In the marital status life table for women based on rates observed in 1983, only 89.7% of those surviving to age 15 marry, their average age at first marriage is 24.5 years, and their average marriage duration is 24.2 years (Schoen, 1987).

Many Western countries have marriage and divorce registration data of sufficient quality and quantity to enable the calculation of marital status life tables. For example, tables for Canada were prepared by Adams and Nagnur (1981) and for The Netherlands by Koesoebjono (1981). My own work involved marital status life tables for twentieth century birth cohorts in England and Wales, Sweden, Belgium, and Switzerland. It showed that marriage and divorce patterns in those Western countries were quite similar to those in the United States (Schoen and Baj, 1987). In particular, all 5 countries showed a steady, virtually uninterrupted increase in the proportion of marriages ending in divorce for cohorts born from the late 1880's to the 1940's. The rate of increase was quite steep in England and Wales, Sweden, and the United States, and rather moderate in Belgium and Switzerland, but the trend was the same. The long term societal forces behind rising divorce are by no means unique to the United States.

We may not be alone, but the United States does have the highest divorce rates of any modern society. What is the current probability that an American marriage will end in divorce? There is great interest in that figure, but it is one that can be calculated in a variety of ways. If a birth cohort lived its life subject to the rates observed in 1983, 44% of all marriages would end in divorce. That figure would be essentially the same if the rates observed in 1975 or 1980 were used instead (Schoen, 1987). However, in an article recently published in <u>Demography</u>, Teresa Castro Martin and Larry Bumpass used data from the June 1985 Current Population Survey (CPS) to calculate "that recent rates imply that about two-thirds of all first marriages are likely to end in separation or divorce" (Martin and Bumpass, 1989, p. 37). More precisely, on the basis of experience in the early 1980's, they estimated that 64% of first marriages would be disrupted. Why the difference between 44% and 64%? Martin and Bumpass looked at marriage cohorts, not birth cohorts, first marriages, not all marriages, and separations as well as divorces. But those factors probably account for half, or less than half, of the difference. To me, the bulk of the explanation lies in the fact that Martin and Bumpass needed to introduce a large and somewhat arbitrary adjustment for the underreporting of divorces and separations in the CPS data. Previous work, notably that by Andrew Cherlin and James McCarthy (1984), showed that the number of divorces reported in the retrospective marital histories collected in the CPS implied a level of divorce substantially below that shown by vital statistics divorce records. On that basis, Martin and Bumpass estimated that the CPS figures were 22% too low, so they raised their proportion divorcing by 22%. Now they may well be right, but throwing in a 22% adjustment factor at the end of a long calculation hardly inspires confidence in the results. Furthermore, it should be noted that Martin and Bumpass, as Preston and McDonald and as Cherlin and McCarthy before them, turned to the vital statistics data on marriage and divorce as their standard for accuracy and completeness.

To this point, we have been emphasizing age and sex, but marriage and divorce records typically contain a great deal more information. The U.S. Standard License and Certificate of Marriage and the U.S. Standard Certificate of Divorce, Dissolution of Marriage, or Annulment also include data on both partners' race, education, birthplace, and marriage order, among other items. A lot can be done with those characteristics. In particular, I would like to share with you work I have done on marriage choice, that is on the question of "who marries whom".

Analyses of marriage choice typically start with the idea that traditional marriage is the exchange of a male's economic resources for a female's domestic services. Things have changed and the economic role of women is now considerable, but studies still show that the economic role of the man is still more important than that of the women in determining the status of a couple. It stands to reason, therefore, that women will put greater emphasis on the economic characteristics of their partner than men will, while men will put greater emphasis on their partner's noneconomic (or social) characteristics. Two important hypotheses that follow from that line of argument can be tested using the variables available in vital statistics data. The first is that women marry men with more education than their own more frequently than men marry women with more education than their own. Because education is highly correlated with economic success, women are expected to "marry up" with regard to education. The second is that exchanges are likely to occur between male economic characteristics (like education) and female noneconomic characteristics (like age, race, ethnicity, and birthplace). The classic expression of this is the Davis-Merton hypothesis (Davis, 1941; Merton, 1941) that most black-white marriages will involve black grooms, as those marriages would allow exchanges between a black male's socioeconomic status and a white female's "caste" status.

The analysis of marriage choice and intergroup marriage demands the comprehensive coverage that only vital statistics registration data can provide. Some types of intergroup marriage are relatively rare, and no survey can hope to provide contemporaneous data on marriages specific to the age, race, and educational levels of the bride and groom. Unfortunately, in the United States, most machine readable marriage records do not have that information either. However, with the help of state registrars, I was able to get the necessary data for California, Hawaii, North Carolina, Virginia, and Wisconsin. The results strongly supported the hypothesis that women married up with regard to education, but less so in 1980 than in 1970. In addition, not only was the Davis-Merton hypothesis sustained in that most black-white marriages involved black grooms, but the data showed a pattern of behavior that strongly suggested exchanges between male economic and female noneconomic characteristics. There were apparent exchanges between male educational level on the one hand and, on the other hand, female race in North Carolina, Virginia, and Wisconsin, female race/ethnicity in Hawaii, female ethnicity and birthplace in California, and female age in North Carolina and Virginia (cf. Schoen and Wooldredge, 1989; Schoen, Wooldredge, and Thomas, 1989) Individual marriage choices thus reproduce societal patterns of stratification because those patterns shape the nature of each marriage exchange. Moreover, social changes imply changes in marriage behavior. The increased labor force participation of women is associated with a decrease in the extent to which women marry up with regard to education. Marriage levels are declining as the characteristics of those marrying are becoming more similar. As there are fewer characteristics to exchange, it appears that the value of marriage itself is diminished.

The extensive data in vital statistics marriage records also allow the characteristics of "marriage markets" to be examined in greater detail than is possible with any other data source. That is of particular significance with respect to black-white differences in marriage behavior. Census data show that the male/female ratio is clearly lower for blacks than for whites, and a number of observers have argued that the lower availability of black males is a major factor behind the more rapid decline in black marriage rates (Spanier and Glick, 1980; Staples, 1985; Wilson, 1978). In a paper with James R. Kluegel, we used male and female marriage rates for North Carolina and Virginia in 1969-71 and 1979-81, specific to the age, race, and educational level of the bride and groom, to analyze the effect of composition. We were able to decompose black-white differences and differences over time into a factor representing population composition by age, sex, and educational level, and a factor representing the underlying propensity to marry (Schoen and Kluegel, 1988). The results showed that compositional effects played only a minor role. The large black-white differences observed could not be explained by impersonal, demographic forces, but reflected real differences in the propensity of blacks and whites to marry.

To sum up, I have tried to illustrate how vital records of marriage and divorce, and the behavioral rates they yield, are important to an understanding of the unprecedented changes in family life that are now taking place in the United States. Because vital records provide continuous, comprehensive, and contemporaneous data on marriage and divorce, they cannot be matched for historical depth, completeness, or accuracy. Indeed, they are the standard against which other data are measured. While some states furnish considerable information on marriage and divorce, national data are needed because of the large volume of interstate movement. As the whole is greater than the sum of its parts, aggregate demographic data give us a much more meaningful picture than a collection of individual events. Marriage and divorce records will always be needed for individual and legal purposes. It takes only a little more to have a system of marriage and divorce statistics comparable to those of most Western countries, and it is well worth the effort.

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MARRIAGE AND DIVORCE DATA IN THEORETICAL POPULATION STUDIES

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Formal demography is principally concerned with relations among fertility, mortality, population growth, and age distribution. Marriage and divorce measurement and modelling have become components of formal demography for two basic reasons. First, the fertility of married people is typically higher than that of the unmarried, so that an accurate accounting of birth rates (and, through them, other demographic features of a population) requires attention to the prevalence of marriage. Second, many of the tools that have been developed to study the behavior of a "population", classically-defined, can be applied directly to the population of marriages or of married persons. These include analysis of single decrement processes, multiple decrement processes, increment-decrement processes, and stable populations. Because of their familiarity with these tools, demographers have come to play an important role in the quantitative analysis of aggregate-level family processes. In this paper, I discuss several recent developments in the formal demographic analysis of marriage and divorce, illustrating the various uses to which vital statistics data on marriage and divorce are being put.

MEASUREMENT

Students of the family have used a variety of quantitative indicators to describe the centrality of the family as a social institution and as an element in individuals' lives. Among these are the probability that an individual will marry in the course of life, the expected number of marriages an individual will experience, the expected duration of a marriage, and the probability that a marriage will end in divorce. If one is dealing with an actual cohort of births or marriages- individuals born in or unions formed in a particular year, say- then constructing these indicators is simply a matter of counting events that are properly ascribed to cohorts in a vital registration system. Typically, however, people are interested in relatively recent behavior or in behavior during a particular time period. In these cases, demographers use the concept of a hypothetical cohort that is exposed to the risk of particular events that is recorded in a particular time period.

If a population is "stationary"- with constant vital rates, zero growth, and constant marital behavior- then the indicators for hypothetical cohorts and real cohorts are identical and both could be inferred from aggregate-level counts without the need for ascribing vital events directly to cohorts. For instance, the probability that an individual will marry in the course of life can be found by dividing the annual number of first marriages by the annual number of births, the expected number of marriages in the course of life can be found by dividing the annual number of total marriages by the annual number of births, the expected duration of a marriage can be found by dividing the total number of currently-married people by the annual number of marriages, and the probability that a marriage will end in divorce by dividing the annual number of divorces by the annual number of marriages.

Unfortunately, the world is rarely so simple. In order to construct these indexes for a hypothetical cohort in a non-stationary population, one of two approaches is necessary. Either life tables can be constructed by relating vital events to an appropriately-defined population at risk (cf. Schoen, 1988), or the relations of a stationary population can be reconstituted by applying a growth adjustment to the data (Preston, 1987). These alternative approaches are available because the indexes are created by referring to demographic accounting identities. Any element of such an identity can be inferred from knowledge of all of the other elements. The choice of an approach to estimation then depends on which data element is missing or considered more suspect. If all elements are available, the system is overdetermined and data redundancy can be used to examine the consistency of the data. Unfortunately, this latter opportunity is rarely exploited.

A simple illustration will help make these matters more concrete. Suppose that we are interested in constructing a table showing marital survivorship by duration of marriage for 1988. Such a table would use information on the survival of marriages by duration in 1988. This information could come from relating divorces, deaths of husbands, and deaths of wives to marriages by duration in 1988, or from comparing the number of marriages of duration x at the start of 1988 to the number of marriages of duration x+1 at the start of 1989. If all of this information is available, then the consistency of the data could be examined and any inconsistencies reconciled. If not, there are two different approaches to estimating the parameters of the table.

These two approaches are presented in Table 1 for the four different measures mentioned above. Column A presents the conventional formulas for computing the measure of interest from rates of event occurrence to populations at risk of the event. Column B presents equivalent formulas that use the number of events, without relating them to the population at risk. Column A is dropping information on observed cross-sectional changes in numbers of individuals, while Column B is dropping information on mortality. Both sets of formulas are identities and should give the same results if the data are accurate. If the population is stationary, all of the growth rates appearing in Column B will be zero and the formulas reduce to simple ratios of the number of events. Otherwise, the formulas include a growth correction that, in effect, reestablishes the relations of a stationary population.

Note that the formulas in Column B assume that the population is closed to migration; if it is not, then a net migration term must be added to the growth rate. Since the formulas in column A do not require such a correction, they have an intrinsic advantage in a population where migration is prominent. This advantage may be forfeited, of course, if the data required to implement the formulas is unavailable or of poor quality. Such a condition may well apply to formulas 3 and 4, referring to the outcomes of marriage. In order to calculate the expected duration of a marriage or the probability that it will end in divorce from occurrence/exposure rates, it is necessary to have information on husbands' and wives' death rates by duration of marriage. Such information is not directly available and must be constructed. The construction has typically assumed that death rates of married people by age are the same as those of the entire population (Preston, 1975; U.S. National Center for Health Statistics, 1980). This assumption almost certainly results in death rates being too high at high marital durations. In turn, the survivorship of marriages is foreshortened and too low a proportion of marriages are estimated to end in divorce. In a comparison of the two approaches for the United States in 1975-80, it was found that Formula 3.A gave a life expectancy for first marriages of 25.8 years while formula 3.B gave a life expectancy of 28.2 years. Differences in marital survival during the first ten years were trivial; the major differences occurred at higher durations. The probability of divorce was .496 according to Formula 4.A and .520 according to formula 4.B (Preston, 1987). Both of these comparisons are consistent with death rates having been overestimated by method A, but it is also possible that the reported marital durations are overestimated in applying method B. In either case, having current vital statistics on marriage and divorce is essential to estimating these measures of considerable popular and professional interest.

PROJECTIONS

The measures described above show the implications for a randomly-chosen individual or marriage of the rates of death, marriage and divorce recorded in a certain period. There are also reasons to be concerned with their implications for a population. Since the current distribution of the population by marital status is a product of rates in the past, it is often a poor indicator of what the future holds. If current rates are maintained, the future distribution will typically differ from the present distribution.

Many characteristics, activities, and conditions are affected by one's marital status, so projections of marital distributions can be valuable devices in social planning. For example, the probability of an elderly American living in a nursing home is about twice as high if the person is unmarried as if he or she is married. In forecasting the need for nursing home facilities, therefore, it is useful to have an estimate of future marital distributions. Himes (1989) combines changes in mortality rates projected by the U.S. Census Bureau with current marriage and divorce rates to project marital distributions at older ages. She finds that the proportion of women over age 85 who are currently married will increase by 50% between 1980 and 2000, so that the demand for nursing homes will likely increase less rapidly than the older population. Such a projection could not be performed without vital statistics on marriage and divorce, particularly since surveys of marital events contain too few older people to form a solid basis for projection.

THE TWO-SEX PROBLEM

A difficulty that must be faced in projecting the number of married persons into the future is what demographers refer to as the two-sex problem. In fact, this term covers a related constellation of problems. One is finding a function that efficiently maps the number of unmarried men and women by age into the matrix of marriages by age of husband by age of wife. A second is understanding the dynamic implications of demographic systems in which both sexes are involved in the childbearing process. Much of this latter work has focussed on questions of the existence, stability, and uniqueness of equilibria, equivalent to the equilibrium established in demographers' classic one-sex stable population model (Pollak, 1986). The two concerns are obviously related because any marriage function provides a specific implication for the age-sex distribution of childbearing in a population wherein childbearing is concentrated among married population.

Finding an efficient marriage function is the more central concern in population projection or in interpreting marital behavior, and it is here that we will focus our attention. Accounts of the search for marriage functions can be found in several recent sources (Schoen, 1988; Keilman, 1986) and it is not my intent to recapitulate them here. Instead, I will attempt to develop a marriage function that is behaviorally based and present some preliminary empirical results from the attempt to estimate its parameters.

In my view, any behaviorally-based marriage function must divide the marriage process into at least two components: the encounter process, in which males of age i meet females of age j, and the offer process, in which men and women extend offers of marriage to a person whom they have met. Only the model of Pollard (1971) explicitly introduces the encounter process into a marriage model, and it is with this model that we will begin.

Let

$M_i(t)$ = number of unmarried males aged i in time period t
$F_j(t)$ = number of unmarried females aged j in time period t
$N_{ij}(t)$ = number of marriages between males aged i and females aged j in time period t
$P(t)$ = total number of unmarried persons at time t =

$$\sum_i M_i(t) + \sum_j F_j(t)$$

The simplest marriage model that we will consider is based upon the following assumptions:

1) Within the pool of unmarried individuals, encounters are random. Thus, the number of encounters between a male aged i and a female aged j during period t will be proportional to

$$\frac{M_i(t)\ F_j(t)}{P(t)}$$

That is, for a male aged i, the proportion of encounters that involve a female aged j is $F_j(t)/P(t)$. A constant of proportionality, R, reflects the rate of encounter. The number of encounters between a male aged i and a female aged j during period t will then be

$$\frac{R\ M_i(t) F_j(t)}{P(t)}$$

2) Define λ_{ij} as the force of attraction between males aged i and females aged j. In the absence of competition, λ_{ij} is the proportion of (ij) encounters that lead to marriage. Thus, the simplest model of marriage is

$$\text{A)}\quad N_{ij}(t) = \frac{R\ \lambda_{ij}\ M_i(t)\ F_j(t)}{P(t)}$$

Model A) is Pollard's (1973) marriage model, although he assumes that encounters are random within the entire population, so that for him P(t) refers to the total population size rather than to the unmarried population.

The second model without explicit competition assumes that men and women can react differently to the underlying force of attraction between them. In particular, the probability that a male i offers marriage to a female j is

$$B_i\ \lambda_{ij}$$

and the probability that a female j offers marriage to a male i is

$$C_j \lambda_{ij}\ .$$

λ_{ij} itself no longer has the character of a probability. Marriage occurs when a man offers marriage to a woman and a woman offers marriage to that man. Hence,

$$\text{B)}\quad N_{ij}(t) = \frac{R\ B_i\ C_j\ \lambda_{ij}^2\ M_i(t)\ F_j(t)}{P(t)}\ .$$

To introduce competition among men for women and among women for men, assume that men "score" the individuals whom they meet in period t and decide whether to offer marriage to a particular woman whom they have encountered based upon the relationship between λ_{ij} and $\lambda_{i\cdot}(t)$, where

$$\lambda_{i\cdot}(t) = \frac{\sum_j \lambda_{ij}\ F_j(t) + \sum_i 0 \cdot M_i(t)}{P(t)}\ .$$

Thus, $\lambda_{i\cdot}(t)$ is the mean score of people encountered by males i during the period, assuming that other males receive a score of zero. The male offer function to a woman aged j is assumed to be of the form

$$B_i\ \lambda_{ij}\ \lambda_{i\cdot}(t)^{-b}$$

where b is the elasticity of male offers with respect to the state of the market. If $b=0$, males are insensitive to the market. If $b=-1$, they are as sensitive to the quality of the market as they are to the characteristics of the woman whom they have encountered, and the offer becomes a function of the simple ratio of λ_{ij} to $\lambda_{i\cdot}(t)$. B_i then becomes the probability of marrying an average-scoring woman, once she has been encountered, assuming that there is no male competition.

Analogously, the female offer function is

$$C_i \lambda_{ij} \bar{\lambda}_{\cdot j}^{\,c}(t), \text{ where}$$

$$\lambda_{\cdot j}(t) = \frac{\sum_i \lambda_{ij} M_i(t)}{P(t)}$$

Once an (ij) encounter occurs, marriage occurs if the man offers marriage to the woman and the woman offers marriage to the man. Thus, the simplest marriage function with

$$N_{ij}(t) = \frac{R\ B_i\ C_j\ \lambda_{ij}^{2}\ M_i(t)\ F_j(t)}{P(t)\left[\frac{\sum_j \lambda_{ij}\ F_j(t)}{P(t)}\right]^{b}\left[\frac{\sum_i \lambda_{ij}\ M_i(t)}{P(t)}\right]^{c}}, \text{ or}$$

$$\text{C)}\quad \frac{R\ B_i\ C_j\ \lambda_{ij}\ \overset{2}{M_i}(t)\ F_j(t)}{\left(\sum_j \lambda_{ij}\ F_j(t)\right)^{b}\ \left(\sum_i \lambda_{ij}\ M_i(t)\right)^{c}}\ P(t)^{b+c-1}$$

If b=c=0, there is no competition and model C) reduces to model B.

ESTIMATION OF MARRIAGE FUNCTIONS

We are estimating the parameters of these and related marriage functions in the United States and Japan. Because the Japanese data set is more compact, we have made more progress with it. The data set consists of marriages by age and sex, and the unmarried population by age and sex, in Japan for 1960, 1965, 1970..1985. The age intervals used are 15-19, 20-24...45-49. Iterative non-linear estimation is used, with the criterion of success being

$$S = \sum_t \sum_i \sum_j [\hat{N}_{ij}(t) - N_{ij}(t)]^2.$$

Table 2 presents the results of this estimation in the form of the sum of squared errors for various models. The simplest model, A, explains 92.1% of the variance about the mean in the number of marriages. [Note that the best-fitting harmonic mean function, which also has one parameter per ij cell, explains 92.5% of the variance; (Schoen, 1988)].

However, time trends are evident in the success of the model. Model B presents three possibilities for introducing trends into the model: trends embodied in R, in B_i, and in C_j. Allowing R(t) to vary with t explains 72% of the variance left unexplained in model A. Allowing $C_j(t)$ to vary with t explains 78%, and allowing $B_i(t)$ to vary with t explains 92% of the unexplained variance. Allowing both $B_i(t)$ and $C_j(t)$ to vary explains 99% of the remaining variance. However, the set of coefficients for model B4 is not entirely plausible. At young ages, $B_i(t)$ is rising and $C_j(t)$ falling over time, while at older ages the reverse is true. Collinearity among the estimates is apparently producing a somewhat unstable set of results.

In many ways, model B2 is the most satisfactory. Parameters are plausible, with $B_i(t)$'s generally peaking in 1965 and declining slowly thereafter. At ages 25 and above, values of B_i in 1985 are less than half of their value in 1965. Clearly, much more variance is explained by letting the male parameters vary with time than the female parameters. We have interpreted the B_i's as a multiplicative component of the probability that a male offers marriage to a female, once encountered. According to this interpretation, male offers of marriage declined systematically after 1965.

Was this decline a function of improved market conditions for males, so that there would be less inclination for a man to marry a woman that he encountered? Market conditions did improve after 1965. $\bar{\lambda}_i(t) = \sum_j \lambda_{ij} F_j(t)/P(t)$ (the mean attractiveness to men in year t of people encountered in a random encounter model) explains virtually none of the variance left unexplained in models A or B_1. In these cases, the λ_{ij} are fixed at their value estimated in Model A. An alternative is to allow an iterative solution for the λ_{ij}'s, as implied in model C. We were unable to estimate the full-blown model C and tried a truncated version in which only $\bar{\lambda}_i(t)$ is included, reflecting the fact that male marriage offers appeared to change more than female. As shown in Table 2, adding this single variable to model B1 reduces variance unexplained by 49%. The new parameter, b, also takes the proper negative sign, implying that, the better are market conditions, the less likely are males to offer marriage to a woman they encounter. However, the coefficient is so large, -3.04, that results are suspect. A 1% increase in the average marital attractiveness of people encountered leads to a 3% reduction in marriage propensity. Furthermore, the values of λ_{ij} became implausible, rising sharply with age. Using a much more plausible set, those estimated in Model A, results in very little additional variance explained by $\bar{\lambda}_i(t)$.

To conclude, we have not succeeded in demonstrating convincingly that marriage propensities in Japan have been affected by the state of the market. We have succeeded, however, in showing that changes in marriage propensities have been far more closely associated with ages of males than with ages of females.

The first four models have also been estimated on U.S. Marriage Registration Area data for 1960, 1964, 1965...1983, 1985, or 22 years in all. Age groups 15-17, 18-19, 20-24, 25-29, 30-34, 35-44, and 45-54 are used. Model A explains only 83.9% of the variance in this case (the harmonic mean explains 88.9%, a considerable improvement). The reason why so much variance remains unexplained is that time trends are so decisive. Introducing a simple multiplicative time parameter into Model A, as in Model B1, explains 99.1% of the variance (whereas introducing a trend term into the harmonic mean explains 99.0% of the variance.) A graph of R(t) for the U.S. is shown in Figure 1. By 1985, R(t) has declined to only 30.0% of its value in 1960. 70% of the decline between 1960 and 1985 occurred during the 1970's.

Was the decline in marriage "rates" more closely associated with ages of men or ages of women? Models B2 and B3, which attempt to answer this question, suggest there was little sex differentiation in the changing propensities. Both explains 99.8% of the variance. However, the variance left unexplained is 8% larger in B2, implying that changes in marriage rates were slightly more closely associated with ages of women than with ages of men. The decline was rapid and monotonic for women below age 25. Women 25-44 had an inverted-U shaped trend, peaking in the late 60's for women 25-29 and 30-34 and the early - 70's for women 35-44. Rates for women 45-54 showed no trend over the period. There is some suggestion of a cohort pattern in the female results, with women born in the low-fertility 1930's having relatively high marriage rates.

Marriage and Divorce Data in Analysis of Households

The analysis of households is an extremely underdeveloped area of formal demography. There is no analogy to the simple accounting identities that are used to study changes in the number of people in a population, let alone an adequate representation of the process by which people choose to live together or apart. It seems likely that marriage and divorce data will play an increasingly important role in developing the tools for studying household change.

For example, let us divide the set of households into two types: those that contain a married couple and those that don't. In 1980, 61% of U.S. households contained a married couple (King and Preston, 1988). However, 75% of the population lived in households containing a married couple because those households were larger than average. Fewer than 1% of married couple households contained more than one married couple, so if we know the number of intact marriages we also know, to an extremely close approximation, the number of married couple households.

Therefore, it is possible to keep track of the number of households in which three-quarters of the American population lives simply by using data on marriage, divorce, and death by marital status, all of which is routinely available in vital statistics. It is likely that the main determinants of the size of these households is the level of marital fertility and their duration distribution, both of which can also be derived from vital statistics. These simple relations provide a solid basis for understanding the determinants of the number and size distribution of households, an understanding that thus far has largely escaped demographers. It could also be used for projecting households, especially when combined with an effective two-sex model. Since these same factors - marriage, divorce, and the death of married people - also affect the number of households without a married couple, it seems evident that marriage and divorce data can play a bigger role in household analysis than they have done to date.

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Table 1. Alternative Formulas for Computing Various Measures in Family Demography

		Computed from Rates (A)	Computed from Events (B)
1.	Probability That An Individual Will Ever Marry	$\int_o^\infty e^{-\int_o^a [\mu^{SD}(x) + \mu^{SM}(x)]dx} \mu^{SM}(a)da$	$\frac{\int_o^\infty M^1(a)e^{\int_o^a r_u(x)dx} da}{B}$
2.	Expected Number of Marriages In A Lifetime	$\int_o^\infty e^{-\int_o^a \mu^D(x)dx} \mu^M(a)da$	$\frac{\int_o^\infty M(a)e^{\int_o^a r(x)dx} da}{B}$
3.	Expected Length of A Marriage	$\int_o^\infty e^{-\int_o^y [\mu^o(z)+\mu^{DH}(z)+\mu^{DW}(z)]dz} dy$	$\frac{\int_o^\infty N(y)e^{\int_o^y r_M(z)dz} dy}{M}$
4.	Probability That A Marriage Will End in Divorce	$\int_o^\infty e^{-\int_o^y [\mu^o(z)+\mu^{DH}(z)+\mu^{DW}(z)]dz} \mu^o(y)dy$	$\frac{\int_o^\infty D(y)e^{\int_o^y r_M(z)dz} dy}{M}$

$\mu^{SD}(x)$ = death rate of single people aged x

$\mu^{SM}(x)$ = rate of first marriages for single people aged x

$\mu^D(x)$ = death rate of all persons aged x

$\mu^M(x)$ = marriage rate of all persons aged x

$\mu^o(z)$ = divorce rate of marriages at duration z

$\mu^{DH}(z), \mu^{DW}(z)$ = rate at which marriages of duration z are ended by death of husband and death of wife, respectively

$M^1(a)$ = annual number of first marriages of people aged a

$M(a)$ = annual number of total marriages of people aged a

M = annual number of marriages

B = annual number of births

$N(y)$ = number of intact marriages of duration y

$D(y)$ = annual number of divorces at duration of marriage y

$r_u(x)$ = growth rate of number of unmarried persons aged x

$r_M(z)$ = growth rate of number of marriages at duration z

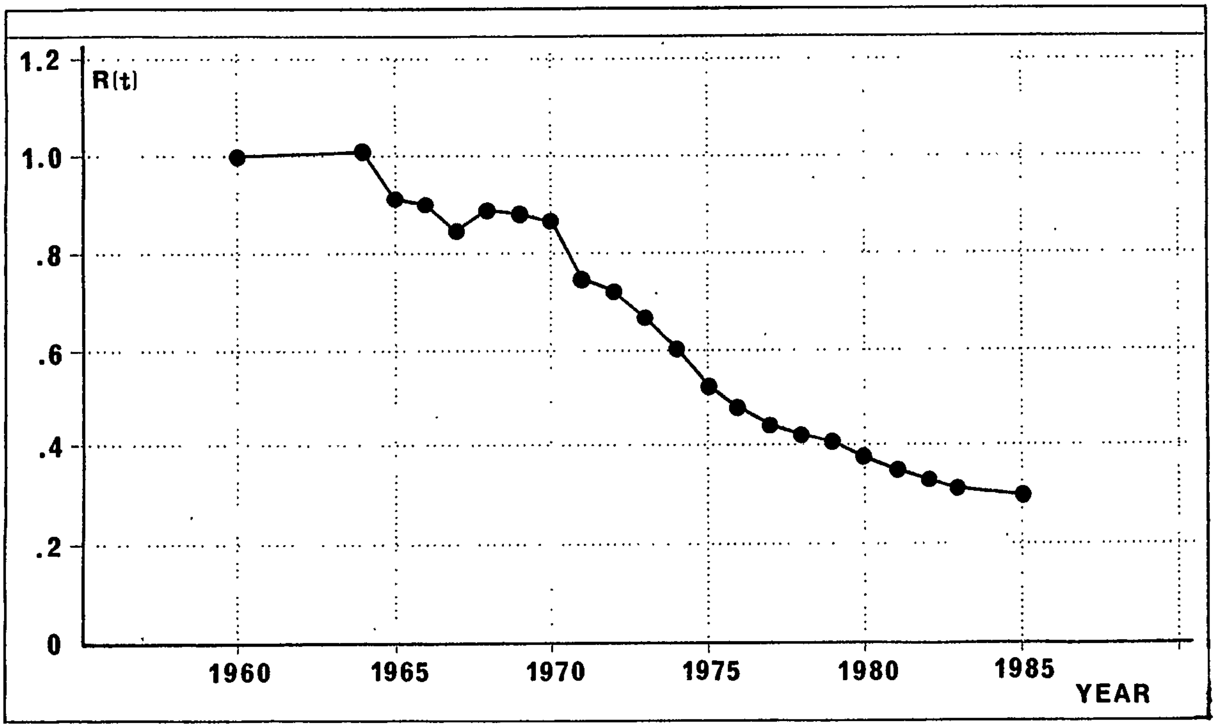
$r(x)$ = growth rate in the number of persons aged x

Table 2. Results of Estimating a Variety of Marriage Models in Japan, 1960-1985 and the United States, 1960-85.

		Number of Parameters		Percent of Variance Explained	
		Japan	U.S.	Japan	U.S.
Model A	$\frac{\lambda_{ij}M_i(t)F_j(t)}{P(t)}$	49	49	92.1	83.9
Model B	$\frac{RB_iC_j\lambda_{ij}M_i(t)F_j(t)}{P(t)}$	49*	49	92.1	83.9
B1:	R is function of t	54	70	97.8	99.1
B2:	B_i is function of t	90	202	99.3	99.8
B3:	C_j is function of t	90	202	99.8	99.8
B4:	B_i,C_j are functions of t	131		99.9	
Model C	$\frac{R(t)\lambda_{ij}\overline{\lambda}_i(t)M_i(t)F_j(t)}{P(t)}$	55		98.9	

*The basic model B, without time trends, cannot be statistically distinguished from model A because its only added variables are scalars to which the λ_{ij} adjust in inverse proportion.

Figure 1. Time Trends in U.S. Marriage Propensities



THE QUALITY OF MARRIAGE AND DIVORCE DATA FROM SURVEYS

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INTRODUCTION

Demographers, social scientists and others interested in the levels and determinants of marriage and marital dissolution in the United States have relied on several different data sources for information. These sources have included the U.S. Vital Statistics systems, the decennial U.S. Census, as well as a number of periodic sample surveys collected both by public agencies and private groups, usually affiliated with universities. Although one or more of these sources has at times been recommended as a substitute for national vital statistics on marriage and divorce, before such a substitution can be considered the quality of marriage and divorce data from alternate sources must be carefully evaluated.

All alternate sources of information on marriage and marital dissolution have in common the fact that they ask people questions about both their current marital status and some aspects of their marital histories. Preston and McDonald (1979) compared the quality of divorce rates from one of these sources, the U.S. Census, with estimates based on vital statistics. They reported that estimates of divorce based on vital statistics were almost always higher than census estimates, and that for the period 1919-1968, the difference averaged 25 percent, a difference they attribute to people's failure to report a divorce in the census. If people are unwilling to report divorces in the census,they may be equally unwilling to report one in an interview. Therefore, the purpose of this paper is to carry out a similar examination of the quality of data on marriages and divorces from another possible alternate to vital statistics, the Marriage and Fertility History Supplement to the Census Bureau's Current Population Survey.

MARRIAGE AND DIVORCE DATA FROM THE CURRENT POPULATION SURVEY

Although there are federally-supported surveys other than the Current Population Survey that collect data on marriage and marital dissolution, the Current Population Survey is the one that is the most likely candidate to serve as a substitute for vital statistics. The other survey that regularly collects marriage histories is the National Survey of Family Growth, conducted by the National Center for Health Statistics. The NSFG is primarily a fertility survey, and hence has a design that is appropriate for the study of current and recent fertility (by limiting interviews to women in the childbearing years), but falls short of the ideal for the study of marriage, divorce and remarriage, since older women and men are not included. Furthermore, the size of the NSFG sample, again one that is appropriate for fertility analysis, is small for analyses of divorce and remarriage. Another limiting factor, and one that is quite important if a survey is seen as a substitute for rather than a complement to vital statistics, is that the NSFG has operated on a somewhat sporadic schedule, with the date of the next survey never quite certain.

Unlike the NSFG, the Current Population Survey interviews both men and women, covers a much wider age range, and both the basic survey and the marriage and fertility history supplements have followed a regular schedule through the 1970s and 1980s. The main CPS is collected every month, and serves as the source of information on unemployment in the United States. In June of 1971, 1975, 1980 and 1985, marriage and fertility history supplements were added to the CPS. The June 1980 CPS,for example, included marriage histories collected from approximately 50,000 ever-married women and 42,000 ever-married men between the ages of 15 and 75. For each person, data on current marital status and number of times married were collected, as well as a slightly truncated marriage history that included the dates of marriage, separation and divorce or widowhood for as many as three marriages: the first, second and most recent marriage.

However, certain aspects of the way in which marriage histories are collected in the CPS raise questions about the quality of the data. First, it is important to note that the questions on marriage histories are a supplement to the CPS and in fact appear on the last page of the questionnaire. CPS interviewers, given the importance of collecting and publishing each month's unemployment data quickly, are under considerable pressure to return completed core questionnaires but under less pressure to return completed supplements. Furthermore, interviewers are likely to be interested in maintaining a rapport with respondents who are interviewed repeatedly throughout the year, a rapport that might be threatened by sensitive questions on marriage and divorce. Second, and more importantly, all questions on the CPS can be answered by one informant for all people in the household. This design is appropriate for the main purpose of the CPS, the collection of monthly unemployment statistics. If you were interested in knowing in each month how many people were employed or unemployed in a household and in getting this information quickly, this design is quite efficient because that information can be provided accurately by any adult in a household. However, marriage histories are another matter, and any adult in the household, a definition that could include an 18 year old child or step-child of the householder, may not be equally well-informed about the marriage histories of all other adults.

Table 1 demonstrates the potential magnitude of this problem with marriage histories from the June 1980 CPS. The considerable majority of marriage histories for men are reported by someone else; whereas women are quite likely to report their own histories. Keeping these results in mind, consider Table 2: those whose histories are reported by someone else are much more likely to have those histories reported in an incomplete manner. Following usual Census Bureau procedures, if an answer to a question or series of questions is not provided or not provided completely, the answer is imputed, using a hot-deck allocation. That is, the respondent with incomplete information on a specific question is matched, according to criteria appropriate to the question, with another complete record in the file. The data from the complete record are then used in place of the incomplete information. Fortunately, in releasing the public-use tape from the CPS, the Census Bureau places a flag next to each question indicating whether the item was recorded directly from the interview, or whether it was produced by allocation, or "imputed".

Table 2 shows that not only are marriage histories reported by others less likely to be complete, but that reports on the most complicated histories are also less likely to be complete. For all categories of gender and reporting status, imputation rates increase with the complexity of the marital history. So for men married and divorced two or more times, whose histories are reported by someone else, more than 60 percent of the data on the end of second marriages had to be imputed, indicating a potentially serious problem with the quality of the data if those more likely to have been divorced are the ones that are also more likely to provide incomplete marriage histories.

Table 1. Reporting Status of Marriage History Data, by Sex and Birth Cohort: June 1980 Current Population Survey

Birth Cohort	Percent Self-Reported	
	Females	Males
1905-09	74	40
1910-14	72	40
1915-19	70	34
1920-24	71	31
1925-29	71	28
1930-34	72	27
1935-39	71	27
1940-44	75	26
1945-49	77	28
1950-54	73	31
1955-59	66	31

Table 2. Percent of responses to marriage history questions imputed, by Sex and Reporting Status: June 1980 Current Population Survey.

	Sex and Reporting Status				
	Female		Male		
	S	P	S	Sp	O
Number of Marriages	7	14	10		
Date First Marriage	10	23	15	13	37
Date First Divorce	22	45	29	50	53
Date First Separation	31	51	38	58	58
Date Second Marriage	14	27	20	17	49
Date Second Divorce	32	56	35	62	64
Date Second Separation	35	57	38	69	64

S = Self response
P = Proxy response
Sp = Spouse response
O = Other proxy response

In the following sections we examine the quality of CPS marriage histories in more detail by considering both the internal consistency of CPS reports of marriages and divorce, as well as comparisons with vital statistics estimates.

Internal Consistency of CPS Marriage Histories

The fact that the 1980 CPS gathered marriage histories from both men and women provides important opportunities to assess the quality of the data. In the aggregate, since both men and women are involved in marriages and divorces, we can expect in a survey like the CPS to get two reports of each event, one from a man; one from a woman. But as Table 3 shows, we in fact don't get the same number of reports from men and women. Men report roughly 90 percent of the number of marriages women report, and roughly 85 percent of the divorces women report; a pattern that holds fairly well across all cohorts.

However, some differences in reports of events in the past from men and women might be expected, since fewer men than women would survive to respond to the survey. Although mortality differences by sex would produce more reports from women, the magnitude of the differences presented in Table 3 are not likely to result from mortality patterns alone. This would be the case particularly in the very recent past, since most of both the men and women reporting on recent marriages and divorces are still alive. To estimate the potential role that mortality differentials have in the reports in Table 3, in Table 4 we present the observed male/female ratios for a few years, along with rough estimates of the ratio of male/female survivors that one would expect simply based on differential mortality. To estimate these survival ratios we assumed that men married on average at 25, women at 20, and that men divorced on average at 35, women at 30. Although these are clearly crude estimates, because mortality for both men and women is so low throughout the 30s and into the 40s, slightly different, more precise estimates would not greatly affect our conclusions. We then used decennial period life table for each of the years indicated on Table 4 (for 1978 the 1980 life table was used), and calculated the ratio of the male survival rate from year in which marriage or divorce was reported to 1980 over the female survival rate for the same period.

Results in Table 4 indicate that the observed ratios for marriages, at least in the recent past, are quite close to what we would expect based on mortality patterns; although even by 1970 a discrepancy of .06 emerges. For divorces, results are far less positive. Based on mortality patterns, we would expect that men would report 99 percent of the divorces reported by women in 1978; in fact they reported on 82 percent as many divorces as women reported. When we consider reports of divorce as far back as 1950, we find that women in the CPS are reporting fewer divorces than we would expect. Based on mortality differences alone, we would have expected men to report 70 percent of the numbers of divorces reported by women; in fact in the CPS men reported 83 percent as many divorces as women for 1950. Based on unpublished analyses of data on marriage histories from the National Longitudinal Survey, we suspect that older divorced women whose former husbands have since died might tend, after that death, to report themselves as widowed rather than divorced. Whatever the source of the differences, it is clear that reports on marriages and divorces from men and women in the 1980 CPS are not consistent, except for the case of marriages in a short period of time prior to the survey.

Table 3. Three Year Moving Averages of Ratios of Marriages and Divorces Reported by Men to Those Reported by Women in the June 1980 Current Population Survey, by Single Year: 1945-1978

Year	Ratio of Male/Female Marriages	Ratio of Male/Female Divorces
1945	.83	.80
1946	.85	.75
1947	.88	.78
1948	.89	.72
1949	.88	.79
1950	.89	.83
1951	.88	.86
1952	.90	.84
1953	.88	.83
1954	.89	.84
1955	.88	.84
1956	.86	.81
1957	.87	.73
1958	.87	.74
1959	.89	.75
1960	.89	.78
1961	.89	.79
1962	.90	.77
1963	.91	.77
1964	.90	.80
1965	.90	.85
1966	.90	.86
1967	.91	.84
1968	.90	.81
1969	.92	.83
1970	.92	.89
1971	.93	.89
1972	.93	.86
1973	.94	.83
1974	.93	.83
1975	.93	.86
1976	.93	.89
1977	.95	.87
1978	.96	.82

Table 4. Observed Ratios of Number of Marriages and Divorces Reported by Men and Women in the June 1980 Current Population Survey, and Ratios Expected From Estimates of Differential Mortality: Selected Years

Year	Observed	Expected
	Marriages	
1950	.89	.85
1960	.89	.95
1970	.92	.98
1978	.96	.99
	Divorces	
1950	.83	.70
1960	.78	.87
1970	.89	.95
1978	.82	.99

Comparison of CPS with Vital Statistics

Beyond looking at the internal consistency of men and women's reports of marriages and divorces, to completely evaluate the utility of the CPS as a substitute for vital statistics it is also necessary to compare rates of marriages and divorces estimated by the CPS with those from vital statistics. For this comparison we focus on divorces and remarriages, since we expect these to be the events most likely to be misreported in the CPS. Figure 1 shows that divorce rates for both men and women as reported in the CPS are below the rates reported by vital statistics, and that, especially in the recent past, rates for men are below those for women. Figure 2 shows that both vital statistics and the CPS report higher remarriage rates for men than for women. However, the discrepancy between CPS and vital statistics rates is substantial for both sexes.

Figure 1. Comparison of Divorce Rates from 1980 Current Population Survey and United States Vital Statistics.

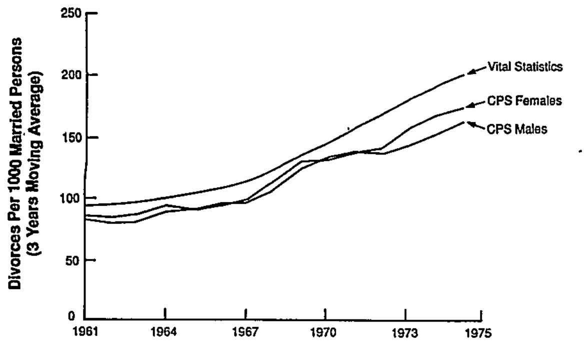
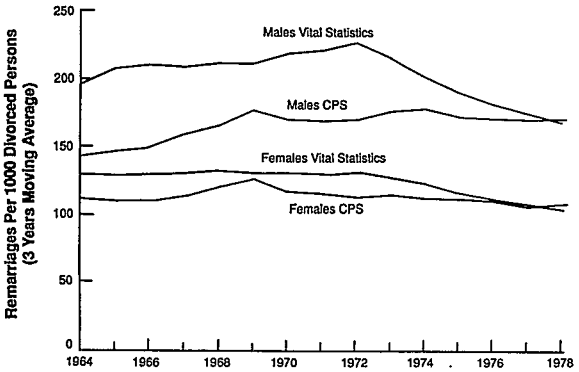


Figure 2. Comparison of Remarriage Rates from 1980 Current Population Survey and United States Vital Statistics.



Although both divorce and remarriage rates based on the CPS diverge from those based on vital statistics, there is an important difference in the exact form of these divergences. Divorce rates from the two sources differ more in level and relatively less in pattern. Both CPS and vital statistics estimates present a picture of increasing divorce over time. In the case of remarriage, however, the differences between CPS and vital statistics suggest both differences in level and time patterns of remarriage. Vital statistics estimates, particularly for males, show that remarriage rates have declined since the early 1970s. CPS estimates show no such decline. These differences suggest that CPS divorce estimates, although still inaccurate, may be more useful because at least the pattern of divorce reported is accurate, and the level can be adjusted rather simply by reference to vital statistics data. That is not the case for remarriage.

The patterns of remarriage rates reported in the CPS make it very difficult to use the results of one survey to analyze levels and trends in remarriage. For example, one of our first interests in analyzing data from the June 1980 CPS was to study the decline in remarriage rates that had been reported by vital statistics. We were especially curious if there was any evidence that this period decline might be the temporary result of people waiting longer following a divorce before remarrying, or whether it might indicate a more permanent reduction in the proportion of divorced men and women remarrying. However, after carrying our the analysis reported in Figure 2, we decided that the CPS could not support such an analysis, since CPS estimates could not replicate the aggregate trends reported in vital statistics. Bumpass, Sweet and Castro-Martin (1989) recently had a similar interest, and also found, in an analysis of the 1985 CPS, that they could not use those data to replicate the decline in remarriage rates among women that had been reported in vital statistics. They were able to replicate this decline, however, when they pooled the 1980 and 1985 CPS data for the five years prior to each survey, carried out an elaborate hazards model, and estimated a coefficient for a trend variable. Although they replicated the trend by using the two surveys and focusing on the periods right before the survey, the levels of their estimates were still 13 percent below those of vital statistics, even for the three years prior to each survey. For 13 years before the survey, they were off by 27 percent.

Bumpass et al. (1989) could only carry out their analysis of the 1985 CPS using marriage histories from women. Our preliminary analyses of the quality of male marriage histories from the 1980 CPS was sufficiently discouraging to result in the dropping by 1985 of the practice of asking marriage histories of men in the CPS.

CONCLUSIONS

What can we conclude from the analysis just presented? First, that there is a clear need for the continuation of vital statistics on marriage and divorce, since none of the currently available surveys provides data of the kind and quality that would be required of a true substitute data source. None of the surveys that include marriage histories can stand alone; all require that the data in them be evaluated relative to vital statistics. The clear conclusion from several studies is that retrospective marriage and divorce histories are valid only for the period immediately before a survey, and the quality of information available differs depending on the exact marital event one is studying (first marriages; divorce after first marriage; remarriage). Also, there is no existing data source that routinely collects marriage histories from men, and the sample sizes in none of the alternatives is sufficiently large to support analysis of important social and regional sub-groups (Bumpass et al., 1989).

Equally important is the essential requirement that data on marriage and divorce from other sources not only be accurate but also be part of a regularly collected series of data. The only long-term series of data now available is from vital statistics; witness the Preston and McDonald (1979) piece on long term trends in divorce in the U.S., a paper that could only have been written with data from vital statistics. The most stable of the alternatives is the CPS, which has collected marriage and divorce histories for little more than 15 years. Although it is likely that the every-five-year June supplements will continue, they do require the cooperation of the Census Bureau, which conducts the basic survey, the Department of Labor, which provides funds for the core survey, and the Center for Population Research at the National Institute of Child Health and Human Development, which has funded the marriage and fertility histories supplements. A change in policy at any of these three agencies could end the series at any time.

In conclusion, on the basic issues of quality and continuity of coverage, the surveys that also collect data on marriage and divorce histories can be viewed as important supplements to vital statistics, supplements that can in theory support a wider range of analysis of the determinants of marriage and divorce than would be possible with vital statistics; but supplements that need to be evaluated for quality and completeness by reference to vital statistics as a benchmark. The elimination of federal involvement in the collection and publication of vital statistics on marriage and divorce in the United States would greatly reduce the quality of information available to the American people on patterns and trends in marriage and divorce, information that is of considerable interest not only to academic demographers and social scientists, but to many in the general public as well.

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Session Q

Quality of Life

PHCRS

SETTING NATIONAL HEALTH GOALS AND OBJECTIVES OR THE YEAR 2000: A ROLE FOR QUALITY-ADJUSTED LIFE YEARS IN PUBLIC HEALTH POLICY

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(Not available for publication)

HEALTH PROMOTION, QUALITY OF LIFE, AND QALYS: A USEFUL INTERACTION

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I have been asked in this presentation to discuss the use of quality-adjusted life-years (or QALYs) in analytic assessments of health promotion efforts. It is helpful to put QALYs in the context of other measures of "quality of life" and "health status" and indeed to grapple with the often confusing rhetoric associated with these concepts.

To incorporate "quality of life" measures into analytic studies of health promotion, one must consider the concept of the quality of life and its application in utility theory. However, this is not a clear-cut, straightforward undertaking. The literature on quality of life and health status can be quite confusing since the terms are frequently used interchangeably, left undefined, or defined in one way and then used in another. In addition, at least three different sets of professionals, often with nonoverlapping subject matter, are involved. First, many of the persons with particular expertise in quality of life and health status have concentrated on measurement and worked on such tasks as developing and testing instruments, ascertaining validity, and constructing scales. These persons compose a somewhat different group than the decision analysts, who tend to use utility theory in the context of individual analyses, often clinical, with a view towards a conclusion expressed in terms of cost-effectiveness or cost-utility. The third group includes health promoters, who tend to be proactive, seeking individual lifestyle and community change and emphasizing intervention over measurement and evaluation. For them, a high quality of life includes the notion of an enhanced sense of well-being due to the practice of positive health behaviors. A cost-utility study of a health promotion activity brings these disciplines together even though their practitioners remain isolated.

Now let's compare quality of life to health status. Bergner considers quality of life much broader than health status, in that the former includes physical activity, social and leisure activity, work, symptoms, loss of income, cognition, self-esteem, anxiety, stress, and overall satisfaction, whereas the latter includes genetic, biologic, functional, mental, and health potential.[1] Spitzer argues that health status is a measurement that should be "reserved for assessments of ostensibly healthy people" and that quality of life should be "restricted to the assessment of a series of attributes among those 'definitely' sick."[2] Torrance describes "overall quality of life" as "an all-inclusive concept incorporating all factors that impact upon an individual's life. Health-related quality of life includes only those factors that are part of an individual's health."[3] He adds, "For health studies, health-related quality of life is the appropriate concept for use."

Such a definition is highly dependent on how one defines health. If the WHO definition of "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" is used, then Torrance's attempt at a noncircumscribed "health-related quality of life" is frustrated. If one considers health promotion as "all the measures that enhance the possibility of a full life, in both extent and quality," there would be few limits on the contributors to quality of life in evaluating a health promotion program. To bring us full circle in this complex area, Breslow states "health status tends to focus on disease states" whereas Spitzer stated that health status should be used to assess healthy people whereas quality of life should be used to assess the sick.[4]

Where does that leave the nonexpert decision analyst, hoping to shed some quantitative light on an activity promulgated as "healthy" by health promoters, viewed as suspect by sedentary nonenthusiasts, and ignored by more medically oriented technology assessors?

Said decision analyst needs to create a model, consult the literature, make some arbitrary choices, and incorporate quality of life and health status into an analysis consistent with the thoughtful approaches taken by Weinstein,[5] Luce, Warner, Oster, Russell,[6] and others.

In decision analysis, when health outcomes involve illness, disability, and death, it is useful to seek a common denominator for these diverse results. An acute illness with pain and disability can be "equated" to a chronic illness and to a premature death by employing QALYs in the analysis. Utility is a concept for measuring the value individuals place on the consequences of various causes of action or outcomes.[7] QALYs involve a utility judgement of how illness or disability diminishes the quality of one's time. The assignment of this value can be based on an actual study of consumer (patient or potential patient) preference, on the expertise of relevant health professionals, or on the arbitrary decisions of the creators of the model being analyzed.

Zeckhauser and Shepard's paper "Where Now for Saving Lives?" published in Law and Contemporary Problems in 1976,[8] and Weinstein and Stason's Hypertension: A Policy Perspective (1976)[5] were landmark publications in the use of QALYs. Zeckhauser and Shepard not only described the QALY and proposed its use but also recognized the related concept of "dysfunction level as a health status index." Thus, even at the outset, QALYs, to be used in decision analysis, were identified as closely related to the health status indices of the health status metricians.

It is also striking that QALYs were first used to assess health promotion, along with more curative technologies. Zeckhauser and Shepard compared coronary care units and low-cholesterol diets by using the outcome measures of dollar cost per additional life-year, both nonquality adjusted and quality adjusted. They considered purely health promotion alternatives in evaluating two interventions to prevent motor vehicle deaths: air bags and the 55 miles-per-hour speed limit.

Creating the value scale for QALYs requires developing a set of "utilities" for health states. "Utilities" are an assigned value on a relative scale for a given outcome--in this case, a health outcome. At its most simple and extreme, such a scale involves two assignments: "health," with a utility of 1.00; and death with a utility of 0.00. These can be considered the reference states. Of course, people often exist in health states intermediate to these references, and our analyses tend to focus on these intermediate conditions.

To illustrate the use of QALYs in an analysis of a health promotion activity, we could look at exercise.[9] Recently, we used cost-effectiveness analysis to estimate the health and economic implications of exercise as a means to prevent coronary heart disease. Basing our assumption on the literature, we assigned nonexercisers a relative risk of 2.0 for a coronary heart disease event. Two hypothetical cohorts (one that exercised and one that did not) of 1,000 35-year-old men were followed for 30 years to observe differences in the number of coronary heart disease events, life expectancy, and quality-adjusted life expectancy. We used jogging as an example to calculate cost, injury rates, adherence, and the value of time spent. Both direct and indirect costs associated with exercise, injury, and treatment of coronary heart disease were considered. The major outcome measure considered was cost per year of life saved, both nonquality adjusted (considering mortality only) and quality adjusted (considering mortality and morbidity).

Quality adjustments were made for the following types of morbidity: nonfatal coronary heart disease and running injuries. We assumed that each year that follows the onset of a nonfatal form of coronary heart disease would be equal to 0.8 of a healthy year. We calculated QALYs for exercise-related injuries by assuming that the quality of the time spent while injured was .9 of an equivalent uninjured time period. In a sensitivity analysis, we varied the QALY weights.

The relationship between the quality and quantity of life summarized in QALYS can be visualized graphically (Figure 1). If we start life in "health," suffer intermittent acute illnesses, and later in life have a longer-term disability, such as a myocardial infarction with residual angina, our total QALYs are summarized by the area under the curve. If the curve were "squared off," our total life-years would, of course, merely be our life span.

For this particular study of exercise, the top line would be pushed upward for persons who enjoyed exercise and found it made them feel better on a daily basis. For some, exercise would prevent or delay the myocardial infarct and reduce the risk of death from coronary heart disease and/or delay that event. Thus, quality and quantity of life might be increased.

Table 1 illustrates how the use of QALYs contributes to the analysis. The last three utilities raise the medical question of whether some states of living are "worse" than death.

Table 1. Arbitrarily Assigned Utilities for Various Health States

Health State	Utility
Healthy	1.00
Side effects of hypertension	0.95-0.99
Mild angina	0.90
Moderate hypertension	0.70
Renal dialysis	0.55
Severe anxiety/depression	0.50
Severe angina	0.50
Blindness	0.40
Hospital confinement	0.35
Dead	0.00
Quadriplegic, blind, and depressed	< 0.00 ?
Confined to bed with severe pain	< 0.00 ?
Unconscious	< 0.00 ?

The conclusion of the study was that the cost-effectiveness of exercise as a preventive approach to coronary heart disease largely depends on the individual's attitude toward exercise--on his or her "utility," as it were. This attitude gets expressed as the valuation of time; the break-even point for the analysis is at $2 per hour indirect cost for exercise (the amount one would have to reimburse an individual to get that person to exercise).

In our base core analysis, with an average wage of $9 and the population distributed among those who would enjoy an exercise program (55%), those who would dislike it (35%), and those who would be neutral (10%), the total cost per QALY gained would be $11,313. This figure compares favorably with other published studies of coronary heart disease interventions, from coronary artery bypass graft surgery to treatment for angina.

In summary, health promotion activities should be as rigorously assessed as other medical technologies. Such assessment should consider issues regarding both health status and quality of life. The use of quality-adjusted life-years in a cost-utility analysis is a helpful outcome measure. The value of such assessment of health promotion activities is well described by Zeckhauser and Shepard:

> Lack of knowledge can lead individuals concerned with balancing health against consumptive pleasure to suboptimal choices of lifestyle. Frequently, the sign of a casual relation is known, but not its magnitude. It is bad to smoke, bad to eat fattening desserts, bad to speed, and bad to eat eggs. For the individual who is willing to give up two of these practices but not all four, it would be nice to know just how bad each is. The tradeoffs become much more difficult to estimate when we choose across the spectrum of individual and collective choice. An individual concerned with the risks of nuclear power might be reassured or dismayed to understand that X pounds overweight is equivalent to residence half a mile from such a power plant. This information may help him when he votes on public issues, as well as when he sits down at the table. Our earlier argument is underscored: substantial gains in lifesaving per dollar expended will perhaps be the most readily achieved if we improve our predictions of the benefits from alternative life-promoting interventions.

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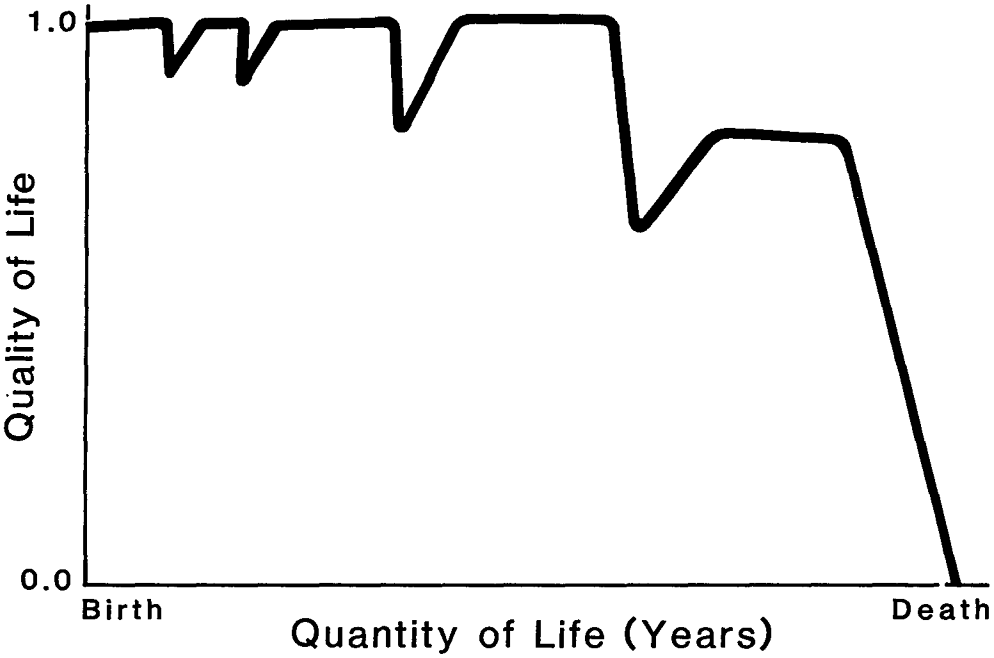
FIGURE 1



ESTIMATING WELL-YEARS OF LIFE FOR A NEW PUBLIC HEALTH INDICATOR

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In recent years, there have been many attempts to define and measure health status (1-3). To convey the most accurate and sensitive characterization of current health status, public health statistics ought to consider both mortality and morbidity. Yet most of our current methods fail to combine these two critical aspects of human health status. Clearly life expectancy is a crucial indicator of health. Equally important, however, are measures of the quality of life prior to death. As suggested by the World Health Organization (4), we must strive to add years to life and to add life to years. In this paper, we criticize traditional public health indicators as tools that are unnecessarily insensitive and ultimately inadequate to evaluate public health programs. Then, we offer a General Health Policy model that might respond to some of the problems with traditional indicators.

Traditional Public Health Indicators

Mortality remains the major outcome measure in most epidemiologic studies and clinical trials. In order to make informed decisions about the nation's health, the Congress receives various reports of statistical indicators including the crude mortality rate, the infant mortality rate, and years of potential life lost. These are important health indicators, but it fail to consider the health status of those who are alive. They give very little information about the presence, distribution, and effects of disabling conditions such as arthritis. Years of Potential life lost, for example, completely ignores those who live longer than 65 years and neglects life quality for those less than 65.

The National Center for Health Statistics also provides information on a variety of states of morbidity. For example, it reports disability days, bed-disability days, work-loss days, school-loss days, and activity limitations. A major problem with these frequently-used indicators is that they are not easy to compare with one another. Administrators often find it easy to interpret years of life or years of potential life lost. Yet comparisons of discrete morbidity categories, such as disability days, or days with activity limitations, are often confusing.

There are several reasons why we need newer and more sensitive measures of health status. First, current measures are very insensitive to variations in health status near the well-end of the continuum. For example, nearly 86 percent of the U.S. population reports no activity limitation (5). In the 1985 National Health Interview Survey, 90% of the population was reported to be in excellent, very good, or good health. Measures of mortality do not represent these individuals and measures of morbidity pertain to only the minority of the population. Yet large numbers of people have minor health problems that cause them to be concerned about their health status, and these minor problems are associated with substantial expenditures on health care.

Over the last 15 years, medical and health services researchers have begun to develop new ways to quantitatively assess health status. These measures are often called quality of life measures. Since they are used exclusively to evaluate health status, we prefer the term "health-related quality of life" (2). In the following sections, we will describe one approach to the measurement of health-related quality of life that combines measures of morbidity and mortality into a common unit. This consistently expresses health outcomes in units analogous to years of life. The years of life figure, however, is adjusted for diminished quality of life associated with diseases or disabilities.

Health-related Quality of Life

The objectives of health care are two-fold. First, health care and health policy should increase life expectancy. Second, the health care system should improve the quality of life during the years that people are alive. It is instructive to consider various measures in health care in light of these two objectives. Traditional biomedical indicators and diagnoses are important because they may be related to mortality or to quality-of-life. We prefer the term health-related quality of life to refer to the impact of health conditions on function. Thus, health-related quality of life may be independent of quality of life relevant to work setting, housing, air pollution, or similar factors (7).

Well-Years

Our approach is to express the benefits of medical care, behavioral intervention, or preventive programs, in terms of Well-years of life produced. Others have chosen to describe the same outcome as Quality Adjusted Life Years (QALYs) (8). Well-years integrate mortality and morbidity to express health status in terms of equivalents of Well-years of life. If a cigarette smoker died of heart disease at age 50, and we would have expected him to live to age 75, it might be concluded that the disease caused him to lose 25 well years. If 100 cigarette smokers died at age 50 (and also had life expectancies of 75 years), we might conclude that 2,500 (100 people x 25 years) well years had been lost.

Yet, death is not the only outcome of concern in heart disease. Many adults suffer myocardial infarctions leaving them somewhat disabled over a longer period of time. Although they are still alive, the quality of their lives has diminished. Our model permits all degrees of disability to be compared to one another. A disease that reduces the quality of life by one-half will take away .5 Well-years over the course of one year. If it affects two people, it will take away 1.0 Well-year (equal to 2 x .5) over a one-year period. A medical treatment that improves the quality of life by .2 for each of five individuals will result in a production of one Well-year if the benefit is maintained over a one-year period. Thus, using this system, it is possible to express the benefits of various programs by showing how many equivalents of Well-years they produce (9,10). Yet, not all programs have equivalent costs. In periods of scarce resources, it is necessary to find the most efficient use of limited funds. Our approach provides a framework within which to make informed policy decisions that require selection between competing alternatives. Special services for the older adults may in this way compete with traditional medical services for the scarce health care dollar. We believe these services can be competitive in such analyses. Performing such comparisons requires the use of a general health decision model. In the next section, the general model of health status assessment and benefit-cost/utility analysis will be presented.

General Model

The Health Decision Model grew out of a substantive theory in economics, psychology, medicine, and public health. These theoretical linkages have been presented in several previous papers (11). Building a health decision model requires at least five distinct steps.

Classification of Dysfunction.

During the early phases of our work a set of mutually exclusive and collectively exhaustive levels of functioning were defined. Three scales representing related but distinct aspects of daily functioning were created: Mobility, Physical Activity, and Social Activity. The Mobility and Physical Activity scales have three levels, while Social Activity has five distinct levels. Table 1 shows the steps from the three scales. Several investigators have used this function status classification (or a modified version of it) as an outcome measure for health program evaluation (12,13). However, the development of a truly comprehensive health status indicator requires several more steps.

Table 1 Quality of Well-being/General Health Policy Model: Elements and Calculating Formulas (Function Scales, with Step Definitions and Calculating Weights)

Step No.	*Step Definition*	*Weight*
	Mobility Scale (MOB)	
5	No limitations for health reasons	-.000
4	Did not drive a car, health related; did not ride in a car as usual for age (younger than 15 yr), health related, *and/or* did not use public transportation, health related; *or* had or would have used more help than usual for age to use public transportation, health related	-.062
2	In hospital, health related	-.090
	Physical Activity Scale (PAC)	
4	No limitations for health reasons	-.000
3	In wheelchair, moved or controlled movement of wheelchair without help from someone else; *or* had trouble or did not try to lift, stoop, bend over, or use stairs or inclines, health related; *and/or* limped, used a cane, crutches, or walker, health related; *and/or* had any other physical limitation in walking, or did not try to walk as far as or as fast as other the same age are able, health related	-.060
1	In wheelchair, did not move or control the movement of wheelchair without help from someone else, *or* in bed, chair, or couch for most or all of the day, health related	-.077
	Social Activity Scale (SAC)	
5	No limitations for health reasons	-.000
4	Limited in other (e.g., recreational) role activity, health related	-.061
3	Limited in major (primary) role activity, health related	-.061
2	Performed no major role activity, health related, but did perform self-care activities	-.106
1	Performed no major role activity, health related, *and* did not perform or had more help than usual in performance of one or more self-care activities, health related	-.106

Calculating Formulas

Formula 1. Point-in-time well-being score for an individual (W):

$$W = 1 + (CPXwt) + (MOBwt) + (PACwt) + (SACwt)$$

where "wt" is the preference-weighted measure for each factor and CPX is Symptom/Problem complex. For example, the W score for a person with the following description profile may be calculated for one day as:

CPX-11	Cough, wheezing or shortness of breath, with or without fever, chills, or aching all over	-257
MOB-5	No limitations	-.000
PAC-1	In bed, chair, or couch for most or all of the day, health related	-.077
SAC-2	Performed no major role activity, health related, but did perform self-care	-.061

$$W = 1 + (-.257) + (-.000) + (.007) + (-.061) = .605$$

Formula 2. Well-years (WY) as an output measure:

$$WY = [\text{No. of persons} \times (CPXwt + MOBwt + PACwt + SACwt) \times \text{Time}]$$

Symptom and Problem Classification.

There are many reasons a person may not be functioning at the optimum level. Subjective complaints are an important component of a general health measure because they relate dysfunction to a specific problem. Thus, in addition to Function Level classifications, an exhaustive list of symptoms and problems has been generated. Included in the list are 25 complexes of symptoms and problems representing all of the possible symptomatic complaints that might inhibit function. These symptoms and problems are shown in Table 2.

Table 2: Quality of Well-being/General Health Policy Model: Symptom/Problem Complexes (CPX) with Calculating Weights

CPX No.	CPX Description	Weights
1	Death (not on respondent's card)	-.727
2	Loss of consciousness such as seizure (fits), fainting, or coma (out cold or knocked out)	-.407
3	Burn over large areas of face, body, arms, or legs	-.387
4	Pain, bleeding, itching, or discharge (drainage) from sexual organs--does not include normal menstrual (monthly) bleeding	-.349
5	Trouble learning, remembering, or thinking clearly	-.340
6	Any combination of one or more hands, feet, arms, or legs either missing, deformed (crooked), paralyzed (unable to move), or broken--includes wearing artificial limbs or braces	-.333
7	Pain, stiffness, weakness, numbness, or other discomfort in chest, stomach (including hernia or rupture), side, neck, back, hips, or any joints or hands, feet, arms, or legs	-.299
8	Pain, burning, bleeding, itching, or other difficulty with rectum, bowel movements, or urination (passing water)	-.292
9	Sick or upset stomach, vomiting or loose bowel movement, with or without chills, or aching all over	-.290
10	General tiredness, weakness, or weight loss	-.259
11	Cough, wheezing, or shortness of breath, *with* or *without* fever, chills, or aching all over	-.257
12	Spells of feeling, upset, being depressed, or of crying	-.257
13	Headache, or dizziness, or ringing in ears, or spells of feeling hot, nervous or shaky	-.244
14	Burning or itching rash on large areas of face, body, arms, or legs	-.240
15	Trouble talking, such as lisp, stuttering, hoarseness, or being unable to speak	-.237
16	Pain or discomfort in one or both eyes (such as burning or itching) or any trouble seeing after correction	-.230
17	Overweight for age and height or skin defect of face, body, arms, or legs, such as scars, pimples, warts, bruises or changes in color	-.188
18	Pain in ear, tooth, jaw throat, lips, tongue; several missing or crooked permanent teeth--includes wearing bridges or false teeth; stuffy, runny nose; or any trouble hearing--includes wearing a hearing aid	-.170
19	Taking medication or staying on a prescribed diet for health reasons	-.144
20	Wore eyeglasses or contact lenses	-.101
21	Breathing smog or unpleasant air	-.101
22	No symptoms or problem (not on respondent's card)	-.000
23	Standard symptom/problem	-.257
X24	Trouble Sleeping	-.257
X25	Intoxication	-.257
X26	Problems with sexual interest or performance	-.257
X27	Excessive worry or anxiety	-.257

Preference Weights to Integrate the QWB Scale

Using the three scales of function and 25 Symptom/Problem Complexes, we can compare populations in terms of frequencies of each scale step (and, if necessary, Symptom/Problem Complex). Although comparisons of frequencies are common in health services research, our system offers a strategy for integrating the frequencies into a single comprehensive expression. If our intent is to say which of these distributions is "better" off and which "worse," it is necessary to integrate the three scales and the Symptom/Problem Complexes in a manner that will allow a single numerical expression to represent each combination of steps on the scales and Symptom/Problem Complexes. The empirical means of accomplishing this is measured preferences for the health states. These might be regarded as "quality" judgments. As we noted earlier, the General Health Policy Model includes the impact of health conditions upon the quality of life. This requires that the desirability of health situations be evaluated on a continuum from death to completely well. An evaluation such as this is a matter of utility or preference, and thus, function level-symptom/problem combinations are scaled to represent precise degrees of relative importance.

Human judgment studies are needed to determine weights for the different states. We have asked random samples of citizens from the community to evaluate the relative desirability of a good number of health conditions. Random sample surveys were conducted in the San Diego community during two consecutive years. The probability sample included 867 respondents ethnically representative of the population. When necessary, interviews were conducted in Spanish. From a listing of all possible combinations of the scale (Mobility, Physical Activity, Social Activity, and Symptom/Problem Complexes), we drew a stratified random sample of 343 case descriptions (items) and divided them into eight sets of computer-generated booklets. All respondents were assigned randomly to one of the eight booklets, creating eight subgroups of approximately 100 respondents each. In a series of studies, a mathematical model was developed to describe the consumer decision process. The validity of the model has been cross-validated with an R^2 of .94 (10). These weights, then, describe the relative desirability of all of the function states on a scale from zero (for death) to 1.0 (for asymptomatic optimum function). Thus, a state with a weight of .50 is viewed by the members of the community as being about one-half as desirable as optimum function, or about halfway between optimum function and death.

Some critics have expressed concern that community, rather than specific population weights are used. The advantage of community weights is that they are general (like the model) and do not bias policy analysis toward any interest group. More important, however, is that empirical studies consistently fail to show systematic differences between demographic groups (14), providers, students and administrators, (15) and Americans versus British (16). Relevant to the general versus disease specific issue, Balaban and colleagues (17) found that weights provided by rheumatoid arthritis patients are remarkably similar to those we obtained from members of the general population.

Using preference weights, one component of the general model of health is defined. This is the "Quality of Well-being Scale," which is the point-in-time component of the General Health Policy Model (18). The Quality of Well-being score for any individual can be obtained from preferences or "quality" judgments associated with his/her function level, adjusted for symptom or problem.

The example in Table 1 describes a person classified on the three scales of observable function and on a symptom/problem. The table shows the adjustments for each of these components. Using these, a weight of .605 is obtained. By including symptom/problem adjustments, the Index becomes very sensitive to minor "top end" variations in health status. The adjustments for particular symptom/problems are shown in Table 2. For example, there are symptom-problem complexes for wearing eyeglasses, having a runny nose, or breathing polluted air. These symptom adjustments apply even if a person is in the top step in the other three scales. For example, a person with a runny nose receives a score of .83 on the Quality of Well-being Scale when he is at the highest Function Level (ie. the top step on each scale shown in Table 1). Thus, the Model can make fine as well as gross distinctions.

Transitions among health states.

The Quality of Well-being Scale is the point-in-time component of the model. A comprehensive measure of health status also requires an expression of prognosis or the probability of moving between health states over time. People who are well now want to remain well. Those who are at sub-optimal levels want to become well, or at least not get worse. A General Health Policy Model must consider both current functioning and probability of transition to other levels of functioning over the course of time. When transition is considered and documented in empirical studies, the consideration of a particular diagnosis is no longer needed. We fear diseases because they affect our current functioning or because they alter the probability that there will be a limitation in our functioning some time in the future. A person at high risk for heart disease may be functioning very well at present, but may have a high probability of transition to a lower level (or death) in the future. Cancer would not be a concern if the disease did not affect current functioning or the probability that functioning will be affected at some future time.

When weights have been properly determined, health status can be expressed precisely as the expected value (product) of the preferences associated with the states of function at a point in time and the probabilities of transition to other states over the remainder of the life-expectancy. Quality of Well-being (W) is a static or time-specific measure of function, while the Well-life Expectancy (E) also includes the dynamic or prognostic dimension. The Well-life Expectancy is the product of Quality of Well-being times the expected duration of stay in each Function Level over a standard life period.

The Benefit-Cost/Utility Ratio.

In a variety of publications, the San Diego group has shown how the concept of a Well-life Expectancy can be used to evaluate the effectiveness of programs and health interventions. The output of a program has been described in a variety of publications as Quality Adjusted Life Years, Well-years, Equivalents of Well-years, or Discounted Well-years (11). Weinstein (8) calls the same output Quality-Adjusted Life Years (QALYs), and this has been adopted by the Congressional Office of Technology Assessment (19). It is worth noting that the Quality Adjusted Life Years terminology was originally introduced by Bush, Chen & Patrick (20), but later abandoned because it has surplus meaning. The term "wellness" or "Well-years" implies a more direct linkage to health conditions. Whatever the term, the Index shows the output of a program in years of life adjusted by the quality of life which has been lost because of diseases or disability.

Sensitivity of the Methods

Many authors have expressed concern about the sensitivity of health outcome measures. In this section, we will consider two aspects of sensitivity. First, there is sensitivity in population studies. Second, sensitivity in clinical studies will be reviewed.

As we have suggested elsewhere (21), about 85% of the respondents in national surveys report themselves to be not limited in major activities. Further, 50% report themselves to be in excellent or very good health. As a result, current health indicators provide little information about "well" populations, or at least those unlimited in their major activity. In contrast, the QWB questionnaire finds very few people who score at the top of the 0 to 1.0 continuum. For instance, a 1975 survey of a random sample of San Diego residents revealed that only 12% were completely functional and had no symptom/problem on a particular day. The increased sensitivity is gained through the greater precision of the questions and through the inclusion of symptoms and problems. Thus, an individual who has itchy eyes, wears eyeglasses, or has a cough scores below the optimal level on the scale.

Defining clinical sensitivity is more difficult. Some investigators (22) suggest that measures be designed in order to maximize differences between treatment and control groups in experimental trials. The quality of life measures, according to these authors should be evaluated by their ability to detect differences between groups of patients treated in different ways. However, a statistically significant difference between groups is not necessarily a clinically meaningful one. For example, in a very large clinical trial, with several thousand patients per condition, essentially trivial differences can be statistically significant. Conversely, relatively large differences in small trials may be statistically non-significant. The issue of clinical versus statistical significance has been debated for many years. One of the advantages of the QWB system is that it presents differences between groups in a well defined unit. For example, a difference of .05 units means that the treated and the untreated groups differ by an amount that is equal to 5% of the utility difference between optimum function and death. If this difference is maintained for one year, each patient will have gained .05 equivalents of a life year. If the effect is maintained 20 years, or if it accrues to 20 individuals, the treatment will have produced the equivalent of one year of life. Within the QWB system, levels of functioning and symptom/problem complexes have been evaluated such that they represent perceived meaningful differences along the death to well continuum. In order to justify two separate levels of function, it was necessary that the perceived difference between them be statistically significant. When differences along the continuum from death to optimum function were too small to be detected by human judges, they were merged into a single level.

QWB Estimates From General Surveys

Several surveys have been used to estimate the QWB values for the general population. One of these was household interview survey involving 867 respondents randomly sampled from the San Diego general population. Data were also gathered about a supplementary probability sample of 370 children and 89 dysfunctional persons identified in the sample households by a screening question. During a 1.5 hour interview, data were gathered about socioeconomic characteristics, role performance, number and kinds of symptoms and problems, and a variety of other health related questions such as physician contacts and numbers of chronic medical conditions.

Age.

According to our conceptual framework, the expected mean value of well-being decreases with greater age in any population. Many studies underestimate the age effect because they represent only the survivors of a birth cohort and do not include those who would be the same age but are not now living. The calculation of the Well-year requires two different data sets. In addition to point-in-time Well-being, a life table is required to specify the proportion of people from each birth cohort who are still alive.

Figure 1. Survival curve and QWB curves for general population and those reporting arthritis, San Diego CA.

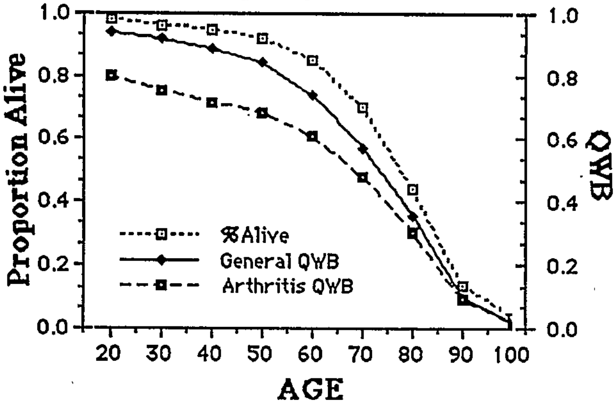

Figure 1 shows an extension of the age graph that includes mortality. The points on the graph are found by multiplying W for age group A by the proportion of persons who would still be alive at age A, according to a life table constructed from current local mortality rates. The area under the curve represents a simple static or nonstochastic approximately of the Well-life Expectancy. As the figure demonstrates, the curve is relatively flat until about age 45. From then on, it assumes a substantial downhill course.

Impact of Arthritis.

The other curves are shown in Figure 1. The top curve in the figure is the percentage of individuals alive at different ages based on life tables from the National Center for Health Statistics (23). The top curve is referenced against the left axis describing the proportion alive at different ages. The remaining two curves are interpreted using the right horizontal axis for QWB score. The area between the first two curves is the difference in life expectancy that occurs as a function of quality adjustment. The bottom curve displays the QWB for individuals who suffer from arthritis as estimated from the San Diego survey. As the figure shows, there are substantial differences in QWB between the general population and arthritis sufferers. Interestingly, these values are most different early in the life course. For example, at ages 20, 30, and 40, the general population and arthritis sufferers differ by nearly .15 QWB units. However, the prevalence of arthritis is not as high in these age categories. Thus, the total public health impact of arthritis still remains relatively small for younger individuals because that arthritis remains a relatively rare disease in younger age categories. Current estimates suggest that juvenile arthritis, although very disabling, affects only about 71,000 individuals. Rheumatoid arthritis, which typically has its onset during mid-life, is severely disabling but affects only about 1% of the population. There are an estimated 2.1 million cases currently in the U.S. The most common form of arthritis is osteoarthritis which affects an estimated 15.8 million Americans. Although less disabling, osteoarthritis has a significant impact upon the public health of older citizens because of its extremely high prevalence (24).

We are currently working on estimates on the number of equivalent life years lost due to arthritis. The impact of arthritis upon older citizens is often difficult to judge because current health indicators either underestimate the impact of the condition, or express the impact in numbers that are not directly comparable to the effects of other illnesses. For example, arthritis has very little impact upon mortality, except in some specific subconditions, such as systemic lupus. Because the disease is not life threatening it is often considered nonglamorous and discounted in public policy decisions. Current methods of assessing the impact of disabling but nonfatal conditions often understate the problem. It has been estimated that 27 million workdays are lost annually to arthritis at a cost of $8.6 billion dollars (24). Yet the older individuals most likely to be affected by arthritis are often out of the work force and are not counted. Indicators that do allow for this accounting are complex and can be confusing to policy makers. The Well-year expresses the impact of a condition in a year of life summary number that combines mortality and morbidity. The unit is not specific to age and can be used to compare investments in programs for the old and the young.

Gender Differences.

Another use of the system is to compare Well-being among groups that have different demographics of clinical characteristics. In a recent paper we estimated the Well-life Expectancy for men and women in San Diego, California. Considering only life expectancy, women have a 7 year advantage (78.3 vs. 71.3 years). However, women experience greater morbidity and mortality after age 40. Combining morbidity and mortality reduces the female advantage to about 3 years. Morbidity considerations reduce the 78.3 year female life expectancy to 62.70 years. For men the 71.3 year life expectancy is reduced to 59.78 year (25).

Comparison of Illnesses.

An important report from the Medical Outcomes Study demonstrated the impact of several diseases upon general health outcomes. They reported that physical and role performance were most affected by heart disease, followed respectively by arthritis and hypertension (26). Although the Medical Outcomes Study is a milestone accomplishment, data from the investigation do not place the relative impact of various diseases along a continuum that is well anchored by death and optimum function. As a result, estimation of equivalents of life years lost cannot be obtained.

Using our small San Diego data set, we estimated the impact of heart disease (N=64), arthritis (N=127), ulcer (N=70), and allergy (N=248). These comparisons are shown in Figure 2. The mean dysfunction associated with heart disease was .695 while that for allergy was .790. Thus, the difference between heart disease and allergy, on average, was about .10. Each decade a heart patient suffers the loss about the equivalent of 1 life year in comparison to allergy victims.

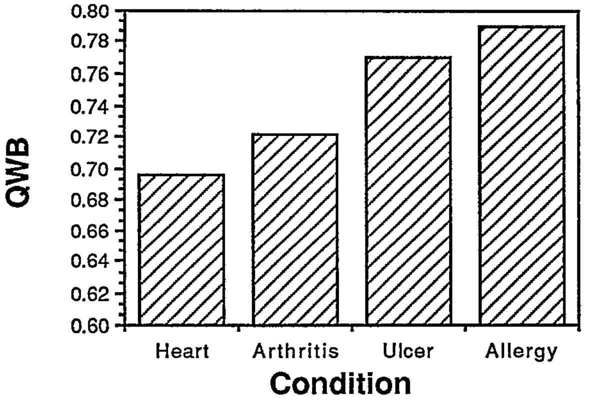

Figure 2. QWB scores for four chronic conditions, San Diego population survey.

Morbidity is only part of the problem for those with heart disease. Considering both morbidity and mortality, we magnify the differences between conditions since heart disease causes significantly early mortality and allergy does not. We are currently working on these analyses.

Estimating Well-years from National Data Sources

Given the advantages of general health status or health-related quality of life measures, it would seem valuable to employ them for national data efforts. However, data have not been collected to directly compute these values. Ultimately, we hope national surveys will include these measures. In the absence of more concrete measurements, the National Center for Health Statistics, in collaboration with Social and Scientific Systems of Bethesda, MD, has been attempting to estimate QWB values from four years of the NHIS. This is possible because items on current-health surveys are similar in many respects to the QWB items. Review of previous NHIS instruments suggested that the years 1977, 1979, 1980, 1984 were the most comparable. The actual methods used for these computations are difficult and rest upon several complex assumptions. The problems are considerable and have been discussed elsewhere (21).

Early evidence suggests that the imputed QWB provides a more sensitive estimate of dysfunction than does the do traditional NHIS indicators. For example, we have previously compared three indicators of well-being: activity limitation, composite measures of function combing mobility, physical activity, and social activity, and the overall QWB score In these comparisons, we simply considered the percentage of persons with no dysfunction. These comparisons were made for those less than age 17, between the ages of 17 and 44, between the ages of 45 and 64, and for those over the age of 65. Using traditional activity limitations as an indicator for well-being finds nearly all of those under age 17 as unlimited (96%). However, the QWB finds less than 70% of the 17 and under group to have no limitations. At the other end of the age spectrum, 45% of those 65 and over have some activity limitation. Yet, the QWB finds almost no persons who are without limitations. Composite measures that focus on areas of dysfunction are more sensitive than activity limitations alone, but are much more similar to activity limitations than are QWB scores. For the total U.S. population, the activity limitation indicator gives an approximately 10% higher estimate of the Nation's health than does the composite function status measure. There is an overestimate of 12% for persons younger than 17 years, and 8% for persons 65 years and older (Erickson, et al, 1989). Comparing activity limitations with the overall QWB score highlights even greater discrepancies. Using the overall QWB score, limitations of activity as an indicator underrepresents QWB function by at least 50% in all categories. (see Figure 3 and reference 21)

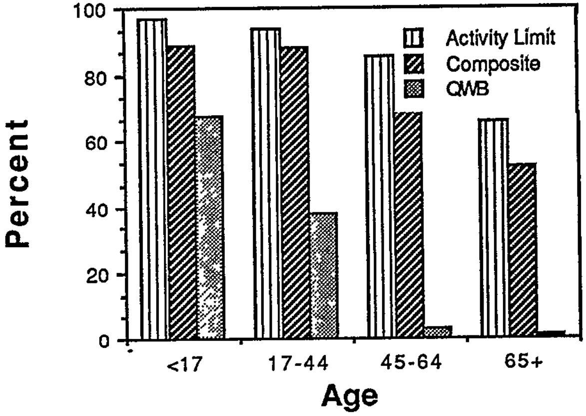

Figure 3. Percent of respondents with no dysfunction in activity, composite or QWB, NHIS, 1980 (Source: ref 21)

Conclusions

Public health planning, health services, and clinical research require new methods for quantifying health outcomes. Traditional public health indicators are deficient for several reasons. First, measures of mortality provide limited information about living. Infant mortality rates ignore all those who live beyond one year while years of potential life lost ignore all those 65 years and older. The life expectancy will probably not exhibit large changes in the near future (27).

In response to these problems, we propose an alternative public health indicator; the Well-year of life. The Well-year of life allows the comparison of treatment interventions that are very different from one another. In addition, it expresses the impact of disabling diseases, such as arthritis, in equivalents of life years. By combining morbidity and mortality, it is possible to express the impact of any health condition in a common unit. The unit reflects the impact of diseases in different organ systems and evaluates the relative importance of various health conditions. The availability of this unit allows for direct comparisons of the cost-benefit/utility of various policy options in health care. A preliminary analysis suggests that these new indicators may also be more sensitive than current approaches for detecting minor variations in health status. However, these minor variations may have important correlates including utilization of health care services. In addition, these methods can be used for policy making. We hope these methods will find expanded applications in future studies.

There are many serious shortcomings with our current methods for estimating Well-years from national data sources. The major ones arise from attempts to estimate refined data from more crude questions. Several studies have documented that specific interview techniques do improve precision (28). For example, studies have suggested that the optimal window for evaluating health status is six days rather than two weeks. Although the NHIS does not ask about symptoms or problems, we know that a considerable portion of the variability in well-being is accounted for by symptomatic complaints. In the retrospective analysis of the NHIS to form QWB-type estimates, information on symptoms and problems was drawn from data collected on self-reported health conditions; this imputation process was based on many tenuous assumptions. The experience from this retrospective analysis indicated that it is possible to collect data for estimating well-years on a national basis. However, it is clear from the assumptions and imputations on which the analysis is based that the best estimates will be obtained if data on all relevant types of functioning and on symptoms and health problems are collected prospectively. It is also clear that in order to apply methodologies such as those employed in collecting data for the QWB, that additional study will be needed to standardize them for the large-scale processing necessary for conducting the NHIS.

In summary, although the work presented here is preliminary, it does suggest it is possible to use the General Health Policy Model to calculate well-years for the U.S. population using large-scale population surveys, and that such estimates provide important information for health policy purposes. To move toward more precise estimates of well-years, we urge the continued research and development needed to modify our national health surveys to collect information for this valuable public health indicator.

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For more information on different approaches to defining and measuring health status and health-related quality of life, contact the Clearinghouse on Health Indexes, Office of Analysis and Epidemiology, National Center for Health Statistics, 3700 East-West Highway, Room 2-27, Hyattsville, MD 20782.

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Session R

The International Experience

PHCRS

DISSEMINATION OF STATISTICAL INFORMATION: THE EGYPT EXPERIENCE

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ALVIN O. ZARATE, National Center for Health Statistics

INTRODUCTION

In 1974 the Egyptian Government, through the Ministry of Health of Egypt, began to put together a Health Information System. The system was patterned after the United States model as designed and implemented by the National Center for Health Statistics. The project was funded through the AID Program with Dr. Ramsis A. Gomma, Under Secretary of Health as the Principal Investigator. Later Dr. Abd El-Moneim Fouad became the Principal Investigator and currently that positions is held by Dr. Abd El-Moneim Mobarez. Dr. Amal Ibrahim, Professor of Medicine, University of Cairo is the Co-Principal Investigator. Dr. Wesly L. Schaible and Mr. Earl Bryant of the National Center for Health Statistics were the primary technical consultants. They began their efforts by implementing a National Health Interview Survey to which a Health Examination Survey was added. Later, they initiated a Health Facilities Inventory. The reasons for this selection of components was to provide a broad base of information that would meet the needs of many potential users. They have completed the data collection phase of the program and are now completing the information dissemination stage. The discussion that follows deals primarily with this later stage.

DATA COMPONENTS

The first component was the Health Interview Survey. It was started in November, 1979 and completed April, 1984. It was patterned after the U.S. Health Interview Survey in terms of design, format, and collection procedures, but differed in the questionnaire. 72,000 Household representing 400,000 persons were included with a non-completion rate of less than 5%.

The second components was the Health examination Survey which was started in May, 1981 and ended in May, 1984. The subjects for this survey were taken as a 10% sub-sample of the Health Interview Survey respondents. The non-completion rate for this survey was higher at about 15 - 20%.

The final component is the Health Facilities Inventory and includes "all health units, their equipment and utilization as well as data of health manpower working in the governmental, public and private sectors". This component is seen as the continuing force in the Health information System as it will provide the linkage between the population health needs and the health care resources.

DATA USE IN EGYPT

The use of data in Egypt for health planning and evaluation today is similar to the use in the United States twenty years ago. They have one advantage in that they should be able to capitalize on our many mistakes. One thing that they have done is identified their data user groups and included them in various aspects of the project.

The plan for dissemination of the results of their surveys is along three different yet related fronts. The first is to use their primary user group (health Planners) for input on the types of information needed and areas that their analyses should be directed too. The second is to prepare and distribute statistical reports on methodology and specific topics. The third is to present their results in as many different forums as possible.

The Health Planners have been involved in the project since its inception in helping to identify the types of information needed, possible analyses, and applications of the results. They have been actively involved and have used the information provided to the best of their abilities. However, the staff of the EHP did not realize the lack of skills in the planners for data analysis and interpretation. Because of this, the staff had to get more involved in planning than they had originally anticipated. They are currently developing a closer working relationship and developing new ancillary projects.

There have been two major conference held in Cairo, Egypt on the results of their survey activities. The first was held in June, 1988 and the second in May, 1989. Both were well attended with enthusiasm and interest expressed by all. The presenters were knowledgeable of their material and held the interest of the audience. The first conference was limited in the use of graphics, but the second conference use graphics in almost all the presentations.

FUTURE CONSIDERATIONS

In terms of data collection the project staff can congratulate themselves on a job well done. While they had a few problems early on, these were recognized and dealt with. However, data collection is the easy part, applying the results is the more difficult part. It is here that much can and needs to be done.

The first criticism of most data systems is timeliness of the results. The users want the results yesterday and the analysts wants to make sure the analysis is correct and all the statistical safeguards have been applied. This is not a new problem or one unique to Egypt, but rather one that will continue to bother us all for some time. In Egypt they still have problems with the computer interface, but this is being solved. The Health Profile of Egypt has considered itself as the primary source of health data to the exclusion of other data sources. In order to be successful and have their data utilized they must incorporate data from other sources such as labor and education. If this is done it will greatly expand the usefulness of their information and give it greater utility. To do this they must agree on a common linkage device, which is probably geography. Attempts in this direction are being made.

To utilize data from other sources means that the Health Profile of Egypt will have to become involved with many other governmental agencies. This may be difficult to accomplish and has been resisted to date.

Finally, the use of graphics needs to be expanded. They currently use Harvard Graphics on a PC and have no capacity for geographic mapping. This one dimension, maps, can greatly expand the use and dissemination of their information.

CONCLUSIONS

While the Health Profile of Egypt is getting their data to the users and making many efforts to see that it is applied to health problems, much needs to be done. As they shift from project status to program status they need to include data from other sources and become involved with other agencies. The data gathering activity in both Health Interview Survey and Health Examination Survey needs to continue with a greater emphasis placed on getting information to the users on a timely basis. Finally, the government of Egypt needs to recognize this activity and make a financial commitment to the program.

In summary, the problems that Egypt has with data use are no different than those faced in the United States.

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The National Health Survey of Pakistan:
Prospects and Problems of a Health Examination Survey in a Less Developed Country

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Introduction

The National Center for Health Statistics (NCHS), Office of Planning and Extramural Programs has provided technical assistance to the government of Pakistan on a health examination survey, the National Health Survey of Pakistan (NHS-P). The survey has been planned and piloted by the Pakistan Medical Research Council (PMRC) in collaboration with the Federal Bureau of Statistics (FBS). The foreign currency exchange program (PL 480) has provided the funding for the project. The National Center for Health Statistics has provided technical assistance at each stage of the project. When completed, it will be one of the first of its type in a less developed country. This paper describes the survey after a successful pilot in which the author participated.

The results of the survey will provide much needed data for health planning and program evaluation. Pakistan has very poor national health statistics. The vital statistics registration system has not developed an accurate way of counting births and deaths or assigning cause of death. National surveys in Pakistan have been successful in providing data on fertility, infant mortality, and health utilization. A national survey of nutritional status, which included body measurements has been completed. However, national estimates of health status, risk factors, and health practices are not available.

Development of the National Health Survey of Pakistan

The National Center for Health Statistics has been through a number of stages of development in this project. An initial effort was made to make a global assessment of the health information needs of Pakistan. Second, the institutional strengths and weaknesses were identified. Third the possibility of a health examination survey was identified.

A plan for the survey was devised using the NHANES survey as a model. Translation of the NCHS model into a plan for Pakistan included consideration of logistic constrains, particular health problems of Pakistan, and culturally acceptable methodologies. The plan was reviewed by numerous public health and medical experts in Pakistan.

A pre-test for the survey was conducted during June 1989 in a Punjabi village. A two week training course was developed for the prototype team. Despite rather severe field conditions the pre-test was successfully completed. The plan was found to be feasible, times and methods working as planned. The villagers were very co-operative and response rates were excellent. The major problem encountered in the pre-test was the large number of people asking for medical attention. An additional doctor, to tend to the medical needs in the rural PSU's, will be included on the examination team as a result of this experience.

Goals

The goals of the National Health Survey of Pakistan are listed in Figure 1. The survey will produce national and provincial estimates on a number of major disease and health status indicators. The areas of health research to be covered include nutrition, child and maternal health, infectious diseases, chronic diseases, and health care and hygiene. The data from NHS-P will be used to assess secular changes in nutrition and health services utilization, comparing the results of earlier surveys. The results of this survey will also make an important contribution to the debate on the need for country specific normative rates. There are serious questions about whether the NCHS growth charts and other normative data are useful in countries like Pakistan.

Figure 1. Goals of the National Health Survey of Pakistan

- national and provincial estimates of diseases and risk factors
- changes in nutrition and health care utilization
- assess needs for Pakistani reference values

Survey Design and Plan

It is estimated that up to 20,000 Pakistanis in eighty randomly selected communities will be interviewed and examined over a two year data collection period. Data will be collected in each of the four provinces of Pakistan and include persons of all ages. Entire families will be selected, interviewed, and examined. The survey was designed to produce estimates on an urban/rural, age, sex, and province basis.

The survey will consist of both a household interview and a medical examination (including individual medical history). The selection of the sample, household enumeration, and the household interview will be conducted by the Federal Bureau of Statistics. This portion of the data collection will precede the exam by several days. The household interviewers will arrange the family examination date.

The examination will be conducted by a team of physicians, medical interviewers, health technicians, and laboratory personnel. The examination will be conducted in a specially arranged mobile examination center. The examination center will be established in a location for approximately two weeks during which the data will be collected. A discussion of the content of the household interview and the examination follows.

Survey Content

The NHS-P will consist of a household interview and a medical examination. The content of the household interview of NHS-P is listed in Figure 2. One person, preferably the head of household, will be interviewed in the home by a trained interviewer. The questionnaire will include items on household composition, residential conditions, family vital events, and utilization of health services. Conditions of individuals, including present illness in the home, paralysis, crippling, and blindness will be asked of a proxy in the home. Immunization cards will be examined by the household interviewer.

Figure 2. Content of the National Health Survey of Pakistan

- -family questionnaire
- -household risk factor (water, sewage, fuel, crowding)
- -family health care utilization
- -individual medical questionnaire
- -physician's examination
- -laboratory (blood, urine, stool)
- -anthropometry
- -vision
- -peak flow

The medical examination will consist of an individual medical interview, a physician's exam, anthropometry, vision testing, peak flow measurement, and laboratory.

The medical interview will include questions on all major diseases, as well as risk factors (tobacco use, pesticide exposure), and health services utilization. Women of reproductive age will receive a special supplement including questions on menarchy, menopause, and fertility. A childhood questionnaire will be used for children up to the age of five years.

The physicians examination will cover a broad range of disease states and organ systems. Special attention will be given to diseases of the skin, eyes, and mouth. Blood pressure will be measured according to the methods established by the Joint National Commission on Hypertension Detection, Treatment, and

Control

Height, weight, and selected circumferences will be measured in the mobile examination center for purposes of assessing growth, overweight, underweight, and from comparison to reference data. Mid arm circumference and head circumference will be measured on children up to the age of seven. Abdominal girth will be measured on all persons over eight.

Vision testing will be done with all persons over six years of age. The test will be used to determine the number of persons with refraction error. Near and far vision will be tested. The illiterate E chart will be used, in addition to alphabetic charts (English and Urdu).

Laboratory analyses of biological specimens will measure nutritional parameters, kidney function, prevalence of infections, prevalence of diabetes, and levels of immunity to measles. Blood chemistries will be done on site though the use of the photoanalyser. Thick and thin smears will be collected and read in the central laboratory of PMRC in Lahore. Blood for antibody detection of hepatitis and measles will be collected on filter paper and processed centrally. Head lice will be assessed by counting lice on combs provided by the survey. Stool will be examined microscopically for parasites in the field. Urine will be analyzed by the dip stick technique.

Conclusion

The National Health Survey of Pakistan is currently in the pilot phase. The project should be in the field for data collection by January 1990. The results of the project will make an important contribution to the understanding of the health of the people of Pakistan. Estimates of the major disease and health conditions will be available for the first time. The survey will also make an important contribution to international public health by demonstrating the possibility and utility of this methodology in a less developed country. If successful, health examination surveys may be applicable to other less developed countries.

NATIONAL HEALTH INFORMATION: THREE APPROACHES (AUSTRALIA, NEW ZEALAND, AND THE UNITED STATES OF AMERICA)

Marlene M. Lugg, Kaiser Permanente of Southern California

According to WHO, a National Health Information System (NHIS) is a family of mechanisms and procedures primarily intended to acquire, analyze and provide within a country the information required (a) by all levels of health planners and managers for the planning, programming, budgeting, monitoring, control, evaluation and coordination of national health programmes, and (b) by other members of the health professions in support of their respective roles in the national health programme.(1)

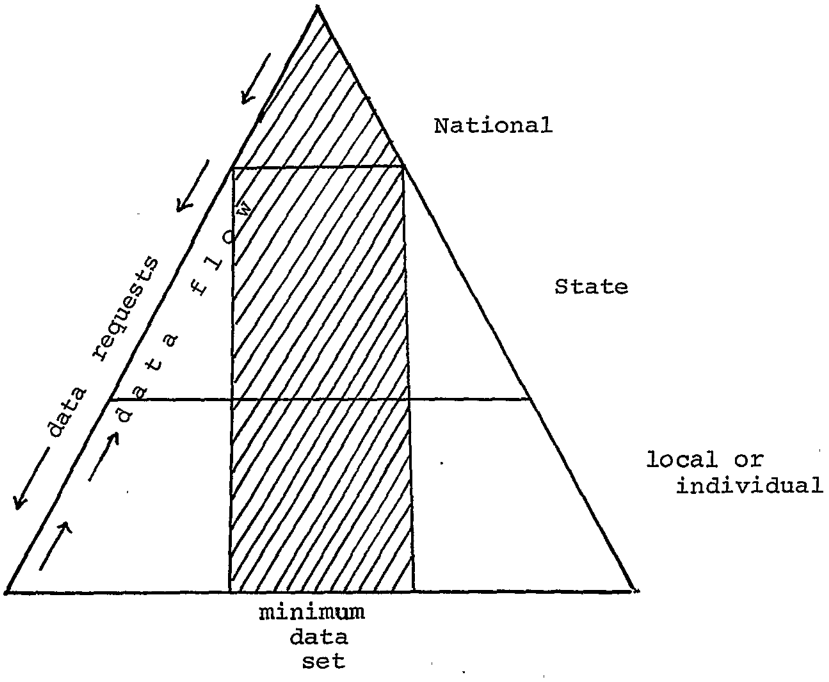
This paper compares three countries' national data systems - but first it is prudent to review some basic health information systems concepts.

A comprehensive Health Information Service must provide regular and ad hoc information which will (a) indicate the populations' health status, (b) indicate needed programmes of health promotion and control, (c) make possible evaluation of the success and adequacy of health measures which are instituted as a result of the above, and (d) serve health research needs.(2)

The system must be flexible enough to adapt to changes in government policy, user needs and data sources; yet it must have continuity of content to permit longitudinal studies.

Also, its good to remember that the further one moves away from the actual operational (or delivery of services) level, the less data is required, as shown on the Health Statistics Pyramid, see Figure 1.(3) The width of the pyramid indicates the relative extent of data required at each level of government. Thus, data for national decision making would not be adequate at local level. Nevertheless, a minimum amount of data should be available at all levels, and if the minimal uniform data set is appropriately planned, it will be almost identical with the data required at national levels. Data should be gathered and processed as near to the bottom of the pyramid as possible, as it is at the actual service level that implications and ramifications of the data are evident and can be interpreted best.

HEALTH INFORMATION PYRAMID (fig. 1)



THE COUNTRIES

It is easy to state that a country has an excellent data system, but because data must be seen in context of the political system, is it really possible to compare data and/or data systems of different countries? A quick description of the geography, government, and health services of Australia and New Zealand is here noted, for comparison with the USA.

Australia

Composed of six states and several territories, Australia is the size of continental USA but has a population of only 20 million. It is a federal/state system in which the nation, state, and local authorities fight over finances as in the USA (complicated by the fact that only the Australian federal government has the right to raise the majority of taxes.) An industrialized, mixed economy, Australia has a high standard of living, similar to the USA. Ninety percent of its employed population works in manufacturing, trade, construction and other urban-oriented industry. The leading exports are coal, wool, minerals and meat. Income and wealth are more evenly distributed throughout the population, with fewer very poor or very rich than in the USA.

The Australian Constitution is patterned on that of the U.S.A., but without a Bill of Rights. Likewise, there are the checks and balances of three branches of government. (The legislative branch, however, is patterned on the British model, where the Prime Minister is not elected directly, but is the leader of the party holding the majority of seats in the lower house.) Without the large number of oversight and other legislative committees, it is easier and can be much faster to create and pass federal legislation, which is not always in the best interests of the nation.

The health services are for the most part fragmented and yet duplicative, as in the USA. Australia has had a subsidized health insurance system since 1938, and since the 70's has twice tried a fee-for-service model national health insurance which assures basic care for all, and private care for those who want and can afford it. A gatekeeper system has been in place since the 1960's, with a high proportion of practicing doctors in general/family practice. (Pediatricians and obstetricians and internists are not primary care providers). Public and private patients are treated in the same hospital; only the patient is "classified" by payment type, not the bed.

New Zealand

Composed of three islands and several dependencies, New Zealand is approximately the size of Colorado, with a population of three million persons. The leading Industries are trades, services and manufacturing (foods, clothing furniture, cement), agriculture and forestry. Over Ninety percent of the country's exports are agricultural. The GNP is slightly below that of the USA, but the country has, over the last ten years, faced difficult economic problems with a declining value of the New Zealand dollar, high inflation and rising unemployment.

The government is of the British Parliamentary type, with local authorities, but no states.

New Zealand has one of the world's most comprehensive social-welfare programs including free hospital care for all, and compensation for all victims of accidents. It is divided into Health Districts for purposes of planning, administration, and delivery of health services. Like Australia, both public and private patients are treated in the same hospitals, with the patient, not the bed so classified. Since the early 1970's there has been a shortage of in-patient beds.

THE DATA SYSTEMS

Although there are differences in the political and health care systems in the three countries, they are similar enough for a comparison of their health data systems to be attempted.

USA

In the USA, the Federal government plus the 50 states and several territories have developed various components of a national health information system. However, no coordinated NHIS exists. Data from the National Center for Health Statistics, is applicable to the USA as a whole and major regions thereof; but due to constraints in funding which restrict sample size, cannot be disaggregated for state or local levels, with the exception of vital statistics, facilities, and special surveys. Attempts to develop a coordinated local-state-and national HIS were blocked in the early 1980's, as the results of legislation passed after the "Final Report of the panel to Evaluate the Cooperative Health Statistics System". (This report, although well intentioned, missed the point of usefulness and necessity of such a system; preferring to concentrate on cost and lack of speed in implementation-which should not have been surprising when trying to coordinate over 50 states and territories.) As a result, only the vital registration system survived nationwide.

Ten states have developed hospital discharge data systems; several maintain facilities surveys, human resources data, trauma systems, specific disease registers, etc., but without national coordination nor standard definitions.

AUSTRALIA

In contrast, Australia attempted to build its information systems from the ground up; i.e., with emphasis at state level data collection and analysis, coordinated at the federal level. In Australia, this federal coordination has until recently occurred through the National Committee on Health and Vital Statistics(NCHVS), with representation from each state and federal health and welfare authority, which has designed minimum data sets and standard definitions for such areas as hospital discharge data, facilities surveys, manpower surveys, obstetric data collection, and extended care facilities and patients. When data collection and analysis occurs at the state level in such a manner that local and state data can be validly aggregated into national statistics; all levels of government benefit.

In the mid 70's, I served as a consultant to the Australian Federal Government. The time was not yet right for a National Center for Health Statistics, even though the NCHVS was considerably less effective because it had no funds nor authority. Nevertheless, it operated by a form of consensus, and made a definite impact in the development of a state and national Health information.

By 1985, some states had progressed far along the path to the creation and operation of health data which could be amalgamated into national data. Queensland and Western Australia had hospital discharge systems covering all discharges from ALL hospitals, public and private. Other states had similar systems, but not yet in place in all hospitals. Most states were contributing uniform data to the National Perinatal Statistics Unit in New South Wales. Western Australia had implemented systems for obstetric data, psychiatric and cancer registers, notifiable diseases, notifiable deaths (anesthetic, maternal, infant), STD, Royal Flying Doctor Service, human resources (physicians, dentists, nurses, physical therapists, health inspectors), and community health services' model patient record systems. Again, other states had some, but not all of these systems in place, constrained partially by individual state government decisions on funding. In addition, Western Australia had exceptionally fine cooperation between the officers in the State Health Department and the Australian Bureau of the Census, resulting in ABS advice, personnel and computer assistance during the early years of health information systems development.

In 1987, the Federal Government created the first Australian national center for health statistics in the form of the Australian Institute of Health. It has a unique opportunity to do things right, hopefully to coordinate the development of a National Health Information System, and not just produce national health data. Whether it will be allowed to do so, remains questionable; dependent upon the politics of the AIH's location in the hierarchy of government departments and Health Ministers Committees.

New Zealand

A much smaller country than either the USA or Australia, New Zealand is able to use a combination of techniques from the USA and Australian Systems, which tailor the NHIS to its needs. Unlike Australia, it has had a viable and efficient National Center for Health Statistics for many years. Time will tell weather the mid-1980's legislation created new health districts from a merger of health and hospital boards will affect the national data system.

Although data is collected nationally, the sample size and methodology allows for disaggregation back to the local level. As in Australia, the hospital discharge system is a 100% sample of patients in all acute care hospitals, thus allowing for "piggybacking" of other data systems such as cancer registers without duplication and at lower cost. The published hospital statistics include not only patient demographic, disease and procedure data, but financial data as well. The Maternal and Child Health Services data systems is so designed that its clients can be tracked over time, as can immunizations, dental consultations, etc.

SUMMARY

Each country has unique attributes of politics, economy, culture and health services which influence the development and operation of any statistical service. In general, the NHIS must be designed for the individual nation, but there are several principles which apply almost universally (Except for the smaller state-nations totally without the local-state-national levels of government.) Of great importance is the ability to define uniform minimal data sets(4) with standard definitions so that a client is a client and a bed is a bed across the nation at all geopolitical levels. It is all too easy for policy makers to compare one state or subdivision thereof with another; and if such comparisons are invalid because of non-uniform data, major service inequities can result.

Data must be collected and processed as near to the work-face as possible, as has been done in Australia, for accuracy of data and interpretation at all levels of government. National data collectors do not know details of the local area which are necessary in order to ascertain if the data is valid, or how to interpret that data. (This is true also in some of the larger states, where further division into local data gathering/processing/ evaluation units is necessary.) The exception to this rule is a small country such as New Zealand, where data managers in the capitol would be familiar with the entire nation.

Most important is a commitment of government and health authority leaders to the need for a national health information system. Political decisions have and will continue to be made without supporting data. How-ever, the quality of such decisions can be greatly improved with timely and relevant information. Political and administrative decision-making closely overlap and interface. Without such a commitment, adequate funding to carry out the task is not available.

And finally, the availability of dedicated Health Information Systems/Service Specialists to develop, implement, manage, apply and evaluate the National Health Information System is vital, for a cost-effective partnership in maintaining and improving the nation's health.

Footnotes

(1) World Health Organization, Report of the Regional Workshop on National Health Data Systems, 1980, Manila, Regional Office for the Western Pacific, World Health Organization, pp 5,6.

(2) Lugg, Marlene M., quoted in Senate Standing Committee on Social Welfare, Through a Glass, Darkly - Evaluation of Australian Health and Welfare Services, Parliamentary Paper no. 71/1979, Canberra, Australian Government Publishing Service, p. 81.

(3) Lugg, Marlene M., "Report on Health Statistics Needs of Australia", (Consultant's Report to the National Hospitals and Health Services Commission, Canberra, 1974-75), quoted in Report of the Conference on the Rationalization and Development of Health Data Collection and Analysis Activities in Australia, Canberra, 9-13 Feb. 1978.

(4) Although the term "minimal data set" has recently fallen into disfavor in the USA, there must be no question about the necessity of a small number of uniformly defined data items to be gathered for the entire defined population, instead of many and/or non-uniformly defined items gathered on a segment of that population. For example, a disease register should contain the minimum uniform set of data items necessary to identify the patient, illness, and provider; make possible his/her follow-up; and allow for the register's use as a sampling frame for selection of subgroups for more in-depth study.

THE INTERNATIONAL EXPERIENCE

Discussant

Linda Vogel, B.A.
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(Not available for publication)

THE INTERNATIONAL EXPERIENCE

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(Not available for publication)

Session S

Clusters Versus Trends

PHCRS

CHANGES IN SUICIDE MORTALITY IN RHODE ISLAND, 1986-1988: CLUSTERS VERSUS TRENDS

Miriam Campbell and Jay S. Buechner, Rhode Island Department of Health

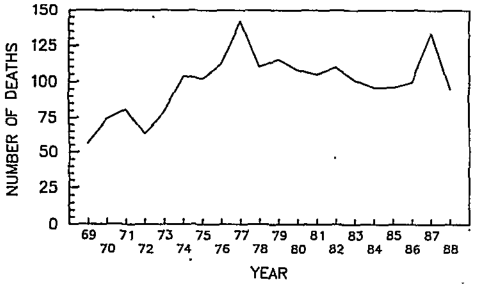
This presentation concerns a relatively brief period of time in the recent past in a relatively small population. The period of study covers three years -- 1986, 1987 and 1988, and the location is Rhode Island, a state in southeastern New England with approximately one million inhabitants. The research questions we asked ourselves are: 1) could clusters of suicides be responsible for a 34% rise in the number of suicides in Rhode Island residents between 1986 and 1987? and 2) did suicide patterns in 1987 differ from those in 1986 or 1988?

Looking at the past 20 years, the number of suicides which occurred in 1987 appears aberrant (see Figure 1). First, it can be seen that the current "normal" level in fact has prevailed for only 15 years, since 1974. Prior to that time, the number and rate of suicides was lower in Rhode Island, as was generally true in the United States as a whole. Second, zeroing in on the most recent years, the Rhode Island count rose from 100 in 1986 and an average of 102 +/- 10 deaths in the period 1980-1986 to 134 deaths in 1987. In the past 20 years, only in one other year, 1977, was there an equivalent above-normal deviation from the average level of suicides. Third, the climb in suicide mortality from 1986 to 1987 was equalled by a decline in self-inflicted deaths from 1987 to 1988.

Because of the interest in the Department of Health in monitoring disease, including injury surveillance, the Office of Health Statistics undertook an investigation into the correlates of the rise in suicides in 1987. As the number of deaths rose over such a brief period -- one year -- and apparently returned to its pre-1987 level the next year, we suspected that clustering of deaths could explain some of the climb.

For example, in the first half of 1989, four teenagers living in the same city in Rhode Island had killed themselves, and newspaper reports suggested that the later deaths may have been associated with the first teen's suicide. The relationship may be no stronger than that the first suicide encouraged another or other teens to carry through an already intended course of action. At the other extreme, the first person's death could promote depression or hopelessness in another, crystallizing that other's thoughts and in effect planting the idea (Evans and Farberow, 1988; CDC, 1988).

FIGURE 1. SUICIDES BY YEAR
RHODE ISLAND, 1969 - 1988



In other instances, a similar motivation may prompt more than one death within close temporal or geographic proximity among unrelated individuals (e.g., Sainsbury, 1986).

Lacking detailed psychological reports or suicide notes left by the decedent, we cannot delineate the causes of the suicides we examined. This difficulty in determining causality in suicide differentiates suicide from the typical public health problem of infectious disease. With suicide, there is no organism that can be identified empirically as the cause of death. Rather, we describe characteristics associated with suicides. The lack of specific, empirical evidence of causality also makes ascertainment of clusters virtually impossible. Rather, we find patterns of characteristics that suggest linkages.

Moreover, the story of the possible suicide cluster that we have described indicates another problem with analysis of clustering in suicide: i.e., suicide tends to be an act committed by an individual or limited to a small number of persons. As a suicide "epidemic" is usually measured by deaths in single digits, the usual methods of demographic analysis are not strongly suited to this task. (For a discussion of cluster definitions, methodology and analytical limitations, see Gould, Wallenstein, and Davidson, 1989; or O'Carroll, Mercy and Steward, 1988.)

On the other hand, the few suicides that occur in Rhode Island on an annual basis are an encouragement to case-by-case inspection of the data. The bulk of our data are death records for 1986 and 1987 stored on magnetic tape and shared with the Office of Health Statistics by the Division of Vital Records in the Rhode Island Department of Health (RIDH). In addition, the Department's Office of the Medical Examiner (OME) made available to us handwritten logbooks of reports for all deaths they investigated. By RI law, all suspicious deaths or deaths due to injury occurring within the state are subject to examination by the OME, which is a single, centralized office for the state. From these logs, we obtained a provisional count of suicides by age, sex, date of death and method for 1988. It should be noted that this count excludes out-of-state deaths of residents, which would be expected to increase suicide mortality in 1988 by about 4%.

FIGURE 2. SUICIDE OCCURRENCE BY
CALENDAR DATE, RHODE ISLAND, 1986

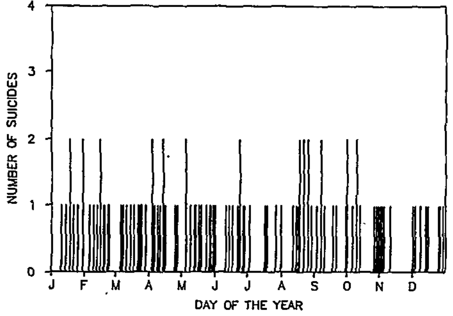


FIGURE 3. SUICIDE OCCURRENCE BY CALENDAR DATE, RHODE ISLAND, 1987

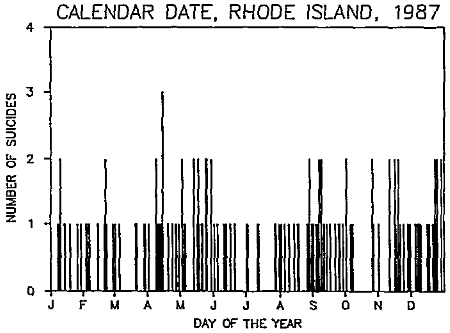
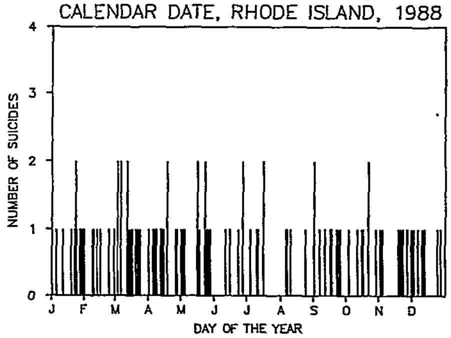


FIGURE 4. SUICIDE OCCURRENCE BY CALENDAR DATE, RHODE ISLAND, 1988



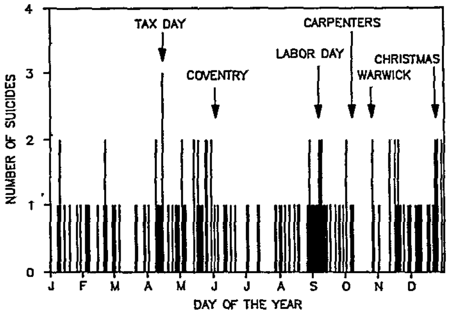
OME reports also offer health or psychological information about the suicide only where it has been provided by family or friends of the suicide. Thus they should be viewed as incomplete and possibly biased. First, less than half of all suicide reports by year have any comments on them concerning motivation for the suicide. Second, and more importantly, willingness to share information, attitude toward the suicide, perception of the pertinence of the information, and availability of informants all figure in whether this detail is given and how complete the information is.

We began our analysis of clusters in 1987 through examination of patterns in date of occurrence (see Figures 2-4). We expected that suicides would cluster temporally. The data show a number of days or groups of days in which more than one suicide was recorded. The figures for 1986 and 1988 suggest substantially less clustering of suicides.

We tested links between deaths in 1987 by examination of residence, age group, marital status, sex, occupation, place of occurrence, method and selected items from the Medical Examiner report. It should be noted again that we cannot identify clusters by any definitive criteria, only potential ties.

Of the 34 instances of multiple suicides on the same or contiguous days, only six appeared to have possible links, based on these parameters (see Figure 5). The first occurred around tax time -- April 4 through April 15, 1987 (TAX DAY). There were 10 deaths, but the only apparent tie between these suicides was date of occurrence. They were otherwise widely dissimilar, ranging in age from 20 to 78, residing in different towns throughout Rhode Island, and with widely differing occupations.

FIGURE 5. SUICIDE OCCURRENCE BY CALENDAR DATE, RHODE ISLAND, 1987



This tendency to suicide around tax day was found in other years, although in lower numbers. In 1986 as well as in 1988, there were four deaths around tax day. The deviation in 1987 then is one of size rather than date. It is tantalizing to suggest that the increase in 1987 was related to the tax reform of 1986, which began with the filing in 1987.

In early July, two young unmarried men (ages 22 and 34) killed themselves in the same small town on concurrent days (COVENTRY). The first suicide had lived in the town of Coventry; the second death was of a man from a neighboring town who had traveled to Coventry to commit suicide. It is possible that they may have known each other or that the second knew of and acted on the death of the first. Both died from shotgun wounds.

Two youths residing in the same census tract in a city of 90,000 (WARWICK) committed suicide on October 26, 1987, but we suggest that these deaths were unrelated. One (age 14) was in school and the other, three years older, was employed. Furthermore, one hanged himself and the other used a firearm.

Between August 27 and September 7, 1987, there were 12 deaths (LABOR DAY). These individuals had resided throughout the state, and they had ranged in age from 29 to 67 and in occupation from a housewife and a patternmaker to the owner of a business. Their only tie appeared to be the date of death. This aggregation of deaths around Labor Day was not found in either 1986 nor 1988 and may constitute a deviation from the pattern in these other years.

The fifth instance of multiple suicides involved three carpenters in adjoining towns who killed themselves on three adjoining days in October (the 6th through the 8th) (CARPENTERS). The second had a history of previous attempts, and the third had a history of depression, and it is possible that the death of the first served as a catalyst for the other acts.

Finally, seven deaths around Christmastime (December 21-25) in 1987 may have been linked to that holiday (CHRISTMAS). Six of the individuals were unmarried, and the seventh had a history of depression. Otherwise, they were dissimilar: in residence, in age, and in occupation. In the other years, there was one suicide each in this holiday period, so that this potential clustering in 1987 around Christmas would have been unique in the three year period under examination.

All other instances of multiple deaths in

1987 appeared random by the characteristics examined. For example, between May 17th and May 19th, there were four deaths, but these had no similarities by age, method nor occupation.

These cases aggregate to a sufficient number of deaths to make the number of suicide deaths in 1987 unexceptionable in relation to suicides in 1986 or 1988. Thus, we draw the conclusion that clusters could be responsible for the rise in suicide mortality from 1986 to 1987.

But did the pattern of suicide in 1987 differ otherwise from that in 1986 or 1988? We examined suicide patterns through crosstabulation using Chi-square and 95% confidence intervals. Parameters included date of suicide, sex, age, and method for 1986 through 1988 and occupation, marital status, and race for 1986 and 1987. Because most of the clusters we may have identified were not distinguished by age or any other variable, we chose to include all deaths by suicide in this analysis.

FIGURE 6. SUICIDE OCCURRENCE BY CALENDAR DATE, RHODE ISLAND, 1986 – 1988

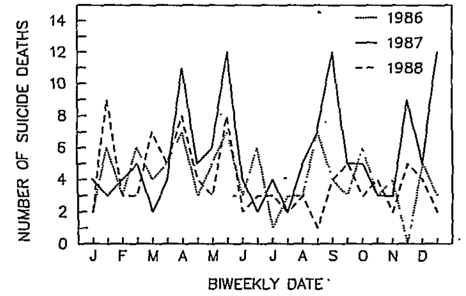
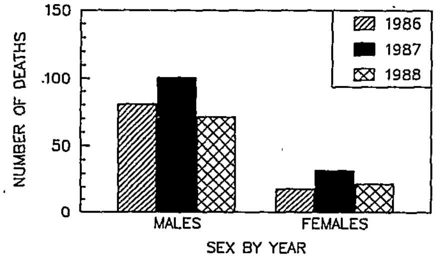


FIGURE 7. SUICIDES BY SEX, RHODE ISLAND, 1986 – 1988



In Figure 6, date of suicide is organized in biweekly intervals. As the figure shows, suicides in 1986 and 1988 are characterized primarily by small fluctuations over the year. The main difference between 1987 and the other two years is greater variability between peaks and troughs in some of the intervals. Although none of the 1987 peaks -- in April, May, September and December -- is significantly different from levels in these periods in 1986 and 1988, the sum of the deaths in peak months is (p=0.03). That is, the rise in suicide mortality in Rhode Island in 1987 is a function primarily of a somewhat higher number of suicides in April, May, September and December of that year.

By sex, there were no significant differences in the number or rate of suicides in these three years (Figure 7).

By age, the largest change in the number of suicides between 1986 and 1987 occurred among the elderly (ages 65 and older; an increase from 8 to 27 deaths). Yet, as seen in Figure 8, rates for all age groups -- with the exception of ages 55 to 64 -- rose slightly from 1986 to 1987. The change in the elderly suicide rate between 1986 and 1987 proved significant at the 0.01 level, but examination over a longer time period revealed that this difference resulted from an unusually low rate in 1986 in addition to the elevated rate in 1987 (i.e., suicides among the elderly numbered 15 in 1985 and 16 in 1988).

FIGURE 8. SUICIDES BY AGE, RHODE ISLAND, 1986 – 1988

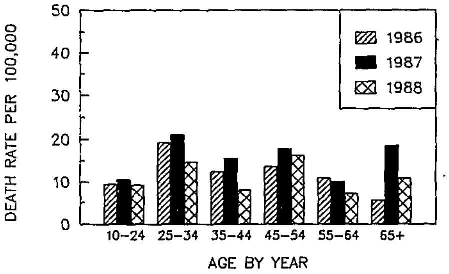
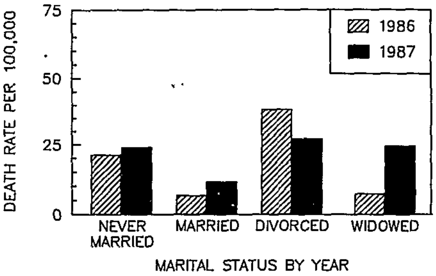


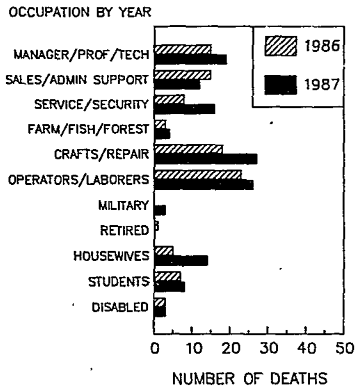
FIGURE 9. SUICIDES BY MARITAL STATUS, RHODE ISLAND, 1986 – 1987



Marital status was not recorded on Medical Examiner reports, and thus frequencies by marital status in Figure 9 are shown for 1986 and 1987 only. As expected, married Rhode Islanders, who comprise 60 percent of the population, represented most of the increase in numbers of suicides in 1987. The figure corrects for population distribution by presenting rates per 100,000. There we see that the married and widowed populations experienced increases in suicide risk between 1986 and 1987, although the difference between the rates in the married population is not significant (p=0.20). The change measured among the widowed population, an older population on average, appears, as with age, to be related to an aberrantly low number of suicides in 1986 rather than a high number in 1987.

Figure 10 shows occupation for major occupational categories, adapted from the 1980 Standard Occupational Classification (SOC) and includes groups not in the civilian labor force (United States Bureau of the Census, 1982). As shown in the figure, three groups account for most of the change in the number of suicides between 1986 and 1987. Increases among those in

FIGURE 10. SUICIDES BY OCCUPATION, RHODE ISLAND, 1986 – 1987



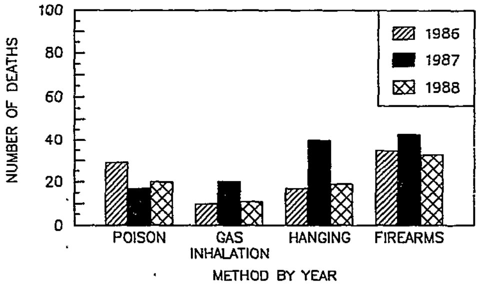
other service occupations (SOC codes in the 400s except 473-499), in crafts, production, and repair (SOC 500-699), and housewives equalled 62 percent of total change. In the varied category of craftsmen and repairmen, one occupational group, carpenters, experienced seven additional deaths between 1986 and 1987. However, occupation was not significantly related to change in mortality in this time period.

Race proved unenlightening as a parameter. It should be noted that 94 percent of the Rhode Island population is white, that 97 percent of reported suicide deaths occurred among whites, and that the increase between 1986 and 1987 was wholly comprised of suicides among whites. In fact, reported suicides among nonwhites declined slightly between 1986 and 1987.

Finally, figure 11 shows the frequency of suicide by method for the years 1986 through 1988. Increases in the number of suicides from 1986 to 1987 occurred in three of the four primary means of suicide: gas inhalation, hanging and firearms. These increases were followed in 1988 by a decline to 1986 levels. The number of poisonings (including drug abuse) declined between 1986 and 1987 from 29 to 17, although this primarily reflects a relatively higher number of suicides by poison in 1986 (in 1985, n=18). In the category hangings, however, the number in 1987 significantly rose above the level of deaths in 1986 from 17 to 40 (p=0.03). In 1988, the number of hangings returned to nearly the 1986 level (n=19).

To sum up the analysis, the number or rate of suicides by none of the examined demographic factors -- neither age, sex, occupation, nor marital status -- showed noteworthy change in 1987 from contiguous years. We found only that the rise in the number of suicides was concentrated in four months -- April, May, September and December -- and that there were more hanging deaths in 1987.

FIGURE 11. SUICIDES BY METHOD, RHODE ISLAND, 1986 – 1988



Our conclusions must be prefaced by a few additional findings. First, it should be noted that hangings in 1987 were distributed throughout the year and thus were not associated with the concentration of suicides in those four months nor with the possible clusters described here. Next, the percentage of suicide deaths that occurred by hanging was associated with neither age nor occupation for any year.

In conclusion, the increase in hangings in 1987 does not appear related to characteristics associated with suicide in Rhode Island. In fact, we suggest that the null hypothesis that 1987 was not an aberrant year for suicides in Rhode Island must be accepted. In relation to age, sex, race, marital status, occupation, and date, 1987 appeared to be insignificantly different from 1986 and 1988.

Why then did the Rhode Island suicide rate rise in 1987? We found potential clusters of suicides in 1987 unmatched in size by suicides in 1986 or 1988 that might account for the rise. We also found most patterns of suicide in 1987 apparently not dissimilar from those in 1986 or 1988. Finally, we found a significant increase in the number dying by hanging. From these findings, we conclude that suicide clusters could be primarily responsible for the increase in suicides in Rhode Island from 1986 to 1987.

While the increase in hanging deaths is an interesting avenue to explore, analysis of changing suicide methods requires data on attempted suicides for that period, which are not available currently.

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RARE HEALTH EVENTS AS SENTINELS OF ENVIRONMENTAL CONTAMINATION

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ABSTRACT

Among the greatest environmental health concerns are those related to contamination of drinking water, air, and soil. Despite the magnitude of these concerns, options for an effective public health response are quite limited. The populations at risk are great, yet the health effects associated with these exposures are exceedingly rare. Exposure definitions are always complex, and many of the highly visible environmental contaminants are associated with only modest increases in disease risk. What is needed is a new way of identifying and investigating environmental health concerns. A surveillance technique is proposed, using the occurrence of rare health events to serve as sentinels of specific adverse exposures. The approach has three elements: (1) a list of a small number of rare health events that are strongly associated with the exposure(s) of interest; (2) population-based case ascertainment; and (3) novel statistical reasoning using a battery of "clustering" tests for decision-making. This method of disease surveillance is an advance in public health technology; it has both ethical and practical advantages.

Key words: Surveillance, epidemiology, environmental contamination, cancer, space-time clusters

INTRODUCTION

Currently there is great apprehension among the general public related to potential deleterious health effects associated with exposure to hazardous materials in the environment. This anxiety is best addressed "head-on" with public education and disease surveillance strategies. This paper addresses the latter aspect of this public health response—disease surveillance strategies. Surveillance is one of the oldest and soundest public health practices (Langmuir, 1976). The National Center for Health Statistics (NCHS) has long recommended a surveillance strategy for addressing environmental health concerns (NCHS Report, 1977). In a recent paper, Thacker and Berkelman (1988) reviewed thoroughly the principle of public health surveillance; they cite as one of the fundamental objectives of surveillance the early detection of increases in disease. This paper proposes a sentinel event monitoring approach as one alternative for achieving that objective.

Sentinel event surveillance is based in principle on the strategy developed by Rutstein et al. (1983) for occupational applications. A justification for the need of such a method can be found in the frustrations with applying "traditional" epidemiologic techniques to many environmental health problems (Heath et al., 1983; Garfinkel, 1987; Caldwell, 1989). In effect, surveillance of sentinel health events is a population-based screening procedure; it embodies many of the same tenets as health screening for individuals (Blumberg, 1957). Sensitive statistical tests, when applied to sentinel event strategies, provide a new way of conceiving the random process of disease occurrence.

RATIONALE

Several significant public health advances have been associated with the "alert clinician" means of detection (Miller, 1981); these include vinyl chloride, DES, analine dye, and Dibromochloropropane (Creech and Johnson, 1974; Herbst, et al., 1971; Cole et al., 1972, and Whorton, et al., 1977). In these instances, the three significant characteristics leading to recognition of the disease pattern were:

(1) The health events were exceedingly rare (e.g., incidence < 1 per 100,000).
(2) The time period of occurrence was relatively short (e.g., 2-5 years).
(3) The degree of association between the event and a specific chemical exposure was substantial (e.g., risk levels > 5.0).

With each of these discoveries, there was eventual confirmation of the findings by conventional case-comparison studies. Yet with the tardiness of the public health response, one could only point back in time and say, "look what happened." This lag in detection of risks is not acceptable to the general public nor to public health professionals, especially with respect to suspected environmental exposures. A decision after several years, when many cases of disease have occurred is, at best, disappointing.

In many instances, a decision about an environmental health risk should have been achievable earlier, when the second or third health event occurred, not after a dozen cases. Such a sequence of thinking leads logically to the application of the "alert clinician" reasoning process to population-based data (Miller, 1981; Aldrich, et al, 1983). The key elements of such a system focus on the three characteristics cited above. The surveillance application will use these criteria for directed, systematic analysis for rare health events that are strongly associated with environmental exposures, and that occur over very short periods of time. However, reasoning over such very small numbers of events requires unconventional statistical methods and modified decision criteria. A broad base of experience with these statistical methods is needed in order to develop this public health practice.

RECOMMENDED HEALTH EVENTS AND CONDITIONS

Cancers represent the predominant public health concern as a sequela from hazardous exposure in the environment. Cancers as a group are extremely common health events—afflicting one-of-four people during their lifetime. This fact is one of the most critical points for health education needs directed to the public. Lifestyle factors are the generally accepted, leading risk factors for the common cancers for either sex (lung, breast, colon, prostate, uterine). Further, these cancers are very slow developing malignancies, and some of these cancers do not offer as significant survivorship gaines via early detection as do some rarer cancers. In short, these diseases do not meet the criteria for good screening factors (Table 1)

(Blumberg, 1957). By contrast, pediatric leukemias, testicular cancers, lymphomas, tumors of embryonal origin, etc. pose excellent sentinel indicators. They are exceedingly rare, they are suspected to have relatively shorter induction periods, and there have been substantial advances associated with the treatment of these cancers. These then form the initial listing of recommended sentinel cancer sites (Table 2). Birth defects or other health events (e.g., neurologic diseases) may be candidates to be added to such a sentinels list.

In adddition to diseases, provocative clinical conditions or extreme biological markers may be used as environmental sentinels. These events rely on the continuing initiative of "alert clinicians"; they represent phenomena that are unusual, in the setting of a conventional medical practice (Miller, 1981). These conditions may serve as sentinels because most of them represent acute phenomena, (or limited latency) that may signal a later cancer risk for the community they represent (Table 3).

TABLE 1
SELECTED CRITERIA FOR EVALUATING SCREENING PROCEDURES*

	Decision Criteria Must Be Highly
Prognosis of the Event with Early Detection	Sensitive
Follow-up Resources for Additional Research	Sensitive
Prevalence of the Disease/Condition	Specific
Risk/Cost of Follow-up Studies	Sensitive
Testing Criteria in Series/Parallel	Sensitive/Specific
Variability of the Testing Criterion	Specific

*From Blumberg, 1957. [With modifications after H. F. Lehman, Univ. Alabama in Birmingham—Personal Communication, 1989].

TABLE 2
SAMPLE LIST OF SENTINEL HEALTH EVENTS (CRITERIA AND ICD-9-CM CODES)

Liver carcinoma (non-smoker/non-drinker)	155.0
Glioblastoma	191.0
Amelanotic melanoma	172.0
Pediatric solid tumors (especially germ cell origin)	any site
Genitourinary cancers in children	179.0–189.0
Exotic Lymphoma Cell types	196.0
Exotic Leukemias (or uncharacteristic age groups)	200.0–208.0
Bladder, lung, or upper respiratory cancer (Non-smoker)	188.0, 162.0, 146.0–149.0
Midline or septal birth defects	749.0, 745.0

TABLE 3
SAMPLE LISTING OF SENTINEL CONDITIONS (CRITERIA AND ICD-9-CM CODES)

Unusual allergies	
Unusual neurological symptoms	
Idiopathic hematuria	599.7
Persistent, unresolved rashes	692.9
Persistent, idiopathic nasopharyngitis	472.2
Extreme liver functions in a non-smoker	
Extreme renal functions in a non-smoker	

SUGGESTED APPLICATION

Sentinel event surveillance is expressly intended to expedite the recognition of an increased risk of disease potentially associated with environmental contamination. The timeliness of reporting is central to a successful application. In Europe, private physician practices are used as sources for the early reporting of selected diseases. In the United States, the Centers for Disease Control uses a reportable disease strategy with 120 medical practices around the country. Some cancer registries in the United States have protocols for expedited reporting. Another example of expedited reporting involves emergency rooms; there a toll-free number is used to acquire rapid information about poisonings. A similar resource for a toll-free telephone number related to cancer information exists in many states.

These methods represent useful options for application to sentinel event monitoring. The occurrence of a sentinel health event is most reasonably reported by the diagnosing physician. Reporting should be expedited, that is, it should not involve a medical record mechanism that may require weeks for filing. A preferable means would involve a toll-free telephone call; this approach may be available in many states through either an American Cancer Society or National Cancer Institute information service.

With sentinel event surveillance, new philosophies of disease occurrence must be adopted. First is a new meaning to statistical significance. The conventional $p < 0.05$ criterion must be replaced with combined statistical and biologic significance. Because repetitive analyses are involved with such a strategy, "family-wise" statistical rules must be employed. Conventional sample size patterns must be reconsidered for procedures that are designed to detect departures from randomness, rather than changes in a population parameter. Sentinel events are rare, by definition, so that small numbers of cases are generally involved. Yet, the few cases that do occur, either "by chance" or as a result of an exposure to some environmental agent, comprise a specific spatial-temporal pattern. Therefore, sensitive decision criteria must be used to interpret whether the observed case(s) are occurring randomly.

Sample Reasoning: Consider acute myelogenous leukemia in North Carolina (Figure 1); approximately 15 cases are expected among children in one year. Because 15 cases can be expected, the first case, second case, etc. do not per se signal a sentinel interpretation. More cases in a large metropolitan area are also

> not "non-random". Yet when a pair of cases occur in a rural setting, that is cause for an "alert," or increased watchfulness. If another case occurs nearby, within a year or two, or if there is a reason to suspect that the cases are living/working proximal to a suspected location of environmental contamination, a community study may be in order. There is no need to delay a public health response until seven, eight, etc. cases have occurred in a single, small community. As few as three cases may represent a sentinel pattern; one case could even signal an increase under certain, biologically significant, circumstances.

Suppose that a myelogenous leukemia case, a primary liver cancer case, and a rare birth defect are recorded in a small community having a suspected industrial emission. These three events must be linked via a concerted surveillance strategy; and appropriate public health investigations should be conducted as well (e.g., environmental sampling, screening of residents, etc.).

Another substantial element for the success of sentinel event surveillance system is its application across a large population (e.g., a state) in a timely fashion, with a sensitive time-series and/or space-time cluster analysis technology. Several statistical methods have been developed over years of interest in these applications (Smith, 1982; Aldrich, et al 1983). These statistical techniques are identifiable through the literature or via a software package currently being developed by the Agency for Toxic Substances and Disease Registry (Medical Epidemiology Section). Routine monitoring of the occurrence of these suggested sentinel cancers, birth defects, or other similar sentinel health events is encouraged by all cancer registries or other disease registries. Experience must be developed with sentinel event monitoring to verify whether such an approach will provide a viable public health response.

CONCLUSION

Sentinel event monitoring is an attractive public health response to continuing public concern for health risks due to environmental contamination. The application of this sort of public health surveillance requires innovative epidemiologic methods and new statistical decision rules. An investment of research funds, by an appropriate agency, is necessary to evaluate this approach. Such an evaluation should be conducted in a large population (e.g., one or more states) over several years.

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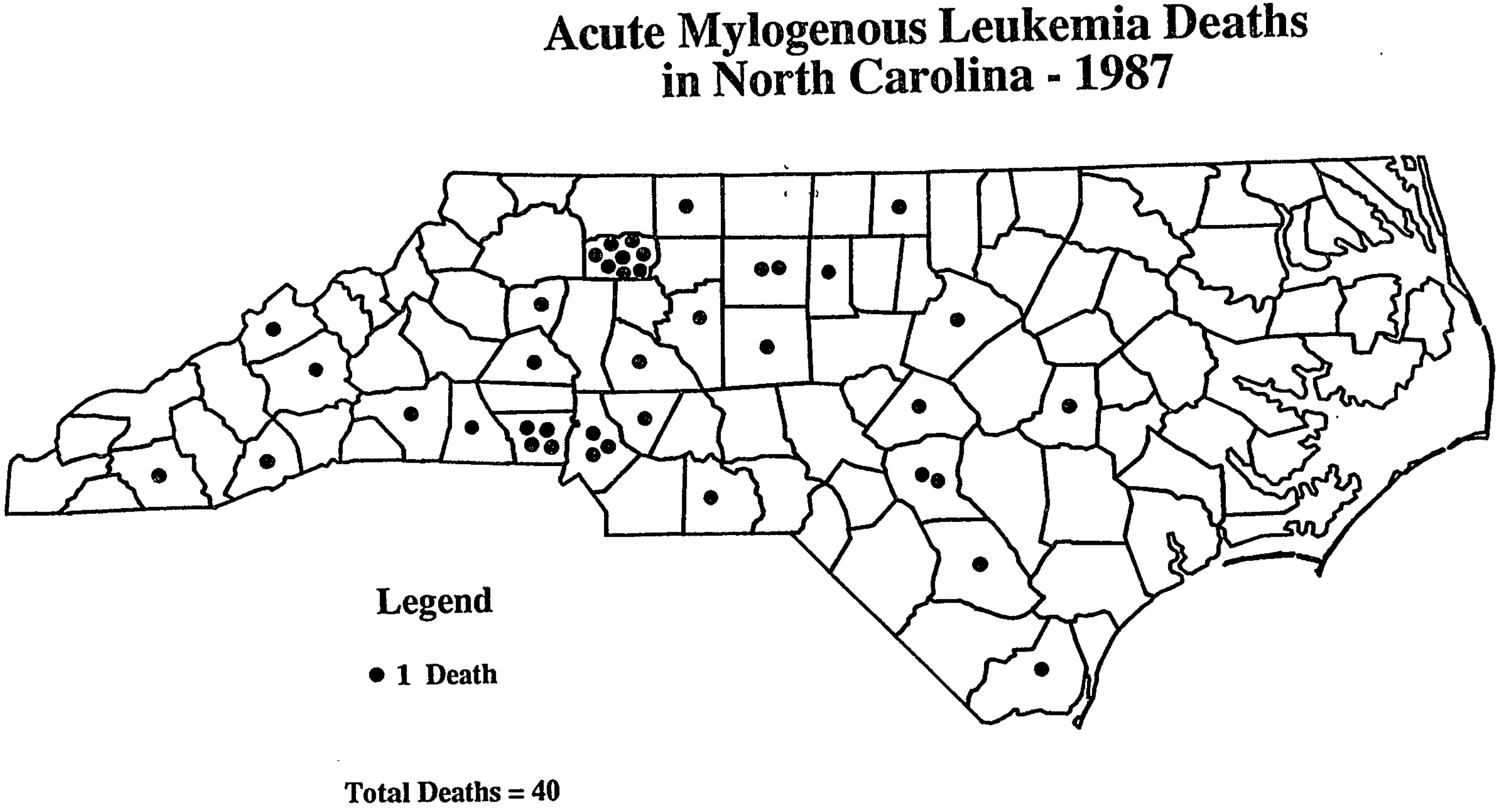

Acute Mylogenous Leukemia Deaths
in North Carolina - 1987

Legend

● 1 Death

Total Deaths = 40

Figure 1: Geographic Distribution of Pediatric Acute Myelogenous Leukemia in North Carolina

ASSESSMENT OF RISK TRENDS AND PATTERNS

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Abstract: This paper provides a versatile method of exploring epidemiologic events that may be represented in rectangular arrays. Specifically, relationships of cases of leukemia in space and time are illustrated, wherein space and time determine the two dimensions of the array. The approach may be easily applied to available point or aggregate data as a preliminary phase, or as the single approach, in investigating hypotheses of disease clustering.

1. Introduction

This paper introduces a versatile approach for evaluating apparent clusters of health related events. The types of events of interest include incidence, prevalence and mortality; the clustering of interest occurs in geographical and/or temporal frames of reference.

The methodology is offered as a first analytical phase that can be easily and inexpensively applied upon emerging concern about a possible cluster. Results of its application would then serve as an adjunct in the decision regarding more extensive investigation. Moreover, the methodology is useful in epidemiology independently of a prompt to respond; it may be used to test for disease patterns in a randomly selected population, for example.

The units of time for which events are usually recorded are hours, days, months, years and decades. Times of onsets of food-borne outbreaks may be given in terms of hours, for example, but long-term cancer trends may be viewed in time periods of years or decades. Accidents have been studied in each of these temporal scales, depending on objectives. Data from events occurring at points in a time continuum but which are necessarily, or conveniently, expressed in terms of defined periods are <u>aggregate</u> data. Annual neonatal mortality rates are an example.

Geographic location is implicit in discourse about events that transpire over periods of time.

Geographically, stationary events (envision fixed points in space) can be related by distance measures. (Houses are stationary but people are not.) However, a health related event can be geographically classified by primary membership in a spatial region. Examples of regions encountered in epidemiologic studies include houses, city blocks, cities, census tracts, counties, states, nations, hospitals, hospital wards, industrial plants, departments in industrial plants, nursing homes, schools, school floor levels, classrooms and seating arrangements.

We shall refer to the combination of a region and a time period as a space-time cell, or <u>S-T-cell</u>.

Configurations of events, whether they are expressed in terms of individual points or in terms of S-T cells, are characterized on the basis of measures of proximity. Spatial distance for aggregate data is not a simple matter[1] but for purposes of this paper we shall be satisfied that an appropriate <u>binary</u> distance measure among S-T cells is found. For instance, two "high risk" S-T cells are, or are not, "close" to one another according to a sensible definition of "close."

It is important to realize that results of an analysis depend profoundly on choices on physical scale for (1) the definition of proximity, e.g. "close" and (2) the definition S-T cell, on which we assess the events, e.g. census tract or county. Some of this will be discussed further in the analysis of leukemia data beginning in the next session.

Space-time <u>interaction</u> usually means that cases occur close together in time <u>if and only if</u> they occur close together in space. Note that this is a two-way implication. Also, this is called simultaneous space-time clustering. Let C_s denote the phrase "close in space" and let C_t denote "close in time." Then we say that interaction occurs among events such as incidence or eventful S-T cells if $C_s \rightarrow C_t$ and $C_t \rightarrow C_s$, or simply $C_s \leftrightarrow C_t$, where the arrows denote logical implication. Knox's test[2] is the primal example of a statistical test for S-T interaction; this test is exemplified in other papers of these proceedings.

However, this type of cluster is one specific type of relationship that may occur, or may be sought, among events. Generally, other types of relationships in space and/or time should be sought lest the analysis should be overly confined.

Some tests for clustering in space-time may involve a single implication. For example, the test by Barton et al[3] tests for whether or not $C_t \rightarrow C_s$. The null hypothesis as well as the form of the test statistic must be apprehended in using a test in order to facilitate proper interpretation of results.

Figure 1 illustrates three scenarios of clustering in space-time. These portray a generalized set of relations that events can assume in space-time but the following sections of this paper reflect on some specific patterns by way of exploring some childhood leukemia data.

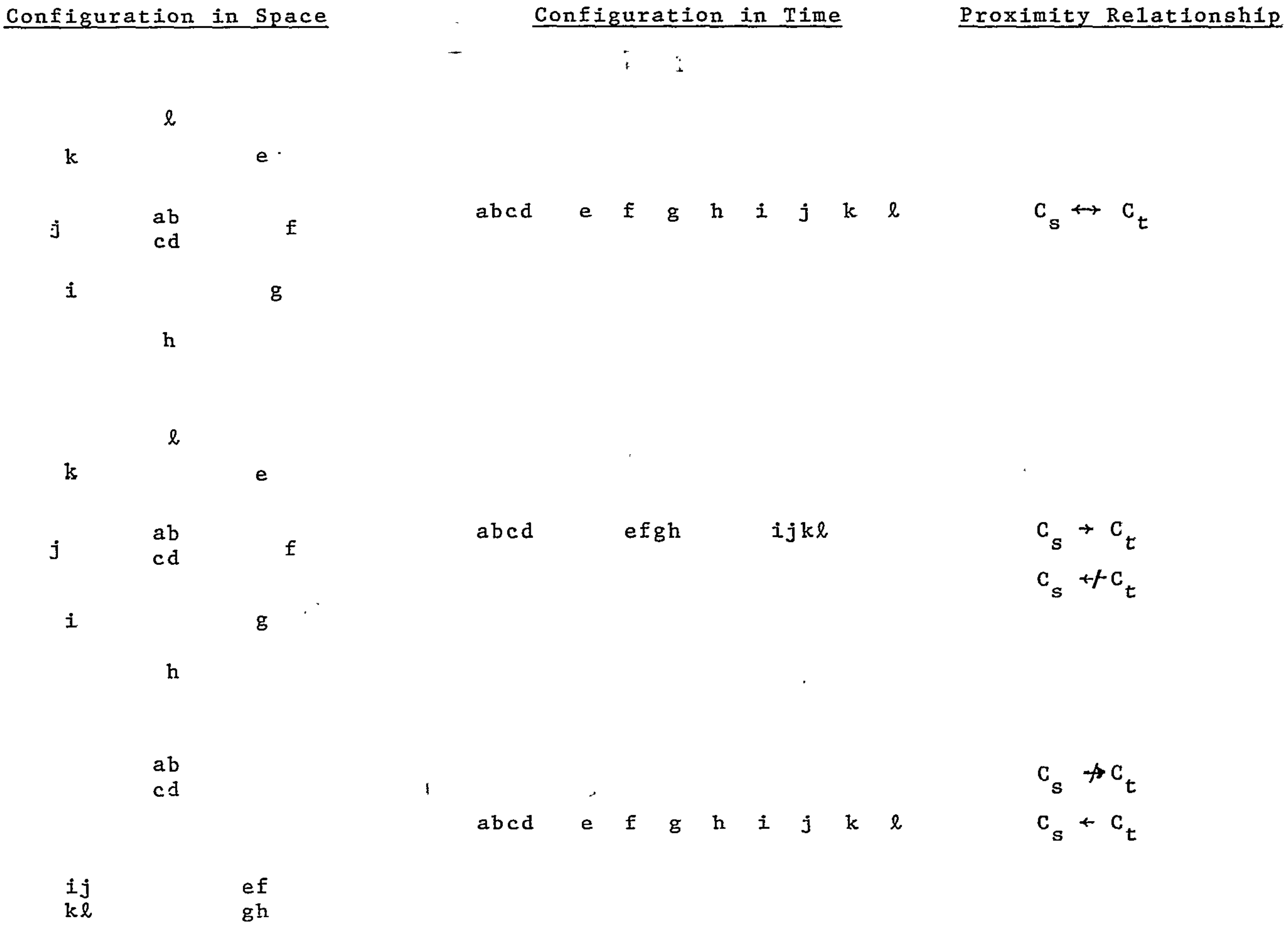

Figure 1

Generalized Scenarios for Relationships of Events in Space-Time

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2. The Leukemia Data

Table 1 displays census tracts and six-month periods in which 53 acute lymphatics were diagnosed among residents of metropolitan Atlanta, Georgia, who were 14 years of age or less. These data were first analyzed by Larsen et al[4] in introducing a statistical test for temporal clustering. Census tracts containing only one or no case over the 14 year time period were disregarded, which for that test is appropriate. For the current discussion these especially sparse tracts would be included but the data are no longer available.

It is instructive to recall the data of Table 1 because they are interesting and they serve as a good example by which to introduce some new analytic approaches.

A "one" in the table indicates one case of leukemia in the indicated S-T cell determined by census tract of residence and date of diagnosis. Conceivably, a cell could contain two or more cases. Most of our analysis is based on binary events for cells so we envision logical criteria for partitioning of the data into "high rate" and "low rate" cells.

For the sparse data of Table 1 we simply dichotomize according to whether or not an S-T cell has a positive rate or, equivalently in this case, a positive count. In most analyses where only the counts are considered over time, one must agree, as Larsen et al did for these data, that population counts for the young age group did not change much over the observed time period. It is clear that the clustering described by Larsen et al is not explained by population changes over time. Ederer et al,[5] Mantel et al[6] and Wallenstein[7] discuss "numerator analysis."

3. Proximity in Space-Time

The 18 census tracts and 28 time periods in Table 1 comprise 504 S-T cells. Two tracts are defined as "close," symbolized by C_s, if both tracts are a

Table 1. Leukemia Incidence by Groups of Contiguous Census Tracts and Times of Diagnosis*

		6-Month Periods of Diagnosis, by Year																											
County	Tract	56		57		58		59		60		61		62		63		64		65		66		67		68		69	
Clayton	3	0	0	0	0	0	0	0	I	I	I	I	0	0	0	0	0	I	0	0	0	0	0	0	I	0	0	0	0
	4	0	0	0	0	0	0	0	0	0	0	0	0	0	0	I	0	0	0	0	0	0	0	0	0	0	I	0	0
Cobb	10	0	0	I	0	0	0	0	0	I	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	I
	11	0	0	0	0	0	I	0	I	0	0	0	I	I	0	0	0	0	0	0	0	0	I	0	0	0	0	0	I
DeKalb	15	0	0	0	0	0	0	0	I	I	I	0	0	0	0	0	0	0	0	0	I	0	0	0	0	0	0	0	0
	16	0	0	0	0	0	0	0	0	0	0	I	0	0	I	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	23	0	0	0	0	0	0	0	I	I	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	25	0	0	0	0	0	0	0	0	0	0	0	0	I	I	0	0	0	0	0	0	0	0	0	0	0	0	0	0
DeKalb	31	0	0	0	0	0	0	0	0	I	I	0	0	I	0	I	0	0	0	0	0	0	0	0	0	0	0	0	0
	34	0	0	0	0	0	0	0	0	0	I	0	0	0	0	0	0	0	0	0	0	0	0	0	0	I	0	0	0
	35	0	0	0	0	0	0	0	0	0	0	0	0	0	0	I	0	0	0	I	0	I	0	I	0	0	0	0	0
Fulton	53	0	0	0	0	0	0	0	0	I	0	0	0	0	0	0	0	0	0	0	0	0	0	I	0	0	0	0	0
	55A	0	0	0	0	0	0	I	0	0	0	0	0	0	0	0	I	0	0	0	0	0	0	0	0	0	0	0	0
	55B	0	0	0	0	I	I	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
DeKalb	18	0	0	0	0	0	0	0	0	0	0	0	0	0	I	I	0	0	0	0	0	0	0	0	0	0	0	I	0
Gwinnett	4	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	I	0	0	0	0	0	0	0	0	0	0	0	I
DeKalb	11	0	0	0	0	0	0	0	0	I	0	I	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	12	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	I	0	0	0	0	0	0	0	0	0	0	I	I

*I indicates incidence of leukemia.

a member of a contiguous group of tracts. Thus, Tracts 15 and 23 are close to one another but Tracts 25 and 31 are not. Two six-month time periods are "close," i.e., C_t, if they are contiguous. For the first analysis, two S-T cells are "close" if they are *either* C_s and in the same time period *or* C_t and in the same tract. This is symbolized by C_sS_t/C_tS_s.

Fifty-three of the 504 cells represent diagnoses of 53 cases of leukemia. Therefore, in these data cases occur close in space, time or space-time according to whether or not their S-T cells are close in these dimensions. Configuration of cells (coinciding with cases in this application) is of primary interest. Cells of special designation (e.g. "high rate") are termed "*events*." These are independent events under the null hypothesis of no clustering. An event is a property of a cell; in the present application an event is the occurrence of diagnosis of leukemia in an S-T cell.

Table 2 displays these data wherein heavy lines connecting events are C_s or C_t. These connections are termed "adjencies." Thus, two events that are close to one another form an adjacency. The adjacencies of Table 2 depict all pairs that are C_sS_t/C_tS_s. Of the 53 cases, 12 are involved in space pairs, 21 are involved in time pairs and 6 are involved in a space pair and a time pair.

Relationships among cells that satisfy properties such as C_sS_t/C_tS_s are terms *proximity structures*; several are described below.

Adjacencies are not independent of one another but the forthcoming statistics account for dependence.[8]

Eighteen adjacencies are found among the 53 cases; it will be seen that the number of adjacencies among events is the test statistic.

What does all of this indicate? First, it has been mentioned that interpretations depend on definitions of event, scale, cell, adjacency, and proximity configuration. These will be varied somewhat in the analysis.

Secondly, interpretation depends upon the descriptive characteristics of the test statistic and its distribution.

In this paper analysis is based upon the following notation:

x = number of cells (e.g. 504).
y = number of "borders" per cell.
n = number of events (e.g. 53).
N = observed number adjacencies among the n events (e.g. 18).

The number of *borders* per cell, y, is the number of adjacencies that each cell has with other cells averaged over all cells. It is twice the number of adjacencies divided by the number of cells, realizing that a single adjacency identifies two borders.

From Table 1, 15 adjacencies among space cells (within tracts) are counted for each of the 28 time periods. Also, 27 temporal adjacencies are counted for each of the 18 tracts. Therefore, the total number of adjacencies among cells in this array of data is (15x28) + (27x18)=

Table 2. Adjacencies for Proximity Structure C_sS_t/C_tS_s

		6-Month Periods of Diagnosis, by Year																											
County	Tract	56		57		58		59		60		61		62		63		64		65		66		67		68		69	
Clayton	3	0	0	0	0	0	0	0	I	I	I	I	0	0	0	0	0	I	0	0	0	0	0	0	I	0	0	0	0
	4	0	0	0	0	0	0	0	0	0	0	0	0	0	0	I	0	0	0	0	0	0	0	0	0	0	I	0	0
Cobb	10	0	0	I	0	0	0	0	0	I	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	I
	11	0	0	0	0	0	I	0	I	0	0	0	I	I	0	0	0	0	0	0	0	0	I	0	0	0	0	0	I
DeKalb	15	0	0	0	0	0	0	0	I	I	I	0	0	0	0	0	0	0	0	0	I	0	0	0	0	0	0	0	0
	16	0	0	0	0	0	0	0	0	0	0	I	0	0	I	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	23	0	0	0	0	0	0	0	I	I	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	25	0	0	0	0	0	0	0	0	0	0	0	0	I	I	0	0	0	0	0	0	0	0	0	0	0	0	0	0
DeKalb	31	0	0	0	0	0	0	0	0	I	I	0	0	I	0	I	0	0	0	0	0	0	0	0	0	0	0	0	0
	34	0	0	0	0	0	0	0	0	0	I	0	0	0	0	0	0	0	0	0	0	0	0	0	0	I	0	0	0
	35	0	0	0	0	0	0	0	0	0	0	0	0	0	0	I	0	0	0	I	0	I	0	I	0	0	0	0	0
Fulton	53	0	0	0	0	0	0	0	0	I	0	0	0	0	0	0	0	0	0	0	0	0	0	I	0	0	0	0	0
	55A	0	0	0	0	0	0	I	0	0	0	0	0	0	0	0	I	0	0	0	0	0	0	0	0	0	0	0	0
	55B	0	0	0	0	I	I	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
DeKalb	18	0	0	0	0	0	0	0	0	0	0	0	0	0	I	I	0	0	0	0	0	0	0	0	0	0	0	0	0
Gwinnett	4	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	I	0	0	0	0	0	0	0	0	0	0	0	I
DeKalb	11	0	0	0	0	0	0	0	0	I	0	I	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	12	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	I	0	0	0	0	0	0	0	0	0	0	I	I

906, and $y = 2a/x = 1812/504 \approx 3.60$. On average, each cell borders on 3.60 other cells. The fact that we are using an average, rather than a matrix of exact descriptions of the adjacency structure for the region and study period, as described by Cliff and Ord[1] in the context of space only, does not affect analyses by any important degree.[8]

Grimson[8] has shown that the expected value and variance for N are given by

$$E(N) = \frac{y(n)(n-1)}{2(x-1)}, \qquad (1)$$

$$V(N) = E(N)\left(1 + \frac{2(y-1)(n-2)}{x-2} + \frac{(xy-4y+2)(n-2)(n-3)}{2(x-2)(x-3)} - E(N)\right). \qquad (2)$$

For the proximity structure C_sS_t/C_tS_s, where $x = 504$, $n = 53$ and $y = 3.60$, formulas (1) and (2) give $E(N) = 9.86$ and $V(N) = 7.90$.

A standardized value of N is given by

$$Z = \frac{N - E(N)}{V(N)^{\frac{1}{2}}}.$$

In the present case, for $N = 18$, we have $Z = 2.89$.

The distribution of Z is closely approximated by the normal distribution unless n and y are quite small, in which case the Poisson approximation is appropriate,[8,9] albeit, a different formulation is given by Cliff et al.

Table 3 summarizes analyses for various proximity structures. The analysis performed above is represented in the first row.

The second row pertains to the proximity structure S_t/C_tS_s, which means that two events are close if they occur during the same time period (same column of Table 1) or if they occur in adjacent time periods of the same tract. Thus, for S_t/C_tS_s the method is sensitive to events that occur during the same time period and/or consecutively within tracts. (The heavy lines in the body of Table 2 no longer apply; they apply to the first analysis. New lines connecting close events could be drawn if desired.) Note that for this second proximity structure the number of adjacencies among the 504 cells is much larger because all events in each column are adjacent.

Note that the notion of "adjacency" has been extended in S_t/C_tS_s. The proximity structures of Table 3 defines a variety of catchment proximities.

The third row of Table 3 summarizes analysis from a third proximity structure, S_t. Here the method is sensitive to large numbers of events that occur during the same six-month period, regardless of tract; it is sensitive to events that "stack up" in certain periods. Other statistical tests such as the Ederer-Myers-Mantel Test[5,6] and the scan test[7] are geared for such clustering wherein the data are counts (not binary events) along time lines, as may be obtained from the leukemia data by pooling tracts.

The sixth row of Table 3 pertains to the proximity structure which defines "close" according to events occurring in the same tract and in consecutive

Table 3. Proximity Statistics for Leukemia Data

Proximity Structure	x	n	a	y	N	$E(N)$	$V(N)$	Z
C_sS_t C_tS_s	504	53	906	3.06	18	9.86	7.90	2.89
S_t C_tS_s	504	53	4770	18.93	72	51.86	40.27	3.17
S_t	504	53	4284	17.00	60	46.57	36.31	2.23
S_s C_sS_t	504	53	7224	28.67	73	78.54	59.77	- .72
S_s	504	53	6804	27.00	67	73.97	56.48	- .93
C_tS_s	504	53	486	1.93	12	5.29	4.25	3.26
C_sS_t	504	53	420	1.67	6	4.58	3.68	.74

six-month periods. (Note that the proximity structures of the sixth and third rows are a partition of that of the second row.) C_tS_s has temporal clustering in the form of runs of binary events. The objective of Larsen's analysis[4] more closely resembles C_tS_s than that of any of the other proximity structures in Table 3. Although Larsen's test statistic is fundamentally different from ours, it tends to approach significance as the number of temporal adjacencies increases. In these data we get $Z = 3.26$, which suggests a type of temporal clustering similar to that reported by Larsen who obtained a value of $Z = 2.61$ based on his test for unimodal clustering.[4]

Note that the Z-values associated with proximity structures that are oriented towards spatial clustering are much smaller than those discussed above regarding time.

From these analyses we find that events appear to occur (1) close together in time within tracts and (2) within select time periods, apparently in the six-month periods around 1960.

4. Time Span of Events

Formulas (1) and (2) can be used to test for occurrence of high incidence during time intervals of specified length or to identify a span of time in which the epidemic has occurred in space-time data that is arranged in a two-dimensional table such as Table 1. Periodicity is not the issue so for clarity we avoid the term "period" in this context in describing events. (We have used "period" for the six-month time units.) Here we are concerned with longer spans of time in which events occur frequently. The scan test, for example, would be appropriate for such data on a single time line.[7] (Periodicity of incidence data may be examined using other tests.[10,14])

For the data in Table 1, "close" is now defined by regarding two events as close if they both occur within a span of k consecutive six-month periods. For instance, the two events of the sequence 0 0 0 I 0 0 I 0 0 0 0 occur in a span of $k = 4$.

The data contain 18 tracts so there are 18 space cells for each six-month period, giving $\binom{18}{2}$ pairs of cells in each period and 18^2 pairs between two periods. For $k = 3$, for example, there are $\binom{18}{2}$ adjacencies among S-T cells within a period and 18^2 adjacencies among cells of a given period and those of the first following period, and another 18^2 adjacencies among cells of the given period and those of the second following period. Thus, there are $\binom{18}{2} + 18^2 \cdot 2$ adjacencies among cells of each of the first 26 (out of 28) periods with cells of themselves and the following two periods. There are $\left(\binom{18}{2} + 18^2 \cdot 2\right)26$ adjacencies enumerated so far. For the last two periods there are $\binom{18}{2} + 18^2$ and $\binom{18}{2}$ adjacencies, respectively, for $k = 3$.

Letting subscripts denote the span of time considered, the number of adjacencies among S-T cells just counted is

$$a_3 = \left(\binom{18}{2}+18^2\cdot 2\right)26 + \left(\binom{18}{2}+18^2\right) + \binom{18}{2}$$
$$= 21456.$$

The numbers of adjacencies among S-T cells for the first few spans, all enumerated by similar reasoning, are given as follows:

$$a_1 = \binom{18}{2}\cdot 28 = 4284.$$
$$a_2 = \left(\binom{18}{2}+18^2\right)27 + \binom{18}{2} = 13032.$$
$$a_3 = \left(\binom{18}{2}+18^2\cdot 2\right)26 + \left(\binom{18}{2}+18^2\right) + \binom{18}{2}$$
$$= 21456.$$
$$a_4 = \left(\binom{18}{2}+18^2\cdot 3\right)25 + \left(\binom{18}{2}+18^2\cdot 2\right) + \left(\binom{18}{2}+18^2\right) + \binom{18}{2} = 29556.$$
$$a_5 = \left(\binom{18}{2}+18^2\cdot 4\right)24 + \left(\binom{18}{2}+18^2\cdot 3\right) + \left(\binom{18}{2}+18^2\cdot 2\right) + \left(\binom{18}{2}+18^2\right) + \binom{18}{2}$$
$$= 37332.$$

(Note the iterative process which helps in calculations.)

For analysis, there are $n = 53$ cases and $x = 504$ cells, as before. For $k = 3$ periods, $y = 2(21456)/504 = 85.1429$. Therefore, from (1) and (2) the expected number of adjacencies among events and the variance are $E(N) = 233.2543$ and $V(N) = 156.3640$.

The observed number of adjacencies among events is easily counted; for a span of $k = 3$,

$$N = \sum_{i=1}^{t}\left(\binom{n_i}{2} + n_i(n_{i+1}+n_{i+2})\right)$$

where t is the total number of periods ($t = 28$ in this application) and n_i is the number of events in period i where $n_i = 0$ for $i > t$. For a span of $k = 4$ the expression $n_{i+1} + n_{i+2}$ in the above equation is to be replaced by $n_{i+1} + n_{i+2} + n_{i+3}$, and so on.

For $k = 3$, $N = 375$. Therefore,

$$Z = 11.34.$$

Table 4 summarizes analyses for $k = 1,2,3,4$ and 5.

(These analyses pertain to several proximity structures of the type C_t, which is similar to C_tS_s on which we focused earlier; the requirement of events occurring in the same tract in C_tS_s has been dropped and varying spans of time for which to define C_t have been included. The analyses for C_tS_s suggested the route of exploring C_t. Note that for $k = 1$, C_t becomes S_t of Table 3.)

Adding to the conclusions made at the end of the previous section, it appears that in these data incidence of leukemia diagnoses optimally occurs in spans of about 1.5 years

5. Concluding Remarks

Clustering of epidemiologic events in space-time assumes one of several possible patterns. This paper employs one example, considers a few proximity structures and exemplifies mainly one, though versatile, statistical method. Hopefully this is enough to illustrate the general analytical approach and to exemplify the variety of ways in which clustering occurs.

Scale may be varied to some degree, depending on the amount of information known about the data. Therefore, it may be prudent to regard scale as a variable in order to find optimal "resolution" or clarification of the clustering (e.g. maximum Z-values).[11] Of course, this notion of optimizing precludes formal hypothesis testing but such testing is often questionable on the basis that the investigated cluster was not randomly selected.

However, the methods of this paper are useful for hypothesis testing under the usual appropriate conditions.

Another consideration in exploring clusters that was mentioned briefly is that different statistical methods offer sensitivities to different nuances of clustering.[12,13,14] One method may provide a low Z-value while another may provide a large Z-value on the same data because the two definitions of the test statistics may capture two very different characterizations of clustering. Dat[12] discusses this in comparing several tests. Two of these tests are the "empty cell" test and a new test, the "0-1 matrix" test, which has not been discussed here but which may also be applied to rectangular arrays of data, although the 0-1 matrix test is not yet "user friendly" for large data sets.

Evidently, one informative technique is the application of Equations (1) and (2) on a particular proximity configuration to conduct an analysis of the span of the epidemic. Such an analysis is similar to that based on the scan test[7] except that in this paper allocation of events in space is taken into account.

Table 4. Statistics Relating to the Time-Span of High Epidemicity

Span of Epidemic in years (½k)	E(N)	V(N)	N	Z
0.5	46.57	36.31	60	2.23
1.0	141.67	102.57	197	5.46
1.5	233.25	156.36	375	11.34
2.0	321.31	198.82	402	5.72
2.5	405.85	231.05	499	6.13

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Session T

Marriage and Divorce Statistics—Part II

PHCRS

USING MARRIAGE AND DIVORCE STATISTICS FOR SOCIAL SECURITY FINANCIAL ANALYSIS

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The divorce and marriage statistics tabulated by the National Center for Health Statistics (NCHS) are important to the work done by the Office of the Actuary in the Social Security Administration. In this paper, several key issues concerning our use of the marriage and divorce statistics will be addressed. These issues are: (1) our need for these statistics; (2) the specific statistics used and how they are used; and (3) results obtained using these statistics.

First, one reason we need marriage and divorce statistics is to aid in keeping Congress informed of the future financial status of the Social Security Trust Funds. The Board of Trustees of the Federal Old-Age and Survivors Insurance Trust Fund and the Federal Disability Insurance Trust Fund is required by law to report annually to Congress on the operations and status of the trust funds and on estimated future results. The Office of the Actuary in the Social Security Administration is responsible for projecting the population which underlies these estimates. In order to fully evaluate the financial status, the population projections are produced by age, sex, and marital status. The marital status breakdown is required because many of the benefits payable under the Old-Age and Survivors Insurance and Disability Insurance (OASDI) program depend on marital status. The OASDI program includes benefits for married or divorced spouses of retired or disabled workers, surviving spouses or surviving divorced spouses of deceased workers, and children of retired, disabled or deceased workers. In addition, our current model uses marital status breakdown in evaluating the income side of the OASDI program. The number of people paying Social Security taxes depends on the number of workers in the workforce which relates to the marital status of the population. Furthermore, marital status is related with other factors in our financial analysis. For example, historical data indicate that differential in mortality by marital status is significant.

In addition to helping keep Congress informed of the financial status under current law, we are often requested to evaluate the financial impact of new legislation being considered. Once again, marital status of the population becomes important in our financial analysis of many of these legislative proposals. The 1983 amendments contained provisions relating to marriage, divorce, remarriage, and widow status. Recently, we have been requested to make financial estimates of proposals concerning sharing of earnings between a husband and wife for the purpose of determining benefit amounts.

The second issue to address includes a description of the statistics on new marriages and divorces which the Office of the Actuary obtains annually from NCHS. These statistics are as follows:

1. Marriages in the Marriage Registration Area by age of bride and age of groom
2. Persons 15 years and over in the Marriage Registration Area by marital status, sex, and specified ages as of July 1
3. Marriages in the Marriage Registration Area by single year of difference between the ages of the bride and the groom
4. Marriages in the Marriage Registration Area by age and previous marital status
5. Total number of marriages in the United States
6. Divorces and annulments in the Divorce Registration Area by age of husband at divorce and by age of wife at divorce
7. Total number of divorces in the United States.

The Bureau of Census provides the data necessary to estimate the starting population by single year of age, sex, and marital status. Also, information from the Bureau of Census is used to distribute the starting married population into a matrix of married couples. Our task is to take the starting population and produce the same information for all future years in the projection period. The comprehensive current and historical data provided by NCHS are used as the basis for projecting marriage and divorce rates that are needed in order to make estimates of future marriages and divorces. The methods for projecting the marriage and divorce rates are described in the next few paragraphs.

Marriage

For years 1957 through 1985, marriage rates in the Marriage Registration Area (MRA) were calculated by age group of male crossed with age group of female using the NCHS data listed above. Because marriage is the combination of a male and a female into a couple, marriage rates can be computed as a ratio of the number of marriages to (1) the number of nonmarried males (not taking into account the number of nonmarried females), (2) the number of nonmarried females (not taking into account the number of nonmarried males), or (3) a theoretical number of nonmarried couples that takes into account both the number of nonmarried males and nonmarried females. The marriage rates referred to in this paper are computed using the third concept of a theoretical number of nonmarried couples as the denominator. The rates were computed as the number of marriages for given ages of husband and wife divided by the square root of the product (geometric mean) of the midyear nonmarried males and nonmarried females of the given ages.

To summarize the marriage experience of a single year and to control for changes in the age distribution of the population from year to year, age-adjusted rates were calculated. The number of marriages depends upon the age distribution of both the nonmarried male population and the nonmarried female population. Thus, an acceptable summary statistic could be calculated by age-adjustment to a set of standard nonmarried populations. When only one population is involved (as in calculating death rates), equal results are obtained by viewing the age-adjusting concept as the weighted average of the age-specific rates or as the crude rate that would occur in the standard population. When two populations are involved (as in calculating marriage rates), these two concepts do not produce the same results.

Using either concept, the first step in calculating the age-adjusted statistic is to determine the number of marriages that would occur in the standard population. We determine this number, the expected number of marriages, by applying the age-of-husband-age-of-wife-specific marriage rates to the geometric mean of the corresponding standard age-specific populations. To age-adjust using the weighted average concept, the expected number of marriages is divided by the sum of all of the factors to which the marriage rates were applied, i.e., the sum of the geometric means of the corresponding age-specific populations. To age-adjust using the crude rate concept, the expected number of marriages is divided by the geometric mean of the total male nonmarried population and the total female nonmarried population. In our work, we have calculated rates (as shown in Tables 1 and 2) under the latter concept, i.e., the crude rate that would be experienced in the standard population, which we express per hundred thousand nonmarried of each sex.

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Table 1.—Age-Adjusted Central Marriage Rates in the Marriage Registration Area by Calendar Year

[Per hundred thousand unmarried of each sex]

Calendar year	Age-adjusted marriage rate
1957	9,975
1958	9,775
1959	10,024
1960	10,015
1961	9,519
1962	9,465
1963	9,716
1964	9,812
1965	9,851
1966	10,158
1967	9,929
1968	10,168
1969	10,129
1970	9,680
1971	9,302
1972	9,412
1973	9,077
1974	8,332
1975	7,687
1976	7,303
1977	6,982
1978	6,784
1979	6,661
1980	6,256
1981	6,120
1982	5,967
1983	5,743
1984	5,623
1985	5,364

Note: The first step in calculating the total age-adjusted central marriage rate for a particular year is to determine an expected number of marriages by applying the age-of-husband-age-of-wife-specific central marriage rates for that year to the square root of the product of the corresponding age groupings of unmarried males and unmarried females in the MRA as of July 1, 1982. The total age-adjusted central marriage rate is then obtained by dividing the expected number of marriages by the square root of the product of the number of unmarried males (aged 15 and over) and unmarried females (aged 15 and over) in the MRA as of July 1, 1982.

Table 2.—Age-Adjusted Central Marriage Rates Assumed for the Social Security Area by Calendar Year and Alternative

[Per hundred thousand unmarried of each sex]

<table>
<tr><th>Calendar year</th><th colspan="3">Age-adjusted marriage rate</th></tr>
<tr><td>1986</td><td colspan="3">5,832</td></tr>
<tr><td>1987</td><td colspan="3">5,797</td></tr>
<tr><td>1988</td><td colspan="3">5,814</td></tr>
<tr><td></td><td>Alternative I</td><td>Alternative II</td><td>Alternative III</td></tr>
<tr><td>1989</td><td>5,728</td><td>5,814</td><td>5,917</td></tr>
<tr><td>1990</td><td>5,643</td><td>5,814</td><td>6,021</td></tr>
<tr><td>1991</td><td>5,559</td><td>5,814</td><td>6,127</td></tr>
<tr><td>1992</td><td>5,477</td><td>5,814</td><td>6,235</td></tr>
<tr><td>1993</td><td>5,395</td><td>5,814</td><td>6,345</td></tr>
<tr><td>1994</td><td>5,315</td><td>5,814</td><td>6,457</td></tr>
<tr><td>1995</td><td>5,236</td><td>5,814</td><td>6,571</td></tr>
<tr><td>1996</td><td>5,159</td><td>5,814</td><td>6,687</td></tr>
<tr><td>1997</td><td>5,082</td><td>5,814</td><td>6,805</td></tr>
<tr><td>1998</td><td>5,006</td><td>5,814</td><td>6,925</td></tr>
<tr><td>1999</td><td>4,932</td><td>5,814</td><td>7,047</td></tr>
<tr><td>2000</td><td>4,859</td><td>5,814</td><td>7,171</td></tr>
<tr><td>2001</td><td>4,787</td><td>5,814</td><td>7,297</td></tr>
<tr><td>2002</td><td>4,716</td><td>5,814</td><td>7,426</td></tr>
<tr><td>2003</td><td>4,646</td><td>5,814</td><td>7,557</td></tr>
<tr><td>2004</td><td>4,577</td><td>5,814</td><td>7,690</td></tr>
<tr><td>2005</td><td>4,509</td><td>5,814</td><td>7,826</td></tr>
<tr><td>2006</td><td>4,442</td><td>5,814</td><td>7,964</td></tr>
<tr><td>2007</td><td>4,376</td><td>5,814</td><td>8,104</td></tr>
<tr><td>2008</td><td>4,311</td><td>5,814</td><td>8,247</td></tr>
<tr><td>2009</td><td>4,247</td><td>5,814</td><td>8,392</td></tr>
<tr><td>2010</td><td>4,184</td><td>5,814</td><td>8,540</td></tr>
<tr><td>2011</td><td>4,122</td><td>5,814</td><td>8,691</td></tr>
<tr><td>2012</td><td>4,060</td><td>5,814</td><td>8,844</td></tr>
<tr><td>2013</td><td>4,000</td><td>5,814</td><td>9,000</td></tr>
</table>

An examination of the age-adjusted marriage rates since 1957 shows that the rates remained relatively stable during the late 1950's and throughout the 1960's. A major decrease in the age-adjusted rate was experienced during the 1970's and continued into the 1980's. The total rates shown in Table 1 range from a high in 1968 of 10,168 per hundred thousand nonmarried persons of each sex to a low in 1985 of 5,364. At first glance the provisional statistics for 1986 and 1987, as shown in Table 2, indicate a reversal of the declining trend. However, the provisional age-adjusted marriage rates are based on United States data, which historically produce higher rates than the MRA data. This is because the MRA does not include the state of Nevada. In order to compare the rates determined from the two sources of data, a factor in the neighborhood of .9 should be applied to the age-adjusted marriage rates based on United States data. Once this factor is applied, the provisional age-adjusted marriage rates for 1986 and 1987 indicate a slight decline.

Because we are uncertain whether marriage rates will increase or decrease, we assumed, for alternative II that future age-adjusted rates of marriage for the Social Security Area would remain at the same level as the average of the 1986 and 1987 age-adjusted rates of marriage for the United States. The use of constant age-adjusted rates does not imply that the crude rate of marriage in the projected population remains constant.

While it is possible that marriage rates will continue to decline, it is not likely that the rate of decline over the past 10 years will continue indefinitely into the future. Taking this into account, for alternative I, we assume that the ultimate age-adjusted marriage rate will decline to 4,000 in the year 2013 and stay at this level for the remainder of the projection period. This ultimate rate is 69% of the 1987 rate of 5,797.

It is also, possible that marriage rates will, on the average, rise above their present low level. We, however, believe that the rates will not, on the average, return to the high levels found in the 1950's and 1960's. To reflect this in alternative III, we assume that the ultimate age-adjusted marriage rate will increase to 9,000 in the year 2013 and stay at this level for the remainder of the projection period.

To obtain the age-of-husband-age-of-wife-specific rates for a particular year from the age-adjusted rate projected for that year, the age-of-husband-age-of-wife-specific rates for the years 1978-1979 and 1981-1985 were averaged, graduated, and proportionally ratioed so as to produce the age-adjusted rate for the particular year. Data for 1980 were not available.

Divorce

Data on divorces (including annulments) in the Divorce Registration Area (DRA) during calendar years 1979-1985 by age group of husband crossed with age group of wife were obtained from the National Center for Health Statistics. For each of the above calendar years, the number of divorces occurring in the DRA (which in 1985 consisted of 31 States and accounted for about 48 percent of all divorces in the U.S.) were inflated to represent the Social Security Area, based on the total number of divorces during the corresponding calendar year in the 50 States, the District of Columbia, Puerto Rico, and the Virgin Islands. Divorce rates for each age of husband crossed with each age of wife were then calculated as the ratio of the inflated number of divorces in the Social Security Area for the given age of husband and age of wife to the number of existing marriages in the Social Security Area with the given age of husband and age of wife. Table 3 contains the resulting rates age-adjusted to the married Social Security Area population as of July 1, 1982.

Table 3.—Age-Adjusted Central Divorce Rates by Calendar Year and Alternative

[Per hundred thousand married couples]

Calendar year	Age-adjusted divorce rate		
1979	2,216		
1980	2,223		
1981	2,273		
1982	2,195		
1983	2,171		
1984	2,182		
1985	2,201		
1986	2,135		
1987	2,108		
1988	2,121		
	Alternative I	Alternative II	Alternative III
1989	2,132	2,121	2,107
1990	2,142	2,121	2,093
1991	2,153	2,121	2,080
1992	2,163	2,121	2,066
1993	2,174	2,121	2,052
1994	2,185	2,121	2,039
1995	2,196	2,121	2,026
1996	2,206	2,121	2,012
1997	2,217	2,121	1,999
1998	2,228	2,120	1,986
1999	2,239	2,120	1,973
2000	2,250	2,120	1,960
2001	2,262	2,120	1,947
2002	2,273	2,120	1,935
2003	2,284	2,120	1,922
2004	2,295	2,120	1,909
2005	2,307	2,120	1,897
2006	2,318	2,120	1,884
2007	2,330	2,120	1,872
2008	2,341	2,120	1,860
2009	2,353	2,120	1,847
2010	2,364	2,120	1,835
2011	2,376	2,120	1,823
2012	2,388	2,120	1,811
2013	2,399	2,119	1,799

Table 3.—Age-Adjusted Central Divorce Rates by Calendar Year and Alternative

[Per hundred thousand married couples]

As shown in the above table, the age-adjusted central divorce rates were quite stable during the period 1979-1985. Age-adjusted central divorce rates for 1986 and 1987 were computed using the age distributions of the DRA data during 1979-1985 and using provisional data estimating the total divorces in the U.S. for 1986 and 1987. The resulting age-adjusted rates are slightly lower than those for 1979-85. For 1988, the age-adjusted central divorce rate was assumed to be equal to the average of the age-adjusted rates for the two provisional years for all three alternatives.

Because age-adjusted central divorce rates have remained fairly constant over the last ten years, we assumed under alternative II that the age-adjusted rate would remain at the same level as the 1988 estimated rate throughout the projection period. For alternative I, we assumed that the age-adjusted rate would gradually increase to 113 percent of the 1988 estimated value in 25 years and then remain at this level throughout the remaining projection period. For alternative III, age-adjusted rates are assumed to decrease reaching approximately 85 percent of the 1988 estimated rate in 25 years and then to remain constant throughout the remaining projection period.

To obtain age-specific rates for use in the projections, the age-of-husband-age-of-wife-specific rates for the years 1979-1985 were averaged and then graduated. For each alternative and year after 1988, the graduated and averaged rates were adjusted by a factor so as to produce the age-adjusted central divorce rate assumed for that particular year and alternative.

As a final issue, results obtained using the procedures described are illustrated in Table 4. These results appear reasonable. Please note that in all three tables, three separate projections, denoted alternative I, II, and III are presented. Alternative II, also referred to as the intermediate projection, is based on assumptions that are thought to be the most likely to occur among the three sets presented. Alternative I is designated as optimistic because among the three projections the assumptions selected produce the most favorable financial effect for the OASDI program. Similarly, the assumptions chosen for alterntive III, designated pessimistic, produce the most unfavorable financial effect. Alternatives I and III are designed to give policymakers a sense of the variation in the financial projections that might occur if the intermediate assumptions are not realized.

Table 4.—Selected Vital Events in the Social Security Area by Calendar Year and Alternative

[In thousands]

Alternative and calendar year	Births	Deaths	Marriages	Divorces
Alternative I :				
1987	3,938	2,193	2,500	1,181
1988	3,978	2,215	2,538	1,202
1989	3,980	2,248	2,529	1,219
1990	3,975	2,281	2,517	1,225
1991	3,963	2,311	2,501	1,227
1992	3,946	2,338	2,481	1,231
1993	3,927	2,367	2,462	1,237
1994	3,909	2,397	2,442	1,244
1995	3,895	2,428	2,424	1,244
1996	3,885	2,459	2,408	1,242
1997	3,882	2,490	2,395	1,239
1998	3,885	2,521	2,386	1,237
1999	3,894	2,552	2,381	1,237
2000	3,909	2,582	2,377	1,234
2005	4,070	2,730	2,375	1,220
2010	4,322	2,883	2,368	1,210
2015	4,496	3,060	2,397	1,193
2020	4,546	3,276	2,476	1,183
2025	4,603	3,541	2,541	1,190
2030	4,729	3,835	2,622	1,208
2035	4,905	4,108	2,713	1,236
2040	5,068	4,310	2,792	1,267
2045	5,189	4,415	2,855	1,298
2050	5,292	4,436	2,918	1,329
2055	5,413	4,418	2,992	1,361
2060	5,563	4,415	3,073	1,395
2065	5,719	4,457	3,155	1,431
2070	5,862	4,539	3,231	1,467
2075	5,994	4,638	3,306	1,503
2080	6,128	4,736	3,383	1,539
Alternative II :				
1987	3,938	2,193	2,500	1,181
1988	3,978	2,215	2,538	1,202
1989	3,951	2,236	2,564	1,213
1990	3,917	2,259	2,582	1,214
1991	3,877	2,282	2,591	1,213
1992	3,833	2,306	2,596	1,214
1993	3,787	2,330	2,597	1,218
1994	3,743	2,355	2,597	1,223
1995	3,703	2,379	2,596	1,223
1996	3,669	2,403	2,597	1,221
1997	3,641	2,427	2,601	1,218
1998	3,619	2,450	2,608	1,217
1999	3,604	2,476	2,619	1,217
2000	3,594	2,500	2,632	1,216
2005	3,624	2,610	2,713	1,213
2010	3,717	2,748	2,783	1,222
2015	3,747	2,911	2,797	1,231
2020	3,703	3,103	2,772	1,236
2025	3,646	3,332	2,755	1,236
2030	3,632	3,590	2,761	1,237
2035	3,655	3,839	2,777	1,238
2040	3,675	4,036	2,781	1,239
Alternative II : (Cont.)				
2045	3,669	4,147	2,771	1,239
2050	3,647	4,171	2,760	1,238
2055	3,633	4,138	2,756	1,237
2060	3,634	4,091	2,759	1,237
2065	3,641	4,067	2,761	1,238
2070	3,641	4,072	2,758	1,238
2075	3,634	4,090	2,753	1,238
2080	3,626	4,098	2,750	1,238
Alternative III:				
1987	3,938	2,193	2,500	1,181
1988	3,978	2,215	2,538	1,202
1989	3,921	2,219	2,605	1,206
1990	3,855	2,225	2,659	1,201
1991	3,785	2,235	2,703	1,195
1992	3,711	2,249	2,737	1,193
1993	3,637	2,267	2,765	1,195
1994	3,566	2,288	2,789	1,197
1995	3,500	2,313	2,810	1,196
1996	3,440	2,339	2,832	1,193
1997	3,387	2,366	2,855	1,190
1998	3,340	2,394	2,881	1,188
1999	3,300	2,439	2,909	1,188
2000	3,265	2,479	2,940	1,186
2005	3,171	2,561	3,102	1,186
2010	3,123	2,602	3,226	1,200
2015	3,037	2,705	3,131	1,221
2020	2,924	2,852	2,926	1,225
2025	2,783	3,034	2,794	1,206
2030	2,672	3,247	2,708	1,180
2035	2,594	3,466	2,633	1,150
2040	2,526	3,657	2,557	1,118
2045	2,446	3,781	2,470	1,085
2050	2,359	3,823	2,383	1,053
2055	2,276	3,794	2,306	1,022
2060	2,205	3,727	2,239	993
2065	2,142	3,660	2,174	966
2070	2,081	3,614	2,108	939
2075	2,019	3,581	2,043	913
2080	1,958	3,538	1,981	888

In summary, the NCHS marriage and divorce statistics are needed to aid in keeping Congress informed of the financial status of the trust funds under current law and in evaluating the financial impact of changes in the law. NCHS marriage and divorce statistics are used in estimating future numbers of marriages and divorces for each year of the projection period. MRA and DRA comprehensive data are used to determine historical trends and to provide an age distribution framework. Results obtained using NCHS data appear reasonable. Alternative assumptions are used to illustrate a possible range in the assumptions.

BUSINESS USE OF MARRIAGE AND DIVORCE STATISTICS

Martha Farnsworth Riche, American Demographics, Inc.

I.

Do any of these terms sound familiar?

° cocooning,
° neotraditionalism,
° comfort food,
° the return to the home,
° the Mommy Track,
° the New Monogamy,
° "Married, With Kids?"

These and similar terms are common in the media today, in both the consumer media and the business media. They both reflect and create Americans' perceptions of where our society is now and where it is going. And that makes them terms that consumer businesses are tempted to use in making million-dollar business decisions. What they all say is that marriage, and the married-couple household, is "in."

The most talked-about advertising campaign of the year is being conducted by *Good Housekeeping* magazine. In a photo reminiscent of a Grant Wood painting, a serenely muscular woman stands in front of a restored turn-of-the-century house, a child on the ground behind her. The advertising copy trumpets "the most significant social movement of the decade"—and implies that that movement is a return to the traditional family. The tag line: "America is coming home to *Good Housekeeping*."

Last spring, a front-page article in the *Wall Street Journal* reported a respected investor's opinion about a new product designed for single-person households. "That would have been a great idea five years ago," he said, "but it will fail now." Why? "Because the singles craze is over," he said; "everybody's married now."

Is everybody married now? Well, the statistics say, "it ain't so." In fact, last year the demographically detailed marriage and divorce reports that came out of the National Center for Health Statistics inspired me to tell consumer businesses that it's time to adjust to doing business in "The Post-Marital Society," one in which most people marry at some time in their lives, but spend an increasing share of their adult lives single. This is a message I'm carrying to every business I work with, but it's always uphill work fighting popular perceptions with government statistics. With fewer of those statistics to go on, the fight couldn't even be waged.

II.

Let me describe for you how marriage and divorce statistics fit into business decision-making. Consumer businesses are beginning to wean themselves from the convenient but oversimplified construct of the mass market. That's because the driving force in business today is the fact that overall, our population is not growing. The only way businesses can grow is to find new customers within the existing consumer market. And the way they are doing that is what they call "target marketing," or market segmentation. That is, they analyze detailed statististics for three demographic characteristics—age, income, and household type—in relation to equally detailed statistics about spending and other aspects of consumer behavior. Their goal is to identify, or target, specific population segments for specific products or services.

What this means is that the outcome of business decisions involving millions of dollars hinges very directly on detailed knowledge of whether people of a particular age group, and a particular income or educational level, are married, never-married single, divorced-single, or widowed single. Business decisions also hinge very directly on equally detailed assessments of how those characteristics are changing. Business people are taking action now based on what we are telling them consumers will be doing in the next five to ten years—not what they are doing now. And the way we make those estimates is by applying the demographically-detailed rates that we get from vital statistics about marriage and divorce events to CPS-type measures of current status.

Business is interested in marriage and divorce events in themselves too. A whole set of spending and asset transformations take place around a marriage or a divorce. In themselves, marriages and divorces represent particular marketplaces for a variety of goods and services—well beyond orange blossoms and all the other panoply of the wedding ceremony. Even there, it is important for business to know, as the NCHS recently told us, that one in three recent brides had been married once before. And that she was older than we typically think when we think brides.

The power of a stereotype is so great that we need to keep hammering home the demographic details of these events. When you say "marriage" to the average business person, let alone the average American, the vision is still of a young couple in their early 20s, starting off on a good half-century of married life. Yet the event records that we get from vital statistics show us a turbulent pattern of coming together, breaking up, and subsequent recombinations—all of which are obscured in the status statistics that we get from periodic snapshots like the Census Bureau's Current Population Survey.

III.

I'd like to show you how we typically move back and forth between CPS and vital statistics in identifying and analysing marriage and divorce trends as they affect business. And I'm going to do it in the context of the question I began with: "Is everybody married?" According to the March 1988 Current Population Survey, nearly half of American households are not married-couple households: 43 percent. This in itself is a revolution: as recently as 1970, fewer than 30 percent of households were not married-couple households.

As I mentioned earlier, businesses no longer find these kind of aggregate statistics very useful, because they are targeting much finer consumer markets. Given that most products and services are closely tied to stages in the consumer's life cycle, they are much more likely to analyze the behavior of a particular age group. Take the current household status of every business' favorite age group (because it is so large that it always dominates the consumer marketplace): the baby boom.

This gives us some understanding of the prevailing perception that everybody's married now. The people who write for magazines or report for newspapers or broadcast media are pretty universally baby boomers now, and as usual, they think the whole world is doing what they are doing. And compared to the adult population as a whole, they are mostly in family households—particularly married-couple households.

However, looking at CPS data, we see that baby boom mores have wrought a difference in baby boom household status:

° families are a smaller share of households: last year 78 percent, down from 92 percent for this age group in 1970.

° married couples are also a smaller share of households: last year just three in five—in 1970, more than four in five households in this age group contained a married couple. And vital statistics tell us that many of these couples have already had more than one marriage.

° thanks to divorce and nonmarital childbearing, the only family household that is growing among baby boomers is the female-headed family, 14 percent last year, nearly double the proportion in 1970.

° over one baby boom household in five is not a family, up from 8 percent for this age group in 1970. This situation represents an unprecedented increase in the proportion of adults aged 25 to 44 who are not married, either because they are divorced or because they have never married at all.

But everybody's getting married, right? Last year we had nearly 2.4 million marriages, and we've had roughly that many every year in this decade. That's well above previous numbers—the only time we've seen totals anywhere near that high was 1946, when the soldiers came home from World War II. Here's where vital statistics come in. Without the corrective to our perception imposed by marriage rates, it would be impossible to rein in the belief that marriage has swept the country. And that would obscure some major target markets for consumer business—particularly the singles market. And single-person households would be farther away than they are now from having their consumer needs met.

Just a few years ago, we based our assumptions about the single-person household market on an age/gender profile that identifies two separate markets: young men, mostly with rising incomes, and older women, mostly with declining incomes. Yet by combining CPS and vital statistics data, we are now identifying a major new market.

We know that young adults have been delaying marriage for some time now. And some of them have delayed it for so long that they may not marry at all. Current Census Bureau estimates are that about 10 percent of the older baby boomers will never marry—that's double the share that has been standard for most of this century. We also know—again contrary to popular perception—that the divorce rate is not declining, but that it has stabilized at a very high level. So coupling never married adults with people single after a marriage means that the aging of the baby boom is producing a larger group of middle-aged singles than ever before. And this is a market that no consumer business understands, because it has never been large enough for them to pay it any attention,

This chart (showing that married couple households without children exceeded married couple households with children beginning in the early 1980s, and that single person households will outnumber married-couple households with children early in the 1990s) puts all these trends in perspective for consumer businesses. These businesses are based on the traditional family household—that's the market they understand and that's the way they like to do business. Hence the success of the *Good Housekeeping* ad campaign—even though it goes directly contrary to the direction government statistics are pointing us in. That's not to say it is malicious or even groundless. It too is based on data—on attitudinal data collected by the Yankelovich Monitor survey that indicate that Americans are yearning for family. But imagine the difference between a business plan predicated on the assumption that Americans are going back into families, and one that understands that Americans are nostalgic for families because fewer of them are likely to be in one. And then tell me which one is going to succeed.

IV.

Let's look at how some specific businesses might use these data. The most successful new magazine launch last year is a magazine called *Victoria*. Its editorial focus is predicated on a return of interest in the traditions that are associated with family life. I worded that statement very carefully, because the magazine's staff understands that the dynamic they are working with is interest in the traditions, not necessarily participation in the lifestyle that created those traditions. That means that their glossy spreads on afternoon tea, for example, are designed to appeal to readers from a broad range of household types, not just those from traditional families.

In home furnishings, businesses have picked up the same interest in tradition—but again, the look of tradition. We are trying very hard to keep them from confusing fashion with trend, from confusing perception with reality. That means exploiting the fashion for tradition with products that can be changed when fashion changes, while avoiding applying it to products whose function is fixed. In other words, Victorian is great for door knobs and drawer pulls, but don't invest in building houses for a large Victorian style family.

For basic housing products and services—not fashionable accessories—we're trying to get consumer businesses to exploit the reality. As I said earlier, these businesses see the traditional family—mom, pop, and children—as their market. And that is their market—now, because that's who they market to. But as I showed you a moment ago, the projections we make based on age-specific statistics about marriage and divorce tell us that that market is declining. And the markets that are growing have money and housing needs too.

Even without the expected surge of middle-aged singles in the homeowner category, we already see diversity among household types among homeowners. Yet, for example, married couples with children represent the largest share of homeowners who remodeled a bathroom last year. Indexes prepared by Simmons Market Research Bureau put that share in the context of the overall homeowner market; they show how each household type relates to the average of all homeowners. The only group with an index above 100—that means more likely than the average homeowner to remodel—is the group of married couples with children. And the group significantly less likely to remodel is the group living alone. To a certain extent, this is bound to reflect the large share of elderly women living in the home after the death of their spouse—they may or may not have resources for remodelling. But given the trends that marriage and divorce statistics signify for specific age groups, the single homeowner market is obviously one for this industry to cultivate.

Married couples with children also made up the largest share of homeowners who bought bathroom plumbing last year. This time, though, there is a more even distribution of the propensity of each household type to buy. The data tell us that no matter what kind of household you are, if the bathroom plumbing needs replacement, you replace it. And all these data together indicate more than one major unserved market for the home industry—markets that we could not identify, let alone analyze in detail, without the detailed knowledge vital statistics give us on trends in marriage, divorce, and remarriage.

V.

The bottom line is that it is crucial for consumer businesses to be able to assess changes in consumer attitudes in the context of changes in consumer demographics. As I told you at the beginning, the three major demographic attributes that determine consumer spending patterns are age, income, and household type.

Thanks to the detailed statistics on births and deaths that come from the National Center for Health Statistics, trends in age are not all that difficult to follow. Age moves in one direction, in annual increments, so all we have to do is to pay careful attention to age- and gender-specific trends in immigration and mortality to know how many men and women we are going to have in particular age-defined markets over the next five to ten years.

Income, on the other hand, is extremely difficult to project. Thanks to vigorous and pioneering research at the Census Bureau, we are just now getting a handle on what is actually happening with income for individual household types. But where income will go in the next decade depends in large part on the state of the economy. There is no absence of attempts by economists to project that state—but there is a pronounced absence of agreement among their projections.

We may not know what the total income pie is going to be, but we do know that the way that pie is divided among consumer spending units hinges on trends in household type. And from the point of view of consumer businesses, the household trends that we are in the midst of are the most significant single factor reshaping those businesses in the last third of the twentieth century.

We are seeing a shift from families to nonfamilies. We are seeing a shift from the household to the individual as the major consuming unit. These shifts are major in size, and they are so rapid in execution that public perception has not caught up with them. Their causes are multiple—women's increasing economic independence, the shift of employment from manufacturing to services, the growth of the knowledge economy, and a life expectancy that exceeds the expectancy of an occupation, an education, a house, a family, and even a marriage. But we have the statistical tools to assess these causes, and to project their effects with some degree of certainty—let's make sure we have the statistics to apply those tools to.

So here's the consumer business shopping list for marriage and divorce data:

Frequency. Annual marriage and divorce rates (including remarriage rates) are crucial, but monthly provisional rates, compared to previous rates, are very important. That is because change has been so rapid that there is a great deal of uncertainty about the direction we are heading in. Given business' short time frame—actions taken now will determine the next two year's activities—it is essential to see that current data confirm (or deny) trends whose existence many people still doubt before new ways of looking at consumer markets can be implemented with any confidence.

We need monthly data for overall rates to signal any change in direction. We need the detailed data annually, and as current as possible. Even the data we get from CPS supplements are really too old to counteract any of the perceptual information I've highlighted and to influence business decisions.

Detail. Geographic detail beyond the four census regions is not crucial. All our analyses of consumer behavior reveal that there are still fundamental regional differences, and computer technology is now allowing national consumer businesses to market to those differences. That's why you'll find a slightly different array of Campbell's soup in the Southwest than in the Northeast, or why the Wendy's you stop at on your vacation trip this summer will have different entrees in Georgia than it will in Iowa. So it is important to monitor any regional differences in marriage and divorce that might produce different trends in household types.

What is most vital for consumer analysis is annual age-specific data. We need these data by education—which we use as a proxy for spending power—and by previous marital status. That includes the duration between marriages. Putting the increase in that duration together with new survey data on cohabitation was the crucial factor in leading me to formulate the concept of a post-marital society.

As I've tried to show you, current trends in business have fostered what I think will be a permanent focus on identifying very specific consumer markets according to age, spending power, and household type. And the clarity of this focus depends on an up-to-date and detailed understanding of present and near future trends in marriage and divorce.

MARRIAGE AND DIVORCE STATISTICS: A STATE'S PERSPECTIVE[1]

Charles E. Sirc and John P. Colby, Jr., NH Division of Public Health Services

This is the last of six papers presented at this conference on the uses of vital-records marriage and divorce statistics. We sincerely hope that it is not the last such presentation in the history of the conference.

This paper describes New Hampshire's experience in the collection and use of marriage and divorce statistics. It is divided into three major sections: 1) the collection and quality assurance of marriage and divorce information; 2) requests for marriage and divorce information at the state level; and 3) the use of vital-records marriage and divorce statistics in health research, planning, and intervention.

COLLECTION AND QUALITY ASSURANCE OF MARRIAGE AND DIVORCE DATA

Beginning in the mid 1800s, NH law required the registration of marriage and divorce as vital events. As with other New England states, New Hampshire's Bureau of Vital Records has traditionally done more than simply act as a central repository for marriage and divorce documents. It has also played major roles in defining, interpreting, and carrying out marriage and divorce laws.

New Hampshire has a population of just over one million. Each year in the state there are approximately 11,000 marriages and 5000 divorces. In the collection of marriage certificates the Bureau deals with 234 town and city clerks who are local registrars for the recording of the events. Reports of divorce are filed with the Bureau by the ten Superior Court clerks as required by law.

We take marriage and divorce registration and certification seriously in New Hampshire. Marriage and divorce are not treated as poor cousins of other vital events; they are subjected to the same type of rigorous editing applied to birth and death. We perform manual and computer edits of certificate information to assure completeness, accuracy, and timeliness of reporting. We also operate a query system as part of our data quality control procedures. When problems with document information are detected, queries are sent to appropriate officials (town clerk, court clerk, attorney, etc.) to rectify or verify information.

In 1988 over 1600 of 11,000 marriage certificates (15%) were queried on one or more data items. The corresponding rate for divorce certificates was even higher, with over 1900 of 5000 certificates (or 39%) having been queried. The excessive query rate for divorce certificates prompted an investigation of error patterns which revealed a high rate of problems with one particular county court. Steps have been taken to resolve these problems.

In sum, we feel strongly that our marriage and divorce statistics are of the same high quality as our birth and death data.

REQUESTS FOR MARRIAGE AND DIVORCE STATISTICS AT THE STATE LEVEL

This section describes requests for marriage and divorce statistics which are routinely received at the New Hampshire Bureau of Vital Records and Health Statistics. Users of our marriage and divorce data cover a wide range of categories. They are private citizens or state agencies requesting copies of individual certificates for personal or legal use. They are journalists and college students seeking aggregate statistics for articles or research papers. And they are sociologists, demographers, and marketing analysts who use the information for theoretical as well as applied research.

Requests for Copies of Individual Marriage and Divorce Certificates

Each year the New Hampshire Bureau of Vital Records entertains close to 2000 requests for individual marriage and divorce records from private individuals, attorneys, state government agencies, and others. Individuals often request transcripts to verify marriage or divorce in order to remarry, to receive social security benefits, to obtain bank loans, for motor vehicle registration, and for insurance purposes. Requests for geneological research are also common. Several state agencies also routinely request individual certificates to verify marriage or divorce to determine program qualification status. One agency requests marriage and divorce information as part of a nationwide system to locate parents (usually fathers) who are wanted for non-support of minor children.

Requests for Aggregate Marriage and Divorce Statistics

The vast majority of individuals and organizations who use our aggregate marriage and divorce statistics are unknown to us because they use data published in our vital statistics annual report. We have not conducted an annual-report users' survey in recent years, but we might remind you of one state's experience of a few years back as supporting evidence of the widespread use of annual-report marriage and divorce statistics. In a 1982 Vital Statistics Annual Report, the state failed for the first time to include marriage and divorce statistics (for reasons beyond their control). As a result the state's vital-statistics office reportedly received many complaints regarding the omission. Marriage and divorce statistics returned to that annual report in 1983.

In addition to our annual-report users, there are individuals and organizations who request marriage and divorce information in more detail than is available in the annual report. The most frequent requestors are marketing firms. Other organizations which routinely request these statistics include social service agencies, mental health centers, state and local government agencies, law firms, the news media, and many others. A common characteristic of many of these requests is the interest in projecting or estimating potential markets or caseloads.

Another characteristic common to these requests is that they are not generally for use in health-related research per se. In fact, none of the previous five presentations this afternoon has directly addressed the issue of marriage and divorce statistics in health research and policy decisions. We would like to turn to that issue now and describe some of the steps we have taken in the direction of remedying what we feel is the underutilization of marriage and divorce statistics in health research.

USES OF MARRIAGE AND DIVORCE STATISTICS IN HEALTH RESEARCH

Some critics suggest that vital-records marriage and divorce statistics are not relevant to public health research because there is no health information per se recorded on marriage and divorce certificates. We do not agree. Our own research over the past few years has shown that marriage and divorce statistics have the potential to play a much more important role in state health department research, planning, and intervention. Some of these uses and potential uses are discussed below.

Incidence vs. Prevalence

One major issue regarding the relevance of vital-records marriage and divorce statistics to health research and planning is that of "incidence" versus "prevalence". Incidence refers to the number or rate of events over a given period of time (usually a year). Prevalence is the distribution of a condition or status in a population at a single point in time. Vital-records marriage and divorce data are acknowledged as the best available incidence data. Therefore the relevance of vital-records marriage and divorce statistics to health research is in large part a question of the relevance of marriage and divorce incidence data to health research.

It is evident from this and earlier presentations this afternoon that researchers in other fields have made good use of marriage and divorce incidence data. Demographers need marriage and divorce incidence statistics to determine trends which they use to make population projections. The housing industry is interested in the number of <u>new</u> marriages (incidence), not the number of existing marriages (prevalence). Child day care centers want the number of <u>new</u> divorcees with minor children in an area, not the number of longer-term divorcees. In short, they recognize the appropriateness of incidence over prevalence for their purposes.

Incidence versus prevalence is also an issue in studies on the impact of marriage and divorce on health. One aspect of the divorce-health relationship we have examined involves families headed by recently divorced females. It is well established that members of single-parent female-headed households are less healthy and less well-insured than others (Weitzman, 1985). To investigate the economic impact of divorce on parents with minor children we recently conducted a pilot linkage of our divorce files with client files of the NH Division of Human Services assistance programs. Our preliminary findings indicate that among divorced women with minors, 28% apply for some form of public assistance within a year of their separation date. Two-thirds of these applicants receive some form of assistance. We expect that further findings from this linkage will be of great value in both public-health and human-services planning.

Another area of health research in which incidence vs. prevalence is an issue involves the impact of marriage and divorce on mortality. The standard vital-records study of marital status and mortality employs marital status as reported on the death certificate and marital status prevalence data from the census. These studies have consistently and conclusively shown that the unmarried - and especially the divorced - have mortality rates far in excess of those of the married (e.g., Smith, 1987; Gove, 1973).

After carrying out our own such study of marital status and mortality several years ago we were left with several questions which we thought could be answered using our own marriage and divorce data. Many of these questions relate in some way to the issue of incidence versus prevalence. Two of the areas we have begun to investigate involve the following key questions:

1) What are the respective health impacts of the divorce <u>event</u> and divorce as a <u>status</u>?

2) What effect does <u>re</u>marriage have on mortality risks of the previously divorced?

Studies Using Linked Marriage-Death and Divorce-Death Data Sets

To explore these questions we designed a series of studies based on two matched data sets: one which links death-certificate information with divorce-certificate information for New Hampshire males who died while divorced; and the other which links death-certificate information with marriage-certificate information of New Hampshire males who died while married. We would like to present some preliminary findings from these studies.[2]

Mortality in the First Years Following Divorce. We know from our marital status and mortality study that at every age divorce carries the greatest mortality risk of any marital status. But we cannot tell from death-certificate and census data to what extent this risk is attributable to the short-term "stressful" impact of the divorce event as opposed to the longer-term effects of lifestyle or health behaviors which might be associated with divorce as a status. By linking death records with marriage and divorce records we were able to calculate death rates for a divorce cohort by length of time since divorce. The marriage-death linkage enabled us to include in this study members of the divorce cohort who remarried and died subsequent to remarriage.

Preliminary findings from this study show that of the 5000 NH males who are divorced each year, at least 12 will die within a year of divorce. The resulting death rate of 2.4 per 1000 divorces is higher than NH's 1987 postneonatal mortality rate of 2.2 per 1000 live births (Table 1). Unlike birth cohorts, however, divorce cohorts do not experience a decline in death rates after the first year. In fact, the death rate of divorced New Hampshire males shows an overall increase over the first five years following divorce.

Table 1. Deaths and death rates per 1000 events by length of time since event: NH resident 1987 birth cohort* and average-annual 1981-1985 divorce cohort.

Length of time since event	One-year birth cohort (N=17025)		One-year divorce cohort (all ages) (N=4976)		One-year divorce cohort (age < 60) (N=4855)	
	Deaths	Rate	Deaths	Rate	Deaths	Rate
< 1 yr.	131	7.7	12	2.4	10	2.0
1-1.99 yrs.	11	0.7	14	2.8	10	2.1
2-2.99 yrs.	4	0.2	12	2.4	9	1.8
3-3.99 yrs.	3	0.2	16	3.2	8	1.7
4-4.99 yrs.	3	0.2	21	4.2	13	2.6
< 5 yrs. (cumulative)	152	8.9	75	15.1	50	10.3

*1987 birth cohort death rates are estimates using 1987 birth and death information.

Table 1 also presents death rates for members of the divorce cohort under age 60. Mortality rates for this age group remain at around 2 per 1000 divorces for each of the first four years. The rate then increases to 2.6/1000 in the fifth year following divorce. Thus, while infancy may be the most dangerous year of life prior to age 60, the first few years following divorce may be described as the most dangerous multi-year period of life prior to age sixty.

The Impact of Divorce on Mortality by Level of Education. The death toll in the first few years after divorce is disproportionately high among members of the lowest education group (Table 2). (Level of education, as reported on the marriage and divorce certificates in this case, is a commonly employed indicator of social class in vital-records research.) Among those with less than 12 years of education the death rate in the first year after divorce is 4.1 per 1000 divorces. This compares to 2.0/1000 for those with 12 years of education, and 1.9/1000 for those with 13 or more years education. The cumulative five-year death rate for the low-education group (28.5 per 1000 divorces) is more than twice that of the middle-education group (13.0/1000) and nearly three times that of divorcees in the high-education group (9.9/1000).

Table 2. Mortality rates per 1000 divorces by level of education and length of time since divorce: Average-annual divorce cohort of NH males, 1981-1985.

Length of time since divorce	Total cohort (N=4976)	Level of Education		
		< 12 yrs (N=1035)	12 yrs. (N=2080)	13+ yrs. (N=1819)
< 1 yr.	2.4	4.1	2.0	1.9
< 5 yrs.	15.1	28.5	13.0	9.9

Remarriage and Mortality. Regarding the effect of remarriage on mortality, "undisputed" evidence from research on stressful life events shows that the loss of a spouse through divorce is associated with an elevated risk of subsequent and proximate morbidity and mortality (Petit and Bloom, 1984:587). There is also strong evidence that the status of being married is protective of health (House, et al., 1987). This evidence led us to investigate two related questions: 1) Is remarriage as protective of life as first marriage?; and 2) Does remarriage protect against the hazards of the divorce event in the first few years following divorce?

Regarding the first of these questions, preliminary findings indicate that remarriage reduces death risks somewhat, but that it is not as protective of life as first marriage (Table 3). Death rates of married men who were previously divorced are significantly higher than their "always married" counterparts, but significantly lower than the death rates of those who were divorced at the time of their death.

Table 3. Mortality rates per 100,000 population by marital status, remarital status, and age: NH Male Residents, 1979-1986.

Age	Married			Divorced
	Total	First Marriage	Previously Divorced	
20-29	83.4	77.8	90.9	266.0
30-39	101.6	91.6	154.3	269.4
40-49	304.9	258.9	477.8	860.5
50-59	857.5	604.6	1976.2	2287.8

Note: Analysis restricted to under age 60 due to inavailability of computerized marriage data from pre-1950.

The results also show that remarriage is somewhat protective of life in the first few years following divorce.[3] Preliminary findings indicate that death rates of the remarried are lower in the first year following divorce than are death rates of those who do not remarry (1.5/1000 for the remarried vs. 2.7/1000 for the married). In addition, death rates of the remarried remain between 1.4 and 1.8/1000 through the first five years following divorce while the death rates of those who remain divorced increase to 4.0/1000 in the fourth year and 4.8/1000 in the fifth year following divorce.

CONCLUSION

The theme of this conference is "Challenges for Public Health Statistics in the 1990's". I would like to close by offering you a challenge: and that is to explore the potential of the marriage and divorce data sets before it's too late (if in fact it's not already too late). Early findings from our studies suggest that these statistics have tremendous untapped potential for use in health research. The extent of risk among the recently divorced also demonstrates the potential value of these data sets in their own right for use in health planning and intervention.

We are not suggesting that every state begin linking their marriage/divorce files with death files and other data sets. But we are calling for resources to be dedicated to explore innovative uses for these files. We would like to see NCHS and CDC set the pace by undertaking marriage and divorce followback studies similar to those routinely carried out with birth and death. We also believe that our federal experts should provide technical assistance to states in order to help us incorporate marriage and divorce statistics into our health-planning processes. Additionally, we think that CDC/NCHS should make available pilot project evaluation funds to states and universities to enable researchers to thoroughly and objectively determine the value of these data sets before they are eliminated from the national system.

We want to emphasize that we are not talking about business as usual with regard to the funding and use of these data sets. Rather, we are calling for a serious and thorough evaluation of marriage and divorce statistics as the way to determine their fate. Funding for the processing of marriage and divorce statistics is a question of resource allocation. It is a question that should be answered on the basis of empirical and objective evidence; not in an arbitrary and capricious manner. After all, if <u>we</u> don't use statistics for decision-making, who will?

FOOTNOTES

1. We wish to thank Kathleen Laughlin and Daniel Swacha for their contributions to this paper.
2. A full description of this matching project is forthcoming in a separate report. We apologize for presenting findings without complete documentation of our methods, matching rates, and supporting statistics. Under the circumstances, however, we thought that presenting preliminary findings would be the best way of demonstrating the potential uses of these statistics in health research and planning.
3. The findings presented in this paragraph are contrary to those reported at the conference in July. We regret any inconvenience this unintentional error may have caused.

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Third Plenary Session

Professional Health Associations:

Health Statistics and Health Care

PHCRS

PROFESSIONAL HEALTH ASSOCIATIONS:
HEALTH STATISTICS AND HEALTH CARE (PANEL)

Margret K. Amatayakul, American Medical Record Association

American Medical Record Association

The American Medical Record Association is the professional membership organization of nearly 30,000 registered record administrators (RRAs) and accredited record technicians (ARTs). Its mission is embodied in the following statements:

I. To achieve and maintain the highest attainable levels of competence in those certified as medical record technicians and medical record administrators.

II. To be the nation's authoritative body on the health record and health information systems.

III. To be an advocate for the profession on governmental, academic, social and business issues that affect the management, content, use and control of health records or health information systems.

IV. To advance the professional standing of those certified as medical record technicians and medical record administrators.

V. To contribute to the development and application of effective systems for creating quality health data and for using and controlling health information and health resources.

As can be seen from these mission statements, AMRA is very involved in issues relating to the content of the health record and data retrieved from it. Medical records and statistics compiled from them have been an important concern of the health care delivery system since the early part of this century. The American College of Surgeons in its hospital standardization program was the impetus for documentation standards. Over the years, medical records have been used for many purposes in addition to serving as a benchmark for accrediting health care institutions.

Medical Record Uses

The medical record has traditionally been used in:

- o Patient care management
  - to serve as a basis for planning individual care;
  - to document the course of the patient's illenss and treatment during each episode of care;
  - to communicate between the physician and other health professionals providing care to the patient;
  - to inform health professionals providing subsequent care.
- o Research and education
  - to provide data to expand the body of medical knowledge;
  - to identify disease incidence so plans can be formulated to improve the overall health of the nation and the world;
  - to provide actual case studies for the education of health professionals;
- o Legal aspects
  - to provide data to assist in protecting the legal interests of the patient, physician, and health care facility,
- o Quality review
  - to serve as a basis for analysis, study, and evaluation of the quality of care rendered to the patient;
  - to serve as a tool for measuring the quality of medical care rendered by a health care facility and its medical staff.
- o Financial reimbursement
  - to substantiate insurance claims of the health care facility and patient.

Since the prospective payment system was implemented, the medical record has assumed even greater importance in the area of financial reimbursement, and a sixth dimension could be added to the list of uses of the medical record:

- o Case mix management
  - to provide data necessary for selecting and promoting facility service offerings;
  - to evaluate use of the facility's resources and manage risk.

NCHS/AMRA Activities

The National Center for Health Statistics (NCHS) is a significant user of data compiled from medical records. Its activities touch on almost every aspect of medical record usage. In addition, AMRA has been directly involved with NCHS in several activities. Three are highlighted.

ICD-9-CM

Of major significance to AMRA is the NCHS's involvement in ICD-9-CM. The NCHS initially became involved in February, 1977, when it was recognized that the *International Classification of Diseases, Ninth Revision* (ICD-9) would require modification for use as an indexing system for hospital records. The NCHS convened a Steering Committee of seven organizations to provide advise and counsel to the development of a clinical modification of the ICD-9. The AMRA was one of these organizations. Others included the American Hospital Association (AHA), Health Care Financing Administration (HCFA), WHO Center for Classification of Diseases for North America, American Association of Health Data Systems, Association of Health Records, and the Council on Clinical Classifications. The Council on Clinical Classifications provided clinical guidance and technical input. It was sponsored by six organizations including the American Academy of Pediatrics, American College of Obstetrics and Gynecologists, the American College of Physicians, the American College of Surgeons, the American Psychiatric Association, and the Commission on Professional and Hospital Activities. As a result, the *International*

Classification of Diseases, Ninth Revision, Clinical Modification was developed for use in the United States.

In 1985, the Department of Health and Human Services established the ICD-9-CM Coordination and Maintenance Committee. The function of the Committee was to develop proposed revisions to ICD-9-CM to reflect new procedures and technologies as well as newly identified diseases. In addition the Committee was to correct errors in ICD-9-CM. The Committee's principal areas of responsibility are shared by HCFA and NCHS, with HCFA having the lead responsibility for Volume 3 (procedures) and NCHS having the lead responsibility for Volumes 1 and 2 (diagnoses).

Coordination and Maintenance Committee membership is limited to representatives from federal agencies, but the meetings are open to the public. AHA and AMRA staff members regularly attend the meetings to comment on issues. All final decisions on new or changed codes made by HCFA and NCHS must be approved by a formal process.

Guidelines to coding are developed by another group, known as the cooperating parties. These are HCFA, NCHS, AHA, and AMRA. Guidelines require unanimous approval of the four parties.

As the responsibility for coding lies primarily in the medical record departments of hospitals, the structure of the *Classification* and associated guidelines are critical to the work of AMRA members. Accurate coding impacts health statistics used for research and education as well as quality review, financial reimbursement, and case mix management.

While coding may currently be the most important function of medical record departments, AMRA has participated with the NCHS in other important activities as well.

Vital Statistics

For the first time commencing in 1983, AMRA participated in redesigning vital statistics forms, some of which (birth and death certificates) are often the responsibility of medical record departments to complete. AMRA was asked by the Division of Vital Statistics of NCHS to serve on the format subcommittee which gathered recommendations from other groups assigned to each form, including certificates and reports of live birth, death, fetal death, induced termination of pregnancy, marriage and divorce, and dissolution of marriage or annulment, and to prepare recommendations for final approval. AMRA was pleased to be able to lend its expertise in forms design, systems, and procedures to the development of the model certificates and forms.

NMIHS

Another activity in which AMRA was pleased to participate was the NCHS's 1988 National Maternal and Infant Health Study. For the study, AMRA guided NCHS on issues of survey design, a pilot study to pretest questions, the content of the mother's Request Statement and introductory brochure, and how to obtain billing information for hospitalization episodes. AMRA formally endorsed the NMIHS, will continue to provide guidance throughout the 1988-90 data collection period, and encouraged the participation of medical record specialists.

The National Maternal and Infant Health Survey is a nationally representative study of 20,000 normal live births, low-birthweight babies, fetal deaths, and infant deaths in 1988. Mothers are mailed questionnaires or interviewed, and approve in writing that their prenatal care providers and hospitals may also be contacted. Their hospitals and prenatal care providers are then asked to complete questionnaires based on medical record information on the mothers and their infants. The NMIHS represents the combined efforts of over a dozen federal agencies and includes input from low birthweight prevention work groups, infant mortality review teams, health care providers, medical researchers, and professional medical associations such as AMRA.

As a result of AMRA's role in this study, the final response rate for hospitals on the pretest was 93.0 percent.

As our mission reflects, AMRA takes a leadership role in health information. AMRA is pleased to participate in NCHS surveys in any way it can.

Public Health Statistics in the 1990's
Physicians, Health Care and Health Statistics

Jan Schneider, Medical College of Pennsylvania

This presentation is designed to consider how physicians perceive and use vital health data. It is of moment to recognize that while physicians are the individuals who complete the certificates and write the records from which most health data directly or indirectly are derived their understanding of the process is most imperfect. The raw units of information from which statistics are ultimately compiled are very much dependent upon the completeness and the accuracy of recording of information. At the end of the process physicians, among others, are heavily dependent for their plans and strategies upon the health trends, needs and challenges which the data reflect. Yet practicing physicians tend to be uncomfortable when confronted with data. Their perception of public health and their understanding of the definitions and crude rates are sketchy at best.

In the compilation of health data the worse the outcome the more information is available. Fatality is fully reported and within the limits of the accuracy and completion of reporting the numbers and causes of death are known. Beyond the statistical value of the mortality rate it must also be recognized that data has a fixed relationship to morbidity. Thus any fall in the mortality rate is an indication of an even greater decline in morbidity. In the case of infants a reduced mortality rate indicates a fall in the number of defective survivors particularly those with central nervous system defects.

In obstetrics there are five vital statistics on which data are accurate and in which reporting is fairly complete. Maternal mortality, fetal mortality and infant and neonatal mortality are reported quite consistently. Finally, the incidence of low birth weight infants, perhaps the most useful measure of the inherent risk of any population, is also accurately known.

Maternal death is the ultimate tragedy in obstetric outcome. It is often forgotten by physicians that the definition of such death is extremely broad and includes the death of any woman dying of any cause while pregnant or within a defined span of time after the termination of the pregnancy irrespective of its duration, its anatomical site or the method of its termination. Definitions do vary somewhat in the interval of time between the completion of pregnancy and the death and span from thirty to 365 days. Since the definition is so broad such deaths are subdivided into three groups; direct deaths which are those maternal deaths due to direct complications or interventions in the pregnancy, indirect deaths which are deaths caused by preexistent or intercurrent disease which is adversely affected by the pregnancy and, finally, the non-related deaths which are not affected by the pregnancy. Clearly there is some gray zone between these groupings and in many cases there is argument whether the causes of death should be classified as direct or indirect. Even such simple issues as a non-related death due to trauma might be related to the pregnancy: A more graceful patient might not have slipped in the bathtub or might have been able to leap out of the way of the truck. However it is important to recognize that only the direct maternal deaths, those attributable to a complication of the pregnancy itself or to an intervention in the pregnancy itself, are counted in the maternal mortality rate.

The maternal mortality rate is in fact a ratio rather than a rate. Because the denominator is live births it is obvious that many of such deaths occur to women who did not contribute to the denominator either because they died while undelivered or died after having aborted or delivered a stillborn fetus. One of the greatest success stories in health care during this century is the dramatic decline in the maternal mortality rate. There are good data to suggest that around the turn of the century the maternal mortality rate was approximately 1000 deaths for every 1000,000 live births. This translates into a 1% incidence of death. Around the turn of the century data from Michigan indicate that the average married woman had five children. Therefore though the data are obviously imperfect, since a woman who died in her first pregnancy would not have had four more babies, in prospect a woman as she walked down the aisle in that era faced a 1% risk of dying five times over or a 5% risk of maternal death. This catastrophic figure does reflect the true biological risk of human reproduction. Just a few years ago a sect in the midwest refused all health care leaving to nature all their recovery from disease. The maternal mortality rate between 1975 and 1982 of this group who did not avail themselves of the advances in health care was 872/1000,000; namely very close to that reported around the turn of the century. The maternal mortality has fallen 100 fold into the range of 10/100,000 over the last 80 or so years. This 100 fold improvement is clearly one of the great triumphs of health care and improved social conditions.

Fetal mortality is probably the least well recorded measure of obstetric outcome. This is particularly true in the gray zone between late abortion and early fetal deaths. Some states, including Pennsylvania, require reporting of any pregnancy beyond the 16th week as a fetal death although by international definition any intrauterine death of a pregnancy beyond the 20th week or where the fetus weighs more that 500 gm is classified as a fetal death. In the lower range there is frequent confusion between a missed abortion of a pregnancy that dies prior to the 20th week but continues beyond that time and results in the delivery of a fetus that weighs less than 500 gm. This makes for confusion and poor reporting. Nonetheless the fetal mortality rate has shown steady improvement and in just 30 years fell from 14 to 7.7. The improvement was most marked in that component of fetal mortality that occurs during the process of labor. Traditionally deaths prior to the onset of labor, the antepartum fetal deaths, represented approximately two-thirds of all whereas intrapartum deaths represented approximately one-third. The decreased intrapartum fetal mortality is attributable to better care in labor and, perhaps, to some of the new monitoring technology.

Whatever may cause death of a fetus in utero may also result in a child liveborn but so damaged that death will occur soon after delivery. Thus the concept of perinatal mortality is widely recognized as a better measure of obstetric success or failure. One concern about perinatal mortality is that there is a series of different definitions. Currently the most frequently used in the United States includes all fetal deaths and all neonatal deaths, namely any death between the 20th week of intrauterine life until the 28th day of post-delivery life. In Europe a narrower definition is generally used spanning from the 28th week of intrauterine life to the 7th day of post-delivery existence. Some states use yet a different definition. It is important when comparisons are made that the definitions are clearly recorded.

Infant and neonatal mortality rates have both shown a dramatic decline. Over the past 40 years there has been a ten fold improvement in infant and neonatal mortality rates. The infant mortality rate has finally slipped into the single digits and is now less than 10/1000 live births. Neonatal mortality represents approximately two-thirds of all infant deaths.

One critically important statistic is the recognition that approximately 75% of all neonatal deaths and therefore 50% of all infant deaths occur to infants with a birthweight of less that 2500 gm. In the United States approximately 7% of all live births fall into this low birthweight group. Whether such babies are small because of intrauterine growth retardation or small because of preterm delivery or because of a combination of the two there is no question that they are the highest risk group. Thus weight is an easy criterion of vulnerability. In the United States the incidence of low birthweight infants has for many years been higher than that in other countries in the Western World. The risk of an individual practice, hospital, community or nation is reflected in the incidence of low birth weight babies.

It is because of the impact of birthweight to prognosis that the importance of linking data from birth and death certificates became obvious. Data such as birthweight, gestational age and maternal age, marital status, education and prenatal attendance obviously are not reported on the death certificate: The same death certificate is used for a tragic neonatal death as for the timely departure of dear old grandma. Therefore the linking of data from the birth certificate which does contain these data and the death certificate has been extremely useful in identifying such trends. The National Center for Health Statistics has produced a series of trials over the last twenty years and most recently completed one that included all fifty states. linked data from birth and death certificates has been extremely useful.

A final source of extremely valuable data available to the physician is from surveys conducted by the Center. Surveys have included data on costs of health care, payment of health care, sources of care and disease prevalence. Data on family growth and upon maternal and infant health have all helped physicians in planning programs in the future. There is surely no area in which vital data more directly reflect the health of a nation than those which relate to the process of reproduction. The work of the National Center for Health Statistics has been extremely useful to those of us in the health care professions who care for the mother and her unborn and newborn child. I thank the National Center for inviting me and for allowing me to give my views as an obstetrician gynecologist upon how statistics can help in the delivery of health care. I believe we can continue to work together to maintain the improvements which have been so gratifying in the past but which leave many challenges for us to meet in the future.

1989 PUBLIC HEALTH CONFERENCE ON RECORDS AND STATISTICS

Peter D. Kralovec, American Hospital Association

Each year the AHA invests considerable dollars and resources to collect data. To date, 1989 is no exception. From AHA's perspective data are considered important for descriptive statistical purposes, research purposes, policy formulation purposes, and to further our understanding of the hospital component of the health care delivery system. This year alone we will conduct at least 13 surveys.

In addition to the AHA Annual Survey of Hospitals which is our general census survey and one which is used to inventory many of the facilities and services that are provided through our nations hospitals and the National Hospital Panel Survey which enables us to monitor key hospital performance indicators monthly, 11 special surveys will be conducted in the areas of:

Hospital Governance
Ambulatory Care Programs
Long-term Care Services
Maternal and Child Health Services
Medical Staff Relationships
Quality Assurance Programs
Hospital Library Services
Coalitions
Psychiatric Services
Substance Abuse Services
Human Resources

In addition to this primary collection work, we are now in the process of updating our National Inventory of Machine Readable Health Care Data Bases, which is simply a listing of such files by subject matter and producer.

Although our 1989 survey agenda represents a significant expansion of our data base, not all of our data needs can be met through primary collection. In response to many of the things that we need to do to adequately represent our membership, we rely greatly on secondary data sources many of which are controlled by the Federal Government. Among the most notable secondary sources that we routinely access are HCFA's Medicare Cost Report and Med Par files which are crucial to our Medicare Policy Work which is clearly the highest priority of the AHA. In addition, we rely on NCHS for information on non-hospital health care providers such as nursing homes. We also rely on NCHS and CDC in general for data that addresses more directly the basic health status of the country.

Specifically, we will be exchanging data with NCHS on Maternal and Child Health issues in that more indepth analysis can occur with respect to both of our collection projects in this area.

Other major federal sources include the Bureau of the Census for population and demographic data, the Bureau of Labor Statistics for general economic indicators and labor data, and the Bureau of Health Professions for the county specific Area Resource File.

I don't mean to imply by these remarks that we rely only on federal data. Significant use is also made of data and information from other national and state hospital associations, national professional associations such as the AMA and at times state and local governmental agencies to name just a few of other data providers.

In general, it is important to the AHA to establish strong and cooperative relationships with major data providers. In order to maximize the usefulness of the information that are collected it is essential that the data are effectively shared with the user community so that duplicative data requests are not imposed upon the nations hospitals and so that relatively scarce collection dollars can be applied to other projects. Also such relationships result in the sharing of knowledge and expertise. For example our relationship with NCHS and other federal agencies have resulted in improvements over time in our collection methodologies. It is hoped that the federal agencies have benefited from their contact with us.

Finally, the AHA has endeavored to endorse or otherwise support many other national data collection systems. The decision to endorse is not taken lightly. Federal surveys including many NCHS projects are considered extremely important in that they address crucial public health issues that would normally not be covered through AHA collection programs. Examples of recent endorsements include:

NCHS's
- National Maternal & Infant Health Survey Follow-up
- National Hospital Discharge Survey
- National Mortality and Fetal Mortality Survey
- National Mortality Survey

to name just a few.

In closing, 1988 data from our National Hospital Panel Surveys indicates that the recently recorded inpatient utilization declines are stabilized. However, admissions for the under 65 population are declining with a corresponding increase in the 65+ population. This observation would tend to suggest that the Medicare Program will play an increasingly significant role as a source of revenue. Also, outpatient utilization is continuing to rise at dramatic rates which tend to suggest that it is in this area where the under 65 population is receiving their care. On the financial side, total margins have remained positive. However, patient margins continue to erode which demonstrates that hospitals are continuing to feel financial pressure which may impact on their viability.

THE USE OF HEALTH STATISTICS: SETTING QUANTIFIABLE GOALS-- THE AMERICAN ACADEMY OF PEDIATRICS

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The focus of this paper is on how the American Academy of Pediatrics (AAP) uses federally generated statistics to help monitor goals set at the highest level of the organization. The AAP is the major professional organization for pediatricians. It has over 30,000 members, and is concerned mainly with continuing education programs in pediatrics, developing recommendations for the medical treatment and general care of children, and serving as children's advocates in the development of national and state health care policy.

Each year the Executive Board of the AAP meets to identify no more than five or six goal areas where new programs will be concentrated. The program areas selected in the spring of 1989 are relevant to programs that will begin in the fiscal year starting in July 1990, so that each AAP department--including those that deal with educational programs, communications, and policy formulating committees as well as research--has time to develop program ideas within the goal areas. An effort is being made to set quantifiable goals, so that the AAP can identify and monitor indicators that measure progress in achieving them. Not surprisingly, these indicators tend to come from federal data collection programs.

In this presentation I will review the AAP goals chosen in the spring of 1989 and the federal indicators that have been identified to measure the baseline and, in some cases, to monitor progress. The process of seeking indicators has pointed out to the AAP where some important indicators are missing from data collection initiatives. Moreover, good programs may be launched which cannot be expected to affect national-level indicators. I will point out where this is particularly evident to us with respect to AAP goals and how national indicators are still useful in the goal setting and monitoring effort.

The goals that were identified in the recent planning session of the AAP are:

* Reduce financial and non-financial barriers to comprehensive health care for children and pregnant women.

* Reduce deaths from intentional and unintentional injuries.

* Promote comprehensive health education in schools.

* Reduce incidence of teen pregnancy.

* Promote pediatricians as primary, secondary and tertiary care providers.

* Increase payment for pediatric cognitive services.

I will review the use of federal statistics in the planning process for each goal in turn.

1. Reduce financial and non-financial barriers to comprehensive health care for children and pregnant women.

This is a major initiative of the AAP at this time, as well as an area that will guide the AAP's work in the next few years, at least. The often quoted statistic that put this on the agenda is the 19% of children in the United States who are uninsured. This statistic comes from the Current Population Survey.[1] In addition, from calculations based on the NCHS monthly vital statistics report, we know that in 1986 24.1% of women did not receive prenatal care in the first trimester, and among pregnant teenagers this figure is 47%.[2] The AAP is currently working with members of Congress to draft a legislative program to provide financial access to all children and pregnant women. In this case, we would hope eventually to see a vast reduction in the percent of children who are uninsured. We would also hope that such financial access would have some positive effect on the indicators of prenatal care.

The statistic that we do not have that would be very helpful in this area is a measure of the "underinsured." Actually, this would need to be a set of indicators to measure the percent who are not covered for various services such as visits for preventive care. From the National Medical Expenditure Survey fielded by the National Center for Health Services Research (NCHSR) in 1988, information to develop such indicators will be forthcoming. There was similar information in 1981 from the National Medical Care Utilization and Expenditure Survey and in 1976 from the National Medical Care Expenditure Survey, also conducted by NCHSR in collaboration with others. However there are no established indicators of underinsured status measured on a regular basis.

In connection with the goal of access, the AAP also has a program with the Office of Maternal and Child Health to fund community-level projects related to access. This program, called "Healthy

Tomorrows," may lead to funding of some projects that address other access barriers, such as lack of transportation and insufficient knowledge, as well as problems encountered by specific populations, such as language barriers. Another program in which the AAP is participating is "Healthy Children," funded by the Robert Wood Johnson Foundation. Through this initiative local groups may receive consulting assistance in resolving a range of access problems. However the emphasis in these programs on non-financial barriers to access dramatizes to the AAP that there are no data collected on a regular basis nationally on such access barriers, and therefore there is a lack of good bench mark information on these issues.

2. Reduce deaths from intentional and unintentional injuries.

As bench mark data for this initiative, there are excellent federal data on the numbers of deaths by age for quite a fine breakdown of injuries, coded using the ICD-9 system's E-codes, which provide information on the source of the injury.[3] These may be used with population statistics from the Current Population Survey of the same year to calculate mortality rates. There are areas, like child abuse, where it is difficult to identify the appropriate categories. Also, even though our goal is phrased in terms of reducing mortality, it would be very helpful to have morbidity indicators in this area in order to better gage the potential harm from a given type of injury.

One new program that will be launched in this area is a bicycle helmet campaign. The program will include about 10 grants to chapters for programs at the state or local level as well as materials to be disseminated through pediatricians' offices. Here it is easy to imagine good programs that may have no measurable impact on national-level data due to the fact that the programs are restricted to certain locations and sites. Yet, the national data still serve to define important dimensions of the problem, and we would hope that a good program--like the mandating of seatbelts and children's car seats--would be picked up by many more communities and providers and ultimately have an effect on the national statistics.

3. Promote comprehensive health education in schools.

In this area federal data are nonexistent on what schools are providing in health education on average. We were able to locate data gathered through other bodies on numbers of states that have various mandates for school health education on specific topics, e.g. AIDS and sexuality,[4] but research in our own department has shown us that mandates tell us little of what schools actually do. Some schools will respond to a mandate with a very limited program, whereas schools in areas with no mandate may have very ambitious programs.[5]

4. Reduce the incidence of teen pregnancy.

Here excellent data are available from the National Center for Health Statistics on the number of women/1000 who become pregnant for different age groups. These are, for 1986, 1.3/1000 for 10-14 year olds, 30.6/1000 for 15-17 year olds, and 81.0/1000 for 18-19 year olds. Another indicator of interest, which may be calculated from the same source, is the percent of adolescent births which are at least second births to the same mother: 28.8%.[6]

Again, the AAP realizes that local programs, or even national programs with limited funding, may have no detectable impact on these indicators. But local areas with higher levels of adolescent pregnancy may be identified using the national norms as bench marks, and they may then be targeted for special programs.

Regarding this goal, the AAP is very pleased about the current funding of the NCHS program to link birth certificate and death certificate data for several years (starting with 1983). These data will be particularly useful in examining infant mortality by age and other maternal characteristics, and will facilitate research at the state level. We hope that funding of this effort will continue.

In addition, in regard to this goal and even more, perhaps, the first one on access to care for children and pregnant women, the AAP has just written a letter of support for the National Maternal and Infant Health Survey Long-term Follow-up (NMIHS-LF), to be carried out by NCHS with other federal agencies. The NMIHS and NMIHS-LF, although parts of a single (as opposed to annual) effort, will provide information critical to the development of programs in these two goal areas.

5. Promote pediatricians as primary, secondary and tertiary care providers. This includes the goal of increasing the percentage of adolescents cared for by pediatricians.

This goal was formulated in part to promote programs that would prepare pediatricians for a variety of roles, including activities such as hot lines and other community resource programs, as well as the provision of direct patient care. The staff of the National Ambulatory Medical Care Survey (NAMCS) has been extremely helpful to the AAP in providing indicators to inform direct patient care programs. As a result we have information for 1985 on the reasons for which children see pediatricians as well as other physicians. In addition, NAMCS has given us data on the percent of children of different age groups who see pediatricians as well as other physicians. With earlier data from the NAMCS on these same items for 1975 and 1981,[7,8] we have been able to look at trends as well, to help give us some idea of the reasons for which children are most likely to see pediatricians in the next few years.

6. Increase payment for pediatric cognitive services.

The major issue here is reimbursement under publicly funded programs that is often lower than cost. Academy research has shown that this is the prime reason that pediatricians sometimes do not accept Medicaid children.[7] Federal research data probably are not as critical here as obtaining the schedules of rates for Medicaid reimbursement, which have been gathered by the AAP from the states. Also important are reimbursement levels from most private third party payors, which limit severely the amounts for pediatric cognitive services. A federally funded effort, the Harvard University Research-based Relative Value Study (RBRVS), has examined the actual time and resource commitment for a variety of medical and surgical services, and will provide another basis for efforts to achieve the goal of increasing payment for pediatric cognitive services.[10] However this is a single research project rather than an ongoing data collection system.

Conclusion

The AAP recognizes that national data sets are critical to informed development of national-level programs. In order to determine program success, the ideal is to track it using quantitative national indicators. Of course such measures cannot respond to good programs of a limited scope. But national indicators can help us to identify local areas and specific populations that need special attention because they measure very differently from the national population norms. In addition, national indicators can help us to shape programs in other ways, such as providing trend data so that programs, especially education programs, may respond to changes we see taking place.

This presentation has also identified several areas where the AAP has recently noted a lack of available national data. Those mentioned include: measures of underinsurance, consumer experience with non-financial barriers to access, injury morbidity (as distinguished from mortality) data, and the content of school health education programs.

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Session U

For Disabled

PHCRS

SERVICE CONSIDERATIONS FROM DEMOGRAPHIC SHIFTS IN POPULATION OF OLDER PERSONS WITH DEVELOPMENTAL DISABILITIES

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Indications are that the current population of older persons with mental retardation or other developmental disabilities has increased in size, as well as visibility, and will continue to grow in prominence in the years to come (Hogg, Moss & Cooke, 1988; Janicki & Wisniewski, 1985; Seltzer & Krauss, 1987). Changes in health care, nutrition, early childhood services, and social and housing conditions have led to an increase in the survivor rate with many more such individuals continuing to live until their 70's, 80's and 90's (NIA, 1987). Expectations are that these trends will continue, particularly given the confluence of federal statutes promoting enriched programs, service entitlements, and general overall improved health status (Ansello & Rose, 1989).

Added to this is the greater number of young adults with mental retardation who are entering the work force after transitioning from school programs set up under provisions of the Education for All Handicapped Children Act (PL 94-142, as amended). Further, epidemiological studies are beginning to show a shift in disability population demographics with fewer children, but more adults, with mental retardation evident in successive contemporary generations (National Board of Health & Welfare, 1988).

The public policy issue resulting from these expectations is how to configure future services for older persons with lifelong developmental disabilities with particular concern to the 1990's? One concern is whether there will be a shifting of the character of the older population as younger age cohorts grow older, retire, and become assimilated within the nation's overall elderly population? Another concern is whether the nation's health care resources can be marshalled to accommodate a growing base of citizens with lifelong disabilities?

To examine the demographic questions that underpin these policy concerns, an analysis was undertaken of the data available from one large Northeastern state's case registry data base. This involved an examination of population trend indicators of an existing point-in-time older population of persons with mental retardation and other lifelong developmental disabilities.

METHOD

Data were drawn from the client information system data base maintained by the New York State Office of Mental Retardation and Developmental Disabilities -- the single state agency in New York responsible for developmental disabilities services. Data were first collected in 1978 as part of a major statewide needs assessment and have been updated periodically as part of the current client information system. The data represent a service population drawn from all over the state and individuals of all ages. The needs assessment survey was primarily directed toward those persons with a developmental disability receiving or in need of developmental services.

The target population included persons of all ages with conditions classified as developmental disabilities. Such conditions include autism, cerebral palsy, epilepsy, mental retardation, and a range of low incidence neurological conditions.

The instrument used was the Developmental Disabilities Information Survey (DDIS). The instrument, data set and data collection procedures are described in Janicki and Jacobson (1982).

The data base contains demographic, disability, and service utilization and need characteristic information on 61,029 individuals considered to be developmentally disabled in New York State. Of this number 28,592 (or 46.8%) were in the age categories of middle age (35 - 59) and older adult (60+). The overall age category 35+ was chosen to allow for examination of impact by data shifting. The mental retardation literature generally acknowledges age 50 as the defining point of older cohorts of this population due to instances of precocious aging, particularly among adults with Down syndrome.

To permit a finer analysis of the changes among population subgroups based upon age, data were examined by five year interval age cohorts. The following data set items were used in the analysis: age; sex; capability in mobility, hearing and vision; skill level in activities of daily living (ADLs); level of mental retardation; and physical/medical condition.

RESULTS

The study population was composed of 28,592 adults age 35 and older (46.8%) drawn from an overall population of 61,029. Age cohort data by select variables are shown on TABLES 1 - 8 and illustrated by FIGURES 1 - 4.

Cohort comparisons

Some age cohort comparisons within the study population are notable. For example, the age groups 60+ and 65+ represented 13.2% and 9.35%, respectively, of the total disabled population -- a smaller proportion than that found in the general population. Also, individuals in the younger middle-age group (ages 35 - 49; N = 15,518) represented 54.2% of older adults and 25.4% of all known cases in the registry (see **TABLE 1**). Further, this group represented about a three-fold increase (309%) against the age group 50 - 59, and about an one and one-half fold increase (166%) against the age group 50 - 69. Given current trends, it is expected that early mortality will probably not decrease this age group in any appreciable manner.

Other demographic factors are notable as well. Most marked was the number of overall middle-age individuals, those in the age group 35 - 59. This large cohort (which includes some of the "baby boomers") included some 70% of the study population (and about a third of the overall disabled population) and overshadowed the cumulative number of all persons in other older age groups. Another noteworthy finding is the relatively small number of persons falling into the old-old or frail elderly group (age 85+); they represented only about 1% of the disabled population -- much less than that in the general population.

Comparisons of the overall middle age cohort (age 35 - 59) against the traditional age categories of young-old (60 - 74; N=5,740), middle-old (75 - 84; N=1,674), and old-old (85+; N=642) showed expected increases. Successive generational groups amounted to 151.3%, 342.8% and 260.7% of each respective succeeding older group. Irrespective of future mortality trends, the expectation is that the number of older adults with mental retardation and other similar disabilities will be much greater in the future than that of the current population. This will be particularly true among older age groups.

Sex differences

General population trends indicate that the elderly female population will decline slightly within the next 30 years (NIA, 1987). By the year 2020, the female-male population between ages 65 and 74 will be almost equal. However, among the oldest-old, those 85+, females will continue to outnumber men by about three to one. From these data, female-male comparisons indicated that males outnumber females until about age 65, then females begin to outnumber males (**TABLE 2**). Major female-male ratio divergence did not occur until about age 80, with older females (85+) outnumbering males, first by about three to two, and then by about three to one. As with the greater population, those among the oldest are mostly females. However, at odds with the greater population is the finding that males continued to outnumber females until much later within the lifespan. In the general population, females begin to outnumber males by about the second decade.

Activities of daily living

With regard to basic activities of daily living (ADLs), most of the persons in the registry were reported to be relatively independent in such skills as toileting, eating, and dressing/grooming, as well in mobility. Those with ADL difficulties represent from 35% to 59%, 27% to 68%, and 43% to 86% of the age groups 60 - 74, 75 - 84, and 85+, respectively (depending upon the skill -- see **TABLE 3**). These data reveal a greater degree of impairment than among older persons in the general population in similar age groups. In the general population, some 6%, 12%, and 31% are noted as impaired among persons in the same age groups (NIA, 1987).

Across age groups noticeable decline in skill levels was observed first among cohorts in their 80's in all three areas, when the beginnings of a gradual decline became evident. Comparatively, the oldest group showed the greatest degree of skill loss. With regard to mobility, the percentage of individuals needing assistance with mobility was observed to increase earlier -- in the 60s (see **TABLE 4**).

Physical and mental conditions

Consistent with trends in the general population, noticeable shifts in incidence with age were found among the following body systems or disorders: musculo-skeletal, sense, respiratory, cardiovascular, neurological, and neoplastic. The systems with the highest incidence were musculo-skeletal, sensory, cardio-vascular, and neurological (see **TABLE 5**). There was a noticeable increase in the incidence of each of these conditions with advancing age, with one exception. With age there was a notable decrease in the incidence of neurological conditions. This decrease is most likely related to an increased earlier mortality rate among those individuals with severe disabilities.

As with the general population, unimpaired hearing and vision were reported for most of the adults. However, with advancing age, sensory impairments were more prevalent among older adults with a developmental disability. The number of individuals with impaired hearing or vision began to increase with age group 75+ (see **TABLE 6, FIGURE 2**). In addition, sensory impairments, particularly hearing, were found with greater frequency among the old-old (age 85+). This was consistent with observations in the general population, where a greater incidence of impaired hearing, rather than impaired vision, is found among older age groups.

The relative distribution of persons by level of mental retardation (mild, moderate, severe, and profound) showed that the proportion of older persons with mild retardation increased with age until the mid-seventies, and then decreased (see **TABLE 7, FIGURE 3**). Possible explanations of this trend are that among mildly mentally handicapped persons in their seventies, greater numbers are assimilated in generic systems of care and are thus potentially lost to the registry; ADL losses they experience due to age cause them to be reclassified as severely or profoundly disabled; or they may suffer a higher earlier mortality due to greater susceptibility to the stresses associated with old age.

The proportion of individuals with profound retardation showed a gradual decline with advancing age (with the exception of those among the very old -- where it increased). This phenomenon among those most retarded is likely attributable to a "survivor effect," with those most hardy living the longest. Although the pattern for those persons with moderate retardation showed little variability across age groups, the pattern for those with severe retardation showed the most variability, with a gradual increase with advancing age.

Living arrangements

When living arrangements were examined, several noteworthy trends were observed (see **TABLE 8, FIGURE 4**). There was a marked increase in the proportion of individuals with advanced age living in institutional settings (such as private and public facilities for the mentally retarded, nursing facilities, hospitals, and the like). These appear to increase in direct relation to the decrease of the numbers of individuals residing independently or with their families.

Interestingly, the proportion of individuals residing in community group homes appears relatively stable across the age cohorts. The numbers in foster family care appeared to indicate that most of the adults served are older. It appears that these community home options may offer the most stable lifespan residential care models.

DISCUSSION

It appears as if the first question -- will there will be a shifting of the character of the older population as younger age cohorts grow older, retire, and assimilate into the nation's elderly population -- needs to be answered in the affirmative. The demographic trends, evident among persons with lifelong developmental disabilities, show that the older segment of the population will increase substantially over the next 30 years and that, at least among the more functional segment, the similarities to other elderly will more evident than the dissimilarities.

Further, there are both similarities and dissimilarities between the disabled elderly population and the general elderly population. Among the older groups, female-male differences mirror those in the general population, although among the younger-older groups males will continue to be more prevalent. Influences of American population demographics, most notably the baby boom phenomenon, will also have a profound effect on the disabled population for the next 30+ years. The near future elderly, now composed of those among the middle aged, should be healthier, more capable, and expected to live longer. Trends in basic activities of daily living skills, as well as impairments or health conditions are expected to be similar to those of persons in the general population (holding constant the effects of lifelong disability).

Studies, such as that done by the National Board of Health & Welfare in Sweden, show smaller numbers of children (i.e., new cases) coming into the developmental disabilities system. Further, because of improved overall population health status, and, more specifically, improved living conditions, habilitation and work programs, and consequent greater lifespan challenge and stimulation, middle age populations are less impaired and show a lesser incidence of medical/physical conditions than the current cohort of persons in old age. It is unknown whether this is related to being healthier or younger; or a combination of the two (although in an earlier report Janicki & MacEachron, 1984, noted that same age cohorts drawn from earlier generations, showed loss of skills earlier in the lifespan). However, if it is due to being healthier (as it might be), then the implications for aging are obvious: a healthier, longer living population of adults with disabilities. Service planners will have to consider the implications of a larger older population of disabled individuals, brought up in community settings with greater range of experiences and expectations.

With regard to this population, the last question is what will be the service considerations based upon changes in these demographics? As an exercise, if one shifts the current middle age cohort by fifteen years (to about 2005) this reveals that the number of persons currently in the middle age group will become an even more markedly larger elderly population of disabled persons. This marked increase in older individuals with disabilities will have tremendous implications for specialized and generic senior programs as they try to cope with an ever increasing number of aging individuals. Certainly, shifting the population by twenty and thirty years indicates an even greater number of older individuals among the future service population. With new cases being added to the "knowns" and a probable further decreased mortality rate, the numbers of persons with a developmental disability in the future who will need some form of specialized long term care and health services will be remarkable.

The findings point to an association between increased mortality and severe disability. Given the expectations that those most disabled, especially where multiple body systems are involved, will not be among the survivors, those who will live to old age will be healthier, more active, and because of raised expectations, place even more demands upon the long term care system -- albeit ones that may be markedly different from those expressed by today's elderly. The mandates of the 1987 amendments to the Older Americans Act for outreach and integrated services should begin to prepare the aging network for the impact of major changes in the 1990's. The influx of more socially and economically needy elderly, as well as those with lifelong disabilities will have a profound effect upon the programs available in each community. Thus, serious consideration needs to be given to enhanced social support and adult day care program availability in the pending reauthorization of the Older Americans Act.

These social support programs, however, are only one facet of meeting the needs of older Americans with special needs -- the others are the long term care and health systems. Whether the nation's health care resources can be marshalled to accommodate the increases in the population of older persons with developmental disabilities can be debated. The National Institute on Aging, in its report to Congress on the personnel necessary to address the needs of the elderly through the year 2020, indicated the need to train more health professionals, as well as secure adequate funding to underwrite such training. Whether Congress will respond by preparing a sufficient workforce to accommodate the expected demand from an increased elderly population will also determine whether the anticipated increased demand for services by elderly persons with a developmental disability will be accommodated.

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TABLE 1

Census of Older Adults with Developmental Disabilities
Ages 35 - 95+

Age	Years	N	% of Older Population	% of All Population
35 - 39	1950 - 54	6704	23.4	11.0
40 - 44	1945 - 49	5155	18.0	8.4
45 - 49	1940 - 44	3659	12.8	6.0
50 - 54	1935 - 39	2577	9.0	4.2
55 - 59	1930 - 34	2443	8.5	4.0
	n=	20,538 (33.7% of all)		
60 - 64	1925 - 29	2347	8.2	3.8
65 - 69	1920 - 24	1948	6.8	3.2
70 - 74	1915 - 19	1445	5.0	2.4
	n=	5,740 (9.4% of all)		
75 - 79	1910 - 14	997	3.5	2.4
80 - 84	1905 - 09	677	2.3	1.6
	n=	1,674 (2.7% of all)		
85 - 89	1900 - 04	396	1.4	.6
90 - 94	1895 - 89	173	.6	.3
95+	1890 - 94	73	.3	.1
	n=	642 (1.1% of all)		

N = 28,592

TABLE 2

Older Adults with Developmental Disabilities
by Sex
Ages 35 - 95+

Age	N	Males		Females	
		N	%	N	%
35 - 39	6704	3646	54	3060	46
40 - 44	5155	2764	54	2391	46
45 - 49	3659	1978	54	1681	46
50 - 54	2577	1363	53	1214	47
55 - 59	2443	1344	55	1099	45
60 - 64	2347	1986	55	1061	45
65 - 69	1948	953	49	995	51
70 - 74	1445	721	50	724	50
75 - 79	997	480	48	517	52
80 - 84	677	283	42	393	58
85 - 89	396	150	38	243	62
90 - 94	173	58	34	115	66
95+	73	21	29	52	71

TABLE 3

Older Adults with Developmental Disabilities
by Reported Independence of ADLs (%)
Ages 35 - 95+

Age	N	Toileting	Eating	Dressing/ Grooming
35 - 39	6704	66	63	45
40 - 44	5155	66	62	42
45 - 49	3659	66	62	42
50 - 54	2577	66	62	43
55 - 59	2443	66	63	40
60 - 64	2347	65	62	41
65 - 69	1948	64	62	41
70 - 74	1445	64	63	42
75 - 79	997	63	66	39
80 - 84	677	58	63	37
85 - 89	396	50	57	32
90 - 94	173	38	53	19
95+	73	30	47	14

TABLE 4

Older Adults with Mental Retardation
by Reported Independence in Mobility
Ages 35 - 100

Age	N	Walks Independently	Some Help	No Mobility
35 - 39	6706	80	15	5
40 - 44	5155	80	15	5
45 - 49	3659	80	16	4
50 - 54	2577	80	16	4
55 - 59	2443	80	16	4
60 - 64	2347	76	20	4
65 - 69	1948	74	22	4
70 - 74	1445	72	24	4
75 - 79	997	67	28	5
80 - 84	677	61	35	4
85 - 89	396	49	41	10
90 - 94	173	36	51	13
95+	73	38	45	17

TABLE 5

Older Adults with Developmental Disabilities
by Physical/Medical Conditions (%)
Ages 35 - 95+

Ages	N	Musculo-Ske-letal	Special Sense	Respi-ratory	Cardio-vas-cular	Neuro-lo-gical	Neoplas tic
35 - 39	6704	9	15	1	4	30	0
40 - 44	5155	10	13	1	4	30	0
45 - 49	3659	10	13	1	5	28	0
50 - 54	2577	9	13	1	7	26	1
55 - 59	2443	11	14	2	7	24	1
60 - 64	2347	10	17	2	11	24	1
65 - 69	1948	10	14	2	13	26	1
70 - 74	1445	12	18	3	17	22	3
75 - 79	997	14	17	4	23	19	2
80 - 84	677	14	20	4	29	14	3
85 - 89	396	16	23	3	29	21	3
90 - 94	173	17	25	5	28	12	3
95+	73	26	36	7	36	7	5

TABLE 6

Older Adults with Developmental Disabilities
by Reported Unimpaired Hearing and Vision
Ages 35 - 95+

Age	N	Unimpaired Hearing (%)	Unimpaired Vision (%)
35 - 39	6704	90	87
40 - 44	5155	90	86
45 - 49	3659	89	87
50 - 54	2577	89	87
55 - 59	2443	87	87
60 - 64	2347	85	85
65 - 69	1948	85	84
70 - 74	1445	81	82
75 - 79	997	77	81
80 - 84	677	72	79
85 - 89	396	62	71
90 - 94	173	51	68
95+	73	37	64

TABLE 7

Older Adults with Developmental Disabilities
by Reported Level of Mental Retardation (%)
Ages 35 - 95+

Age	N	Mild	Moderate	Severe	Profound
35 - 39	6704	32	22	18	29
40 - 44	5155	31	21	21	28
45 - 45	3659	29	21	22	28
50 - 54	2577	30	21	22	26
55 - 59	2443	31	21	24	24
60 - 64	2347	32	25	21	23
65 - 69	1948	34	20	25	21
70 - 74	1445	36	19	26	20
75 - 79	997	33	21	27	19
80 - 84	677	28	18	27	19
85 - 89	396	28	24	28	20
90 - 94	173	27	16	33	23
95+	73	23	16	29	32

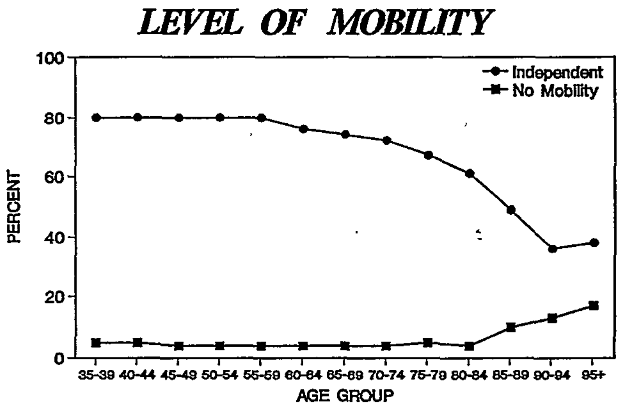

Figure 1

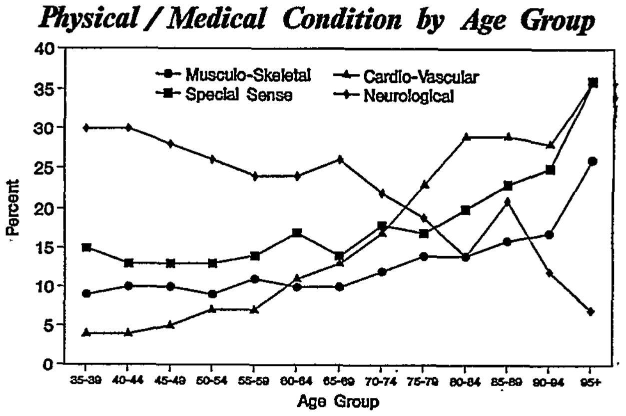

Figure 2

TABLE 8

Older Adults with Mental Retardation
by Reported Place of Residence
Ages 35 - 100

Age	N	Institutional Setting	Independently/ Family	Foster Family Care	Group Homes
35 - 39	6706	29	39	4	27
40 - 44	5155	34	31	6	30
45 - 49	3659	33	27	9	32
50 - 54	2577	33	24	11	32
55 - 59	2443	33	21	12	34
60 - 64	2347	34	17	15	34
65 - 69	1948	36	14	20	30
70 - 74	1445	42	8	23	35
75 - 79	997	43	6	25	26
80 - 84	677	53	2	25	20
85 - 89	396	60	5	18	17
90 - 94	173	72	0	13	15
95+	73	78	0	7	15

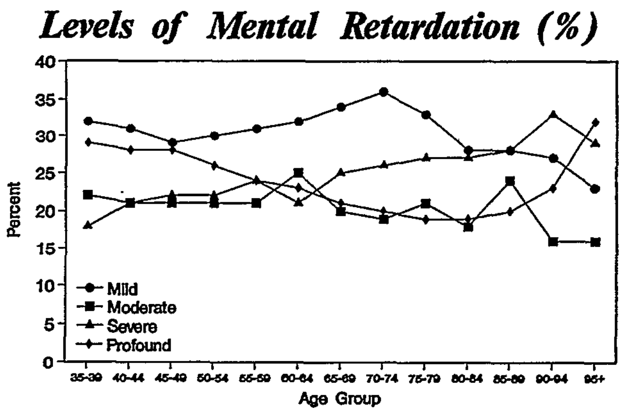

Figure 3

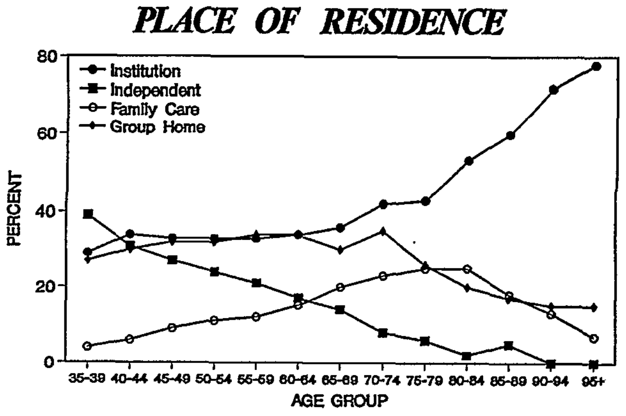

Figure 4

TRENDS IN HEALTH CARE AND OTHER SERVICE NEEDS AMONG OLDER PERSONS WITH MENTAL RETARDATION

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INTRODUCTION

This paper focuses upon some of the major issues pertaining to the appropriateness of residential placement of older persons with developmental disabilities/mental retardation (MR/DD) in nursing homes compared to facilities licensed by developmental disabilities agencies, with particular attention to health issues among this age group.

Historical Overview and Rationale

First, it is important to briefly indicate the rationale for studying this group. Currently, it is estimated that persons 65 and older comprise approximately 12% of all persons with MR/DD, similar to the nonhandicapped population. Although the **proportion** of persons with MR/DD who live to an older age is still lower than for the population in general, their **rate of increase** is the highest of all age groups, and this trend is expected to continue well into the future, due in part to improvements in health care, residential services and educational opportunities.

However, there has been little attention to planning for this age group, in part because of the historical focus on younger persons with developmental disabilities, as well as because of the fact that, until recently, persons with MR/DD usually did not live to an older age. Current policies in most states typically have not actively planned for concrete ways in which to provide for appropriate residential and day program services, not to mention health services, for this burgeoning population. In addition, older persons are the most likely to be institutionalized in some type of formal, highly restrictive setting of all persons with MR/DD, most often a nursing home or state institution for persons with MR/DD. Nevertheless, they are less retarded, on the average, than their younger peers living outside of their natural home.

It is also important to look at this group because they tend to be underserved with respect to the standards set for all persons with MR/DD. Little attention has been paid to the issues of the least restrictive environment, normalization, community integration, and active participation in activities for the purpose of improvement and/or maintenance of skills. This is partly due to the fact that it is assumed that older persons with MR/DD have significant health impairments which require care in a medically oriented facility. This perception derives in part from the historical separation of aging and developmental disabilities agencies, so that the comparison group for older persons with MR/DD has typically been younger persons with MR/DD, rather than their same age peers without MR/DD in the community or in nursing homes.

The present paper will briefly describe the changes from 1977 to 1985 in the population with mental retardation diagnoses living in nursing homes from the National Nursing Home Surveys (NNHS) of 1977 and 1985 (National Center for Health Statistics 1979; 1987). Findings from two major databases, the NNHS of 1985 and the Center for Residential and Community Services (CRCS) 1985-6 national study (Anderson, Lakin, Bruininks & Hill, 1987) of older persons with mental retardation, will then be described, with particular emphasis upon health and related conditions, in order to examine the appropriateness of medically intensive settings for the vast majority of older persons with mental retardation.

METHOD

Sample

NNHS sample: The National Nursing Home Surveys of 1985 and 1977 provide the only national statistics on the numbers and characteristics of persons with mental retardation and related conditions in nursing homes. The 1977 NNHS identified 79,812 persons as "having the condition" of mental retardation, 42,424 as having a primary diagnosis of mental retardation at the time of their last medical examination, and 37,388 as having a diagnosis of mental retardation which was not a primary diagnosis (Lakin, 1985). Restricting the sample of persons surveyed to those having a primary diagnosis of mental retardation or a primary diagnosis of epilepsy with an additional diagnosis of mental retardation [a conservative definition which minimizes confounding conditions related to aging and conditions acquired beyond the first 21 years], there were 19,841 persons with developmental disabilities aged 54 or less, 9,956 aged 55-64, and 13,958 aged 65 and older, for a total of 43,755 persons (Lakin, Hill, & Anderson, in press).

In 1985, there were an estimated 49,757 persons with primary diagnoses of mental retardation (including persons with a primary diagnosis of cerebral palsy or epilepsy with an additional diagnosis of mental retardation) living in nursing homes (all ages combined). An estimated total of 7,772 (15.6%) persons with mental retardation were under the age of 40, another 12,203 (24.5%) were aged 40-54, a similar number, 11,983 (24.1%), were between 55 and 64 years of age, and the largest group, 17,799 (35.8%) were age 65 or older.

It should be noted that the definition employed for the present analysis of the 1985 NNHS included *any* indication of mental retardation, unlike the 1977 NNHS analysis, which was restricted to the "time of the last medical examination." In addition, it included persons with cerebral palsy with additional diagnoses of mental retardation. Using the more restrictive 1977 definition, the total number of persons estimated to have primary diagnoses of mental retardation in 1985 would have been 40,539.

In addition, an estimated 33,280 persons had a mental retardation diagnosis, but had primary diagnoses other than mental retardation or another developmental disability. Among this "secondary diagnosis" group, 7.8% were aged 0-39, 14.3% were ages 40-54, 16.1% were between ages 55 and 64, and 61.8% were 65 years or older. A variety of indicators, such as the statistics on marriage and children, discussed further in the results section, suggest that a substantial number of the secondary diagnoses of mental retardation are questionable, and hence the comparisons in this paper will focus upon those considered to have primary diagnoses of mental retardation.

CRCS sample: In 1982, the CRCS conducted a national study of all residential facilities owned, operated or licensed by developmental disabilities agencies (Hauber, Bruininks, Hill, Lakin & White, 1984). A total of 15,633 facilities were identified, of which 2,291 reported one or more persons aged 60 or older. These data were used to select a 10% national sample of facilities with one or more persons aged 63 years or older in 1985. Each eligible residential facility had an equal opportunity to be selected for study, regardless of size. Facilities were stratified into four types, including foster care facilities, small group homes (15 or fewer residents), large private facilities (16 or more residents) and large public (state) facilities (16 or more residents). Information was requested on up to two residents of this age group per facility. The final sample consisted of 69 foster care facilities (29% of all facilities sampled), 88 small group homes (37%), 51 large private facilities (22%) and 27 state institutions (11%), for a total of 235 facilities (10.2% of all facilities identified as having one or more persons of this age group) and 370 residents aged 63 or older.

Analysis

The National Nursing Home Survey employs a weighted sample to estimate the numbers of persons having different characteristics who reside in nursing homes. The actual number of persons with primary diagnoses of mental retardation in the 1985 NNHS, for example, was 177, including 59 aged 65 and older and 43 aged 55-64. These persons are used to project the total estimated population, which is nearly 300 times the original sample size. In order to provide the most meaningful picture of the similarities and differences found among the sample groups, weighted estimates are used for reporting percentages, but unweighted actual samples are used for calculating statistical results. This method, which is essentially a conservative method, eliminates the problem of statistical differences being due to inflated sample sizes. In all cases, differences reported are statistically significant at the level of p <.05 or less, using unweighted samples.

RESULTS

NNHS of 1977 vs. 1985

Nursing homes are still the primary placement for older persons with MR/DD. In 1977, it was estimated that slightly over half of all persons 65 and older with mental retardation in some type of residential placement were in nursing homes, with the remaining half about evenly divided between state hospitals and community residential facilities such as group homes and foster care. Between 1977 and 1985, there were few changes for this population. The size of the total population of persons with a primary diagnosis of mental retardation in nursing homes was stable, although their percentage of the total population within nursing homes declined from 3.6% to 2.7% due to the substantial increase in total numbers of older persons in general in nursing homes over this time period (Lakin et al., in press).

Over this same time period, however, there were few obvious reforms in nursing home care. In 1977, only 12% of persons with MR/DD were admitted for a medical reason, nor were they receiving specialized medical treatments such as tube feedings. Similarly, in 1985, exceedingly few persons were admitted primarily for medical reasons (specialized medical treatments could not be ascertained on the 1985 NNHS). In both years, there was a relatively low prevalence of substantial physical and sensory limitations. Nursing home admissions could not be justified by services rendered in either year. The generally low level of services reported in 1977 for older persons with MR/DD (Anderson et al., 1987) persisted in 1985.

Age-related Differences

Typically, older persons with MR/DD have been compared with their younger cohorts with MR/DD, and have been found to have more chronic conditions, poorer health, greater use of medication, and other indicators suggesting a greater need for health care among the former. Within nursing homes, however, age-related differences are less clear. The oldest (65+) persons with MR/DD were more likely than younger persons with MR/DD to be diagnosed as having senility/organic brain damage (14% vs. 0% of persons 0-39 years), had less favorable health ratings, with only 47% being rated as having excellent or good health compared with 70-75% of other age groups with MR/DD, were more likely to have certain chronic conditions, including diabetes, stroke and heart disease, and were more likely to be considered to have an anxiety disorder. The youngest (age 0-39) persons with MR/DD, however, were more likely to have Down Syndrome, and were reported more often than older persons with MR/DD to be physically abusive, to have impaired judgment, to have difficulty with bowel control and to need assistance to go outside the grounds.

There were no statistically significant differences attributable to age in the type of residence they had lived in prior to placement in a nursing home. An estimated 29% of all persons with primary diagnoses of mental retardation in nursing homes had lived in private facilities, most of which were their natural family homes, and 63% had lived in health, mental health or mental retardation institutions.

There were no statistically significant differences due to age in any demographic variables, including sex, race, ethnic origin, marital status, whether the individual had children or not, and urban/rural location of the nursing home. There were significant differences in services, however. Persons 65 and older with mental retardation were particularly neglected with respect to services. This group was less likely than persons under the age of 55 to have received therapy services, speech and hearing services, mental health evaluation or treatment from either an M.D. or a psychologist, social services, and "other" therapeutic services.

Older Persons With and Without Mental Retardation in Nursing Homes

Demographic characteristics: Older persons without mental retardation ("elderly" persons) were compared with persons having primary diagnoses of mental retardation (including persons with primary diagnoses of a developmental disorder such as cerebral palsy or epilepsy and an additional diagnosis of mental retardation) and persons with secondary or "other" diagnoses of mental retardation (persons with primary diagnoses other than mental retardation or a developmental disability).

The "elderly" population was 75% female, but females accounted for only 60% and 59% of persons with primary and secondary mental retardation respectively. Racial and ethnic differences failed to reach statistical significance, ranging from 93 to 99% white among the three groups; Hispanics accounted for from 2.6% to 4.8% of the nursing home population.

There were vast differences in marital status, however. Only 12% of the "elderly" population had never been married, compared with 91% of persons with primary and 55% of persons with other diagnoses of mental retardation. Similarly, 68% of the "elderly" population had children, compared with only 4% of persons with primary and 27% of persons with other diagnoses of mental retardation. The group with primary mental retardation diagnoses closely resembles their counterparts in facilities licensed by developmental disabilities agencies in the CRCS survey, 94-98% of whom had never married, and is also consistent with other samples of persons with developmental disabilities.

The secondary or "other" mental retardation group, however, is quite dissimilar in their marital history, suggesting that the mental retardation diagnosis may not have been appropriate for a substantial number of persons in this category. When coupled with an additional finding, that the highest rates of "mental illness of an organic nature" occurred among those persons diagnosed as having nonprimary, or "other" mental retardation diagnoses, it suggests that Alzheimer's, senility, neurological damage and a variety of similar disorders may be mistaken for mental retardation among many persons with "other" diagnoses of mental retardation. In order to avoid confounding mental retardation with conditions which may affect mental functioning but which are not considered mental retardation, the comparisons indicated below will be between "elderly" persons (with no mental retardation) and persons with primary mental retardation diagnoses.

Slightly over two-thirds (68%) of "elderly" persons were living in metropolitan area nursing homes, compared with only 48% of persons with primary diagnoses of mental retardation. Persons with secondary diagnoses of mental retardation closely resembled the "elderly" group, with 65% in urban areas.

Admitting conditions: The primary admitting condition indicated for persons with a diagnosis of mental retardation, regardless of age, was mental retardation or a developmental disability, with a small percentage having "other nervous system diseases". Less than 5% had other health-related reasons as the primary reason for admission (see Graph #1).

When all admitting conditions were combined for persons 65 and older, persons with primary diagnoses of mental retardation were less likely than "elderly" persons to have mental illness of an organic nature, Parkinson's disease, heart disease, cerebrovascular disease, respiratory disorders, arthritis or other nonspecific disorders. They were more likely than their "elderly" counterparts to have only two disorders as one of their admitting conditions, epilepsy and "other" nervous system disorders. Differences failed to reach statistical significance for other conditions, including diabetes, endocrine system disorders and others.

Current conditions: When all current conditions were combined, the situation was similar, with "elderly" persons having higher rates of mental illness of an organic nature, Parkinson's, cerebrovascular disease and arthritis, with heart disease just failing to reach statistical significance; persons with primary diagnoses of mental retardation had higher rates of epilepsy and other nervous system disorders.

Figures from the National Health Institute Survey of 1985 (National Center for Health Statistics, 1986) of persons in general 65 and older living in the community as well as from the CRCS survey of persons 63 years and older with mental retardation living in MR/DD facilities in 1985 (Anderson et al., 1987) suggest that the most prevalent health conditions among this age group were high blood pressure, arthritis and heart disease. Among the (1985) nursing home sample, heart disease was the most frequent health condition upon admission indicated for "elderly" persons (37% vs. 17% of persons with primary mental retardation diagnoses). Cerebrovascular disease was rare among all groups except "elderly" nursing home residents, 20% of whom were so diagnosed compared with 4% of persons 65 and older with primary mental retardation diagnoses; mental illness of an organic nature and other nervous system disorders also occurred infrequently.

In the CRCS sample, between 20 and 28% were reported to have high blood pressure, depending upon the type of residential setting, compared with 39% of older persons in general living in the community; between 18 and 26% of the CRCS sample were indicated as having arthritis, compared with 47% of the older population in general, and only 16% in each of the four facility types were reported to have heart disease, compared with 30% of older persons in the community. Statistical tests were performed within the nursing home population groups and within the CRCS sample of persons in different facilities (foster care, group homes, large private institutions and state institutions), but not between the nursing home groups and the CRCS groups, due to different sampling and survey methods. However, a visual examination suggests that persons 65 and older with primary diagnoses of mental retardation are similar to their same age peers in the community in their rates of heart disease, higher than their peers in facilities operated by developmental disabilities agencies, and lower than "elderly" persons in nursing homes, and that they have lower rates of high blood pressure than all of these groups (see Graph #2).

Health-related limitations: Only 9% of "elderly" persons in nursing homes and 4% of persons with primary diagnoses of mental retardation aged 65 and older were said to have a condition influencing their health status. In the CRCS survey, between 6 and 28%, depending on facility type, were said to have a health problem which had a major effect on their activities. Among persons 65 and older in the community, 24% were said to have a limitation in a major activity. Substantial differences in the questions asked in these three surveys render them incomparable.

Health status: In the NNHS of 1985, 37% of "elderly" and 47% of persons with primary diagnoses of mental retardation were said to have excellent or good health (differences were not statistically significant). Community respondent's assessment of their health status (age 65 and older and living in the community [National Center for Health Statistics, 1986]) was excellent or good 69% of the time.

Hospitalizations: In the CRCS survey, between 16 and 22% had been hospitalized in the year prior to the survey, depending on facility type, for an average of between 6 and 13 days. Among persons in general living in the community, aged 65-74 years, 16% had been hospitalized, for an average of 12 days. NNHS data is not comparable.

Physician visits: In the CRCS sample, all but state hospital residents averaged between 7 and 10 visits per year; state hospital residents averaged 18. Persons 65-74 in the community averaged 8 physician visits per year. These data were not obtained on the NNHS.

Other health indicators: In the NNHS sample, "elderly" persons were more likely to have been admitted from general hospitals than persons with primary mental retardation diagnoses, among whom this was atypical.

Summary of health indicators: Although older persons with mental retardation have more health impairments than younger persons with mental retardation in general, these differences are not as clear within the nursing home setting. "Elderly" nonretarded individuals in nursing homes have higher rates of a number of chronic, disabling health conditions than older persons with primary diagnoses of mental retardation, with the exception of certain conditions related to developmental disabilities. Although direct comparisons are not possible, it appears that there is considerable overlap between older persons with mental retardation in nursing homes and their counterparts in facilities licensed by developmental disabilities agencies, although, when differences occur, they tend to favor persons in MR/DD facilities.

In addition, older persons in both MR/DD facilities and in nursing homes with primary mental retardation are similar to older persons in general living in the community in many of their health needs, conditions and limitations. It appears that other factors in addition to health status may have influenced the placement of a significant number of older persons with mental retardation into nursing homes. Hence, factors which are often associated with higher levels of care needs such as sensory impairments, mobility and self-care limitations were examined, as well as behavioral indicators and psychological conditions.

Sensory impairments: Most persons 65 and older, regardless of facility type or diagnosis, had no visual problems, with highly similar findings among nursing home residents and residents of facilities licensed by MR/DD agencies. However, there were substantial differences in the proportions of "elderly" persons in nursing homes with glasses (67%) and the number of persons with primary mental retardation diagnoses with glasses (32%), which were not clearly related to visual acuity differences. Similar differences were found between persons in foster care, group homes and large private facilities when compared with state institution residents, the latter being significantly less likely to have glasses.

Among nursing home residents, there were no significant differences in the use of a hearing aid (7% of "elderly" and 2% of persons with primary mental retardation diagnoses.)

Activities of daily living: Self-care and mobility limitations are somewhat difficult to assess, because they may be confounded with institutional practices. For example, if a facility emphasizes independence, skill maintenance and improvement, staff are more likely to expend efforts to train individuals to be self-sufficient. If a facility emphasizes care and medical support, staff efforts may emphasize other values, such a patient safety and efficient delivery of services. In brief, the habilitative and medical emphases within MR/DD facilities and nursing homes respectively may result in different outcomes for clients as well as different perceptions of their abilities. The individual who might be trained to eat independently in one facility may be fed in another. With these caveats in mind, i.e., that institutional practice and need may be confounded, the findings from the different facilities are presented.

Nearly two-thirds (63%) of "elderly" persons 65 and older were reported to need assistance in transferring from their bed, compared with a significantly lower number (40%) of persons of this age with primary mental retardation diagnoses. With the exception of state hospital residents, this appeared to be significantly higher than for persons in foster care, group homes and large private facilities (state institution residents required significantly more assistance in this task than other persons in MR/DD facilities). Similarly, significantly greater proportions of "elderly" persons (56%) required assistance in walking than did nursing home residents with primary diagnoses of mental retardation (31%), but the latter figure was similar only to state institution residents, who differed considerably from residents of other MR/DD facilities (see Graph #3). Within nursing homes, "elderly" residents were more likely than persons with primary diagnoses of mental retardation to be chairfast (44% compared to 30%), to require assistance in transferring from a bed or chair (63% vs. 40%) or in walking (56% vs. 31%), to need assistance in walking with equipment (63% vs. 38%), and to not use the toilet (e.g., because of having an ostomy/catheter (12% vs. 1.5%).

Although direct comparisons are not possible, a visual examination suggests that, with the exception of state hospital residents, there were sizable differences in needs for assistance in bathing, toileting, dressing and eating between nursing home residents, who were reported to be highly similar to one another, and residents of MR/DD facilities. However, it must be recalled that this may reflect institutional practice more than need.

Behavior problems: Persons with primary diagnoses of mental retardation, aged 65 and above, were more likely than their nonretarded age peers in nursing homes to display two of six reported behavior problems (screaming and stealing). The prevalence of these two problems was 26% and 10% respectively for persons with primary mental retardation, compared with 11% and 2% respectively. The CRCS study findings are incomparable on this issue, since the behaviors measured differ considerable from those assessed on the NNHS.

Psychological and other conditions: "Elderly" persons in nursing homes had a higher incidence of depression (14% vs. 3%), anxiety disorders 13% vs. 7%) and senility/organic brain syndrome (48% vs. 14%) than persons with a primary diagnosis of mental retardation in nursing homes. The only condition in which the latter exceeded the former was in the diagnosis of schizophrenia, diagnosed in 10% of the latter and 3% of the former. The incidence of chemical dependency, severe mental illness, depression, anxiety, epilepsy, and Down Syndrome was similar among older persons with mental retardation in nursing homes and in MR/DD facilities.

Services

"Elderly" persons were more likely to have received physical therapy than persons with a primary diagnosis of mental retardation, but the reverse was true for recreational therapy, speech and hearing therapy and mental health evaluation or treatment by a physician. However, the overall level of these services was low. Among persons with a primary diagnosis of mental retardation aged 65 and older, 18% received recreational therapy, the most common therapeutic service in the month prior to the survey (a decline from 1977), 10% received occupational therapy, 10% received mental health evaluation or treatment by an M.D. other than a psychiatrist, and only 2% received physical therapy. An additional 9% received mental health evaluation or treatment by a psychiatrist or social worker, not one person with a primary diagnosis of mental retardation was seen by a psychologist during this time period, and 16% received social work services.

In contrast, among persons of this age group in facilities licensed by developmental disabilities agencies, 12% in all but foster care received physical therapy, between 14 and 29%, depending on facility type, saw a psychologist, and between 50 and 69% saw a social worker over a month's time, indicating a much higher level of services in these facilities.

DISCUSSION

These findings raise a number of questions. One of the questions concerns the adequacy of the diagnoses of persons with mental retardation in nursing homes. As previously discussed, there is a substantial segment of the nursing home population which has mental retardation listed as an additional (nonprimary) medical condition for whom this diagnosis appears to be dubious. In addition, the extraordinarily low reported rate of arthritis as a current condition for persons 65 years of age and older with primary diagnoses of mental retardation, 5%, compared with 20% of "elderly" nonretarded persons in nursing homes, between 18 and 26% of persons in MR/DD facilities, and over 45% of older persons living in the community, is peculiar, given that this disorder is one of the most prevalent conditions among this age group in general. Similarly, the reported rate of use of glasses among persons with primary diagnoses of mental retardation aged 65 and older was surprisingly low, with only 32% wearing them, compared with twice this number in the older nursing home population without mental retardation. Differences in the incidence of severe visual problems do not explain these findings. The low reported rates of high blood pressure among this group, less than half that reported in any of the MR/DD facilities and less than one-third that of older persons in the community, is also puzzling. It is possible, although the data are not sufficiently detailed to be certain of this, that insufficient attention has been paid to certain health and visual problems of persons with mental retardation in nursing homes.

Second, it is not apparent that most persons with mental retardation in nursing homes are in need of medically intensive services. The primary reason for admission was rarely health-related, but rather was that the individual had a developmental disability, including mental retardation. On most health measures, they appeared to be healthier, and more mobile, than "elderly" persons without mental retardation in nursing homes, and in many respects they overlapped with persons living in MR/DD facilities.

Third, the availability of services for older persons with mental retardation in nursing homes did not justify their placement in these facilities, since they received considerably fewer services in nursing homes than their same age peers in MR/DD facilities.

It is undoubtedly the case that some older persons with mental retardation are best served within a nursing home environment. However, taken as a whole, the data suggest that availability, rather than suitability, may have been the major determinant for residential placement of many older persons with mental retardation. They were more likely than their same age nonretarded peers in nursing homes to be living in rural areas. From the CRCS survey, it was apparent that foster care, which accounts for only a very small proportion of residential placements for this age group, and state institutions, which have been steadily depopulating over the last decade, are the predominant care models in rural areas, with group homes concentrated primarily in metropolitan areas. Given the pressure to deinstitutionalize, this increases the need for suitable alternatives for older persons with mental retardation, who tend to be the last persons considered for smaller, community based living options. Flexible alternatives, such as foster care or small group homes with effective case management and strategies to manage intermittent health care needs as they arise could assist in addressing this need. Specific, proactive planning for the needs of this population could be immensely helpful in meeting the spirit of the recently enacted Omnibus Reconciliation Act of 1987 (P.L. 100-203) (OBRA) legislation, which otherwise may be implemented in ways quite unlike those imagined by its originators.

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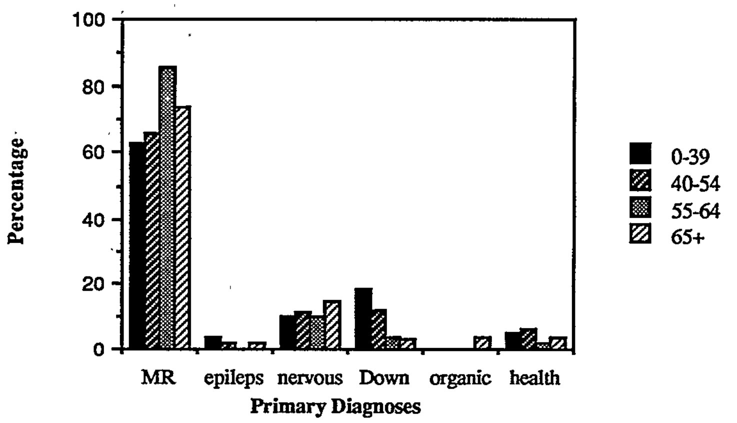
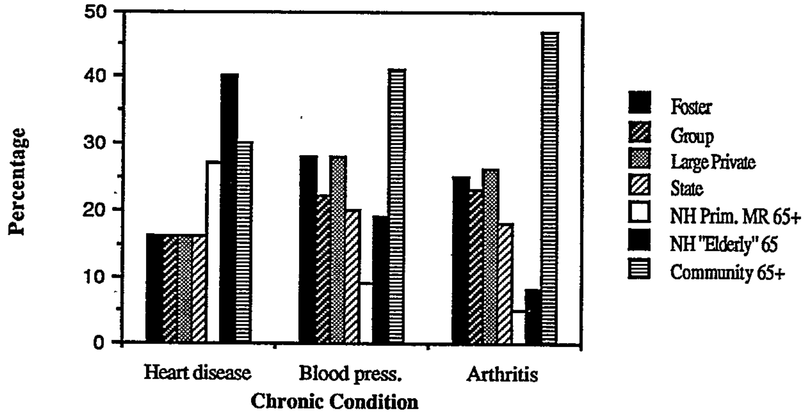
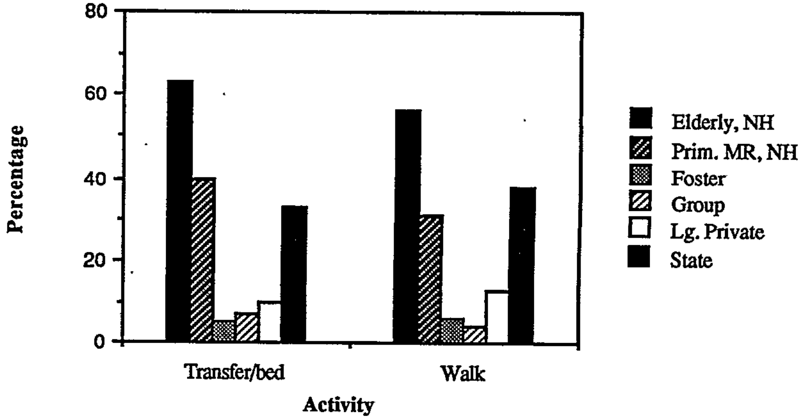

Primary Admitting Condition of Persons with MR in Nursing Homes by Age

GRAPH 1


Major Chronic Conditions of Oldest Age Groups by Residence

GRAPH 2


Mobility Assistance Required by Oldest Age Groups by Residence

GRAPH 3

CHANGES IN DISABILITY AMONG PERSONS WITH ARTHRITIS

Lois M. Verbrugge, The University of Michigan

Abstract

This paper reports rates of change over two years in physical and social disabilities for older U.S. adults with arthritis (largely osteo) vs. those without arthritis. The data source is the Longitudinal Study on Aging conducted by the National Center for Health Statistics (NCHS). It has information on 12 physical functions (gross mobility and specific motions or strengths) and 11 social ones (personal care and household management activities) in 1984 and 1986, for a national probability sample of persons 70+ years old. Of 4714 community dwelling respondents (1984): 3963 were still community dwelling in 1986, 150 were institutionalized, 604 were dead. Using the NCHS definition of Arthritis (ICD codes for osteo, rhematoid, spinal, and rare forms) based on self-reported diagnoses and symptoms, 50.6% of the population 70+ had arthritis in 1984. We study disability transition matrices that show shifts from t0 (1984) status to t1 (1986) status.

Results: (1) Rates of physical and social disabilities are higher for arthritis persons than nonarthritis ones, at both t0 and t1. (2) Among <u>nondisabled</u> people (at t0), those with arthritis are more likely to become disabled over two years than their nonarthritis peers. (3) Among <u>disabled</u> people (t0), those with arthritis are more likely to regain social functions, but less likely to regain physical ones, than nonarthritis people. This reflects arthropathies' enduring consequences on physical performance, countered by adaptations so that social tasks can still be done. (4) Regardless of initial disability, nonarthritis people are more likely to be institutionalized or die in two years than arthritis people.

In sum, arthritis people experience more changes in function --both loss and restoration-- over time than other people. Disability is a particularly dynamic, rather than static, experience for them over their extended lives.

Introduction

Chronic health problems tend to accumulate for individuals as they age. Once conditions have crossed some threshold of severity (such as professional diagnosis), they are typically permanent features of a person's life. Their most frequent consequences are <u>not</u> death, but instead symptoms and disability.

In contrast to the "once gained, never lost" character of chronic conditions, disability is a highly dynamic feature of health. It fluctuates over time in response to disease activity and to medical and personal interventions. It can increase as a disease progresses and as buffers inserted by medicine or self prove ineffectual. It can decrease as drugs slow the disease course or symptoms, assistive devices are obtained to enhance mobility and task performance, physical therapy restores movement abilities and strength, etc.; in short, as inserted buffers prove successful.

To track the real-world dynamics that people experience, longitudinal data are now being collected for middle-aged and older people. Their levels of physical, social, cognitive, and emotional functioning are measured at two or more time points.

This paper looks at changes in physical and social disability over a two year period among U.S. adults ages 70+ who have arthritis, and compares them to nonarthritis people those ages. It asks if the dynamics of disability for arthritis people are special in certain ways, compared to people with other kinds of health problems (not specificially differentiated in this analysis).

Arthritis

Why select arthritis for special attention?

Arthritis is the highest prevalence chronic condition for middle-aged and older people in the U.S. It surpasses all other nonfatal conditions in prevalence, and all fatal ones as well, based on National Health Interview Survey data. By gender, Arthritis ranks as the most common condition for middle-aged women (ages 45-64) and older women (ages 65-74, 75+), and ranks first or second for men those ages [1-2].

Arthritis is the most frequently cited cause of activity limitations by middle-aged and older women, and first or second rank by men those ages. Specifically, the rates are "conditions causing limitation in major or secondary activity, per 1,000 population". These rates are actually a function of two components: (a) a condition's prevalence and (b) its disabling potential (impact among people who have the condition). Elsewhere, we have shown that the reason arthritis is the leading limiter stems from the combination of (a) very high prevalence and (b) moderate impact compared to other chronic conditions [3].

Not surprisingly, the leading daily symptoms in mid and late life are musculoskeletal ones [4-5]. The proportion of musculoskeletal symptoms attributed to arthritis, rather than to injury or overextertion, rises with age.

The importance of arthritis in people's everyday lives is not witnessed in outpatient medical care settings. There, cardiovascular and neoplasm problems ascend and surpass arthritis in importance. This is especially true at middle ages, reflecting the earlier stage of arthritis and relatively little botheration it poses for most people. Arthritis is even less evident in short-stay hospitalizations, and it seldom appears as an underlying cause of death.

In short, we select arthritis because of its great frequency in late life, and because its impact is concentrated on living (thus, disability) rather than dying.

Analysis Questions

There are three central questions. One is static: (1) Do Arthritis people have more problems in physical and social functioning than Nonarthritis people? We compare the two groups at a given time point. The other questions are dynamic: (2) Are Arthritis people more likely to acquire functional difficulties over time? (3) Are disabled Arthritis people more likely to regain functional abilities over time? The former question concerns Becoming Disabled, and the latter Become Nondisabled. We compare the experience of Arthritis and Nonarthritis people over time.

Data Source

The data source is the 1986 Longitudinal Study on Aging (LSOA). It is a followup survey of older persons (ages 70+) who were initially interviewed in the Supplement on Aging (SOA), a component of the 1984 National Health Interview Survey (NHIS) conducted by the National Center for Health Statistics (NCHS).

The Longitudinal Study on Aging has a probability sample of the U.S. civilian population ages 70+ in 1984 (N=5151). In 1986, interviews were obtained for 4717 of these persons. At that time, 84% (3963) were still community dwelling, 3% (150) were institutionalized, and 13% (604) were deceased. We call 1984 t0 and 1986 t1.

Arthritis status (its presence or absence) is based on self-reports of chronic conditions/symptoms in NHIS for which interviewers probe details. Later, medical coders assign the most specific International Classification of Diseases (ICD) code possible to each condition, using all the information elicited. The medical coding scheme is conservative; for example, an ICD code for Arthritis occurs only when the respondent states that a physician or physician's assistant named the condition as "arthritis" (just that name or a more specific one such as osteoarthritis), or when a nondiagnosed respondent uses that name and all additional details about the condition corroborate it. [For readers familiar with the SOA, we do not use its direct Yes/No question about arthritis presence, but instead the ICD codes generated from the Condition Records.]

We define Arthritis in the same way NCHS does for its published prevalence rates. The ICD-9 codes included in the title Arthritis are 711.0,9; 712.8,9; 714-716, 720.0, 721 (no decimal entries here means all fourth digits 0-9 included). The great majority of ICD codes assigned in the survey pertain to osteoarthritis (715 Osteoarthritis & allied disorders; 716.9 Arthropathy, unspecified - coded for the name "arthritis" when no more specific form of arthropathy is evident). Thus, our results can be read as reflecting the impact of osteoarthritis, the most common arthritis of all.

Arthritis status is determined at t0 but not t1. This lets us look at changes for people who do or do not have the disease at the start of the data. Incident cases (people who acquire arthritis over the two years from 1984 to 1986) are not ascertained, so we cannot see their (possibly special) pace of disability. Such people remain in the Nonarthritis group of this analysis. This situation restricts but does not damage the analysis. It simply signals the data set's 'thinness' of disease information relative to its disability information.

Arthritis rates derived from the SOA show a sharp increase with age (the SOA sample starts at ages 55; rates level off at the most elderly ages 85+) and are notably higher for women than men at all ages [2]. Rates of Osteoarthritis (ICD 715, 716.9) follow the same age and sex patterns.

The LSOA sample is limited to persons ages 70+ in 1984. Just over half of them (50.6%) have ICD-coded Arthritis. The remaining 49.4% are the Nonarthritis group.

There are important subgroups of Arthritis people and also of Nonarthritis people. The Arthritis people are a collection of (a) those who have just arthritis and no other chronic condition (9.9% of the Arthritis group), and (b) more typical ones who have additional chronic problems (90.1%). The Nonarthritis people are a mix of (a) very healthy people who have no chronic problems at all (18.4% of the Nonarthritis group), and (b) more typical people who do have one or more chronic conditions (81.6%). Some of our comparisons are for the whole Arthritis vs. Nonarthritis groups, and some are for the four subgroups. The subgroups' distribution in the LSOA sample is: Zero Chronic Conditions (9.1%), Arthritis Only (5.0%), Other Chronic Conditions Only (40.3%), and Arthritis Plus Other CC (45.6%). For brevity, we refer to the subgroups as Zero CC, Arth Only, Other CC, and Arth Plus.

The results do not have controls for age, race, or sex differences among groups. This is purposeful since we want the results to reflect real-world collections of people as they appear in clinical and community settings. In fact, the Arthritis and Nonarthritis groups scarcely differ in age and race distributions; they do differ in sex distribution (69% female for Arthritis, 53% for Nonarthritis). The subgroups show age differences (age increases from Zero CC to Arth Plus), but scant race differences; the two arthritis subgroups are more female.

All results are weighted to adjust for disproportionate sampling and response. Thus, the arthritis rates and disability levels stated are estimates for the national population.

Disability

We define disability as difficulty in performing a given physical or social function due to a chronic condition. This perspective differs from many federal statistics on disability, which refer to dependency; that is, having personal assistance to get a physical or social function done. We prefer difficulty as the outcome of interest since it indicates the impact a chronic condition has on a person's intrinsic capability to do a task. By contrast, dependency really tells us about use of a particular kind of buffer placed in the pathway between the condition and disability --thus, an effort to diminish difficulty. (The federal rationale for using dependency items is that they reflect 'severe difficulty'. I prefer direct questions about degree of difficulty for this, and use personal assistance questions to indicate buffers.)

This analysis assumes a hierarchy of outcomes as follows: No Difficulty-Community Residence is the least disabled status, Yes Difficulty-Community Residence is next, Institutional Residence is more disabled, and Dead is still worse (more disabled). This scaling of No, Yes, Institional, Dead is common in contemporary analyses of disability.

Twelve physical funtions are studied: 2 pertain to mobility, and 10 to basic motions and strength of upper and lower extremities. Eleven social functions are studied: 5 pertain to personal care (commonly called ADLs, or basic activities of daily living), and 6 to household care (called IADLs, or instrumental activities of daily living).

Levels of Disability

We begin by comparing levels of physical and social difficulty for Arthritis versus Nonarthritis people in 1984 (when all were community dwelling) and in 1986 (for interviewed survivors). TABLE 1 shows the comparisons.

1. Arthritis people have more difficulty in physical and social functions than Nonarthritis people do, both at t0 and also two years later (t1). At the outset, disability rates for Arthritis people are typically about twice those for their Nonarthritis peers. A key reason for the differential is the higher overall morbidity in the Arthritis group. The specific contribution of arthritis to disability is considered elsewhere [1-2,6].

2. The gap between Arthritis and Nonarthritis people is larger at t0 than t1. This narrowing with time is partly due to higher mortality in the Nonarthritis group (see next section) --a greater siphoning off of persons with serious fatal conditions that caused substantial disability at t0. This makes the two surviving groups more similar in disability than before.

3. Disability increases over the two years for both the Arthritis and the Nonarthritis groups. (Note that in 1984 all are living in the community, and in 1986 most are living in the community and some in institutions.) The increases are not consistently greater for one group than the other. Increased disability reflects overall (net) worsening health among survivors.

Further analyses show the problems researchers face in interpreting changes in disability over time: Levels of disability were computed for people who remained in the community (residing there in both 1984 and 1986). (They may not have been there throughout the two years so the term 'remain' is not entirely accurate; but it suffices here to convey the continued ability of this group to reside there.) They can be compared to the people who survived but became institutionalized (community dwelling in 1984, institutional residence in 1986). We call the groups Still Community Dwellers and Institutionalized, respectively. Results:

4. People who continue residing in the community show larger increases in disability than those who become institutionalized (data not shown; available on request). This seems counterintutive at first, but the reason is simple: Disability levels (t0) are already high in the later Institutionalized group, and they do not rise much thereafter. This is called a 'ceiling' effect. By contrast, disability levels are low for the Still Community Dwellers group, giving them much more room for loss; they experience it in the two years of observation.

Procedures for Studying Change

To assess changes in disability, we prepared transition tables. A transition table is a crosstabulation of t1 (1986) disability status by t0 (1984) status. With the data thus arrayed, we ask two questions: what happens over the two years to each t0 group --the people initially nondisabled, and the people initially disabled?

Disability transition tables were estimated for the whole LSOA sample, called Initial Community Dwellers (t0)(FIGURE 1, left side). The outcomes of interest for t1 are No Difficulty, Yes Difficulty, Institutional, Dead.

Tables were also estimated for the subgroup fortunate enough to remain in the community, called Still Community Dwellers (t1) (FIGURE 1, right side). Here the outcomes of interest at t1 are No Difficulty and Yes Difficulty.

These transition tables were produced for each of the 12 physical and 11 social functions.

Changes in Disability

We begin by comparing Arthritis and Nonarthritis people. Differences between them are not tested for statistical significance. Instead, it is the power of consistent results --seeing the same pattern of differences for many variables-- on which our conclusions rely. TABLE 2 shows results for four items on the left side (others available on request).

We begin with Initial Community Dwellers (the whole LSOA sample).

1. Among nondisabled persons (No) at t0: Arthritis people are more likely to acquire physical and social disabilities over a two year period than Nonarthritis people. (To be entirely clear: For a given function, Arthritis people are more likely to become disabled in the time interval.) This results reflects, I believe, the specially fast pace of disability onset for musculoskeletal conditions relative to other types. Musculoskeletal diseases have prompt implications for physical abilities in the affected regions and for social tasks that rely on those physical abilities.

2. Among disabled persons (Yes) at t0: Arthritis people are much more likely to regain social functions, but Nonarthritis people are more likely to regain virtually all physical ones. The sole exception in the physical domain is walking; Arthritis people who start out with

trouble walking do improve more often in this critical function. But physical functions that require endurance, strength, or dexterity are less likely to improve for them than for other people. These results reflect the enduring nature of physical dysfunctions but remediable nature of social ones for musculoskeletal conditions, relative to other chronic conditions. Stated otherwise, Arthritis people find ways to overcome their social disabilities --by reducing the task and its physical demand, by making accomodations in exactly how they accomplish a task, by drugs to control pain--, though the basic physical dysfunction persists.

3. Regardless of initial disability status (No or Yes at t0): Nonarthritis people are more likely to be institutionalized or, especially, to die over a two year period. This reflects the nonfatal nature of osteoarthritis, compared to other chronic conditions common in late life.

These results for Initial Community Dwellers are repeated for Still Community Dwellers (data not shown). Only results #1 and #2 are applicable for Still Community Dwellers.

To see changes attributable to Arthritis more precisely, we compared three subgroups: Arth Only, Arth Plus, and Other CC. Everyone in these subgroups has health problems --Arth Only have the fewest (just 1.0 chronic condition), Other CC are next (average 2.5), and Arth Plus have the most (4.3). The Zero CC group is dropped here because of its extremely low levels of disability. TABLE 2, right side shows four transition tables for the subgroups.

The results stated above continue to hold true. (1) People with just arthritis and nothing else (Arth Only) are more likely to incur physical disability than people with other chronic conditions (Other CC), despite the fact the arthritis group is on average less 'sick'. They are less likely to develop social disability. Arth Plus people have higher incidence of all kinds of disability than Other CC. (2) Arth Plus people show greater recovery of social functions and walking, and less recovery of all other physical functions, than the Other CC group. (There are too few cases of Arth Only people for these comparisons.) (3) Both Arth Plus and (limited data) Arth Only have much lower risks of institionalization and death compared to Other CC people. These results buttress our explanations about the distinctive consequences that Arthritis has for people's functioning over time.

Discussion

We now answer the initial questions:

(1) Do Arthritis people have more problems in physical and social functioning than Nonarthritis people? Yes.

(2) Are Arthritis people more likely to acquire functional difficulties over time? Yes. They acquire both physical and social disabilities at a faster pace than Nonarthritis people do.

(3) Are disabled Arthritis people more likely to regain functional abilities over time? For social functions, yes. And for basic mobility (walking), yes. But not for other physical functions that require endurance, strength, or dexterity. Medical interventions and personal accomodations apparently succeed better in restoring social capabilities to Arthritis people than to those with other kinds of chronic conditions. But medical and personal inputs are less able to restore physical capabilities to Arthritis people. The dividing line between social and physical changes reflects first, arthritis' primary and enduring impact on musculoskeletal function, compared to other diseases whose primary impact is elsewhere in the body; and second, the ability of Arthritis people to make accomodations in face of the disease so they can 'undo difficulties' and return to social tasks they value --albeit in a more limited or roundabout manner than before.

Health Services for the Disabled

Understanding risk factors for disability, and differentials in disability levels and trajectories, is called the 'epidemiology of disability'. The researcher's interest is not etiology of disease, but 'etiology' of disability among persons with a target disease. A conceptual framework that helps us think about the epidemiology of disability is shown in FIGURE 2. Disease status sits at the left of the diagram; it is the starting point whose implications are studied. The two principal kinds of disability (physical and social) ensue to the right. Interventions that are inserted to blunt the pathways from disease to disability are arrayed at the top and bottom.

Health services are buffers. They are medical and other health professional activities aimed at the main pathway that links disease with disabilty. We conclude this paper with comments about where health services for arthritis now succeed.

(1) Primary Prevention - Preventing Disease. Can physicians help people prevent arthritis onset? The question is essentially moot. Knowledge about etiology of osteoarthritis is modest, and physician-patient encounters relevant to arthritis seldom occur before disease onset and symptoms.

(2) Secondary Prevention - Preventing Disability Onset. Can physicians and other health professionals help Arthritis people avoid disability altogether? This is an increasing concern of rheumatologists, geriatricians, and other physicians caring for persons with arthritis. To prevent disability completely, one must be able to detect arthritic changes (the pathological process) early. This seldoms happens in regular medical care, and its ethical merits would be questioned by physicians since it requires repeated examination and radiographs for many joints (esp. hands, knees, hips, spine) when there may be no manifest symptoms or dysfunctions. Even if early detection occurs, physicians can do little more than caution patients about overuse of their affected joints.

(3) Secondary Prevention - Managing Arthritis Disability. Can physicians help

disabled people maintain their status or even improve it? This is a key aspect of contemporary care for arthritis patients by rheumatologists, clinical nurses, physical therapists, and occupational therapists. Therapeutic regimens using drugs and physical modalities are aimed at restoring function and preventing any further declines. Most personal interventions occur at this stage too, such as home remedies, changes in structural features of home and worksite, acquisition of assistive devices, changes in coping attitudes, etc. The relative efficacy of professional versus personal interventions is a topic of keen research interest. Clinicians recognize that people's own skills in overcoming arthritis disability or adjusting to it can surpass medical ones, --and the disease provides most people years of experience to hone those skills.

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Table 1. Levels of Disability for Arthritis and Nonarthritis Persons

	1984(Commty.Dwelling)		1986(Intwd.Survivors) *	
	Arth	Nonarth	Arth	Nonarth
	% with any difficulty		% with any difficulty	
Physical Functions				
Mobility:				
Walking	30.6%	13.2%	40.6%	22.0%
Getting outside	16.0	7.9	21.9	11.8
Specific Motions&Strength:				
Walk 1/4 mile	45.1	23.8	46.8	27.1
Climb 10 steps	38.6	18.8	39.7	22.7
Stand two hours	51.5	26.9	61.0	38.1
Sit two hours	16.3	6.0	22.6	10.7
Stoop/crouch/kneel	58.0	28.2	57.7	33.7
Reach up over head	25.0	10.9	19.3	16.9
Reach out	3.2	1.8	4.4	2.7
Use fingers to grasp	17.8	5.7	19.7	8.7
Lift 25 pounds	53.7	31.4	60.2	40.0
Lift 10 pounds	22.8	12.0	31.0	18.0
Social Functions				
Personal Care:				
Bathe/shower	15.8	7.8	20.9	14.7
Dress	9.6	4.6	13.4	9.4
Eat	2.4	1.6	6.2	3.9
Get in/out of bed/chair	13.8	5.2	23.3	12.0
Get to and use toilet	7.1	4.0	10.3	7.0
Household Care:				
Prepare own meals	10.7	6.2	14.9	8.9
Shop for personal items	18.1	10.6	22.1	13.1
Manage own money	7.1	6.1	12.1	10.0
Use telephone	6.6	5.8	15.2	14.2
Heavy housework	36.1	18.4	47.3	30.3
Light housework	11.4	6.1	13.9	8.9

* 1986 Household Care items are asked only of community dwellers.

Figure 1. Disability Transition Tables

Initial Community Dwellers(t0)

1984 \ 1986	No	Yes	Instit	Dead	
No diffic					100.0%
Yes diffic					100.0%

Still Community Dwellers(t1)

1984 \ 1986	No	Yes	
No			100.0%
Yes			100.0%

Table 2. Changes in Physical and Social Function

Results are for Initial Community Dwellers (t0). Left side shows Arthritis and Nonarthritis. Right side shows three subgroups. () means weighted n<10. Arth Only not shown when subgroup<10.

Walking Difficulty

1986:	No	Yes	Instit	Dead
1984:				
No Diffic				
Arth	64.4	25.7	1.4	8.5
Nonarth	75.5	13.0	2.2	9.3
Yes Diffic				
Arth	23.8	52.2	7.2	16.8
Nonarth	18.9	44.7	8.0	28.4

	No	Yes	Instit	Dead
No				
Arth Only	75.8	19.2	()	5.8
Arth Plus	62.7	26.6	1.5	9.2
Other CC	71.9	15.2	2.7	10.1
Yes				
Arth Plus	23.5	52.3	7.3	16.9
Other CC	18.8	44.9	7.6	28.6

Stoop/Crouch/Kneel Difficulty

1986:	No	Yes	Instit	Dead
1984:				
No Diffic				
Arth	58.0	33.0	1.3	7.7
Nonarth	71.5	18.3	2.2	8.0
Yes Diffic				
Arth	22.3	59.6	4.6	13.5
Nonarth	24.8	48.4	5.1	21.7

	No	Yes	Instit	Dead
No				
Arth Only	66.4	29.6	()	()
Arth Plus	56.4	33.6	1.3	8.6
Other CC	68.0	20.6	2.7	8.7
Yes				
Arth Only	33.5	55.6	()	()
Arth Plus	21.7	59.8	4.7	13.8
Other CC	23.7	48.8	5.1	22.4

Bathe/Shower Difficulty

1986:	No	Yes	Instit	Dead
1984:				
No Diffic				
Arth	77.6	11.4	2.1	8.9
Nonarth	79.9	8.2	2.3	9.6
Yes Diffic				
Arth	25.0	43.4	8.9	22.7
Nonarth	13.8	37.4	11.1	37.7

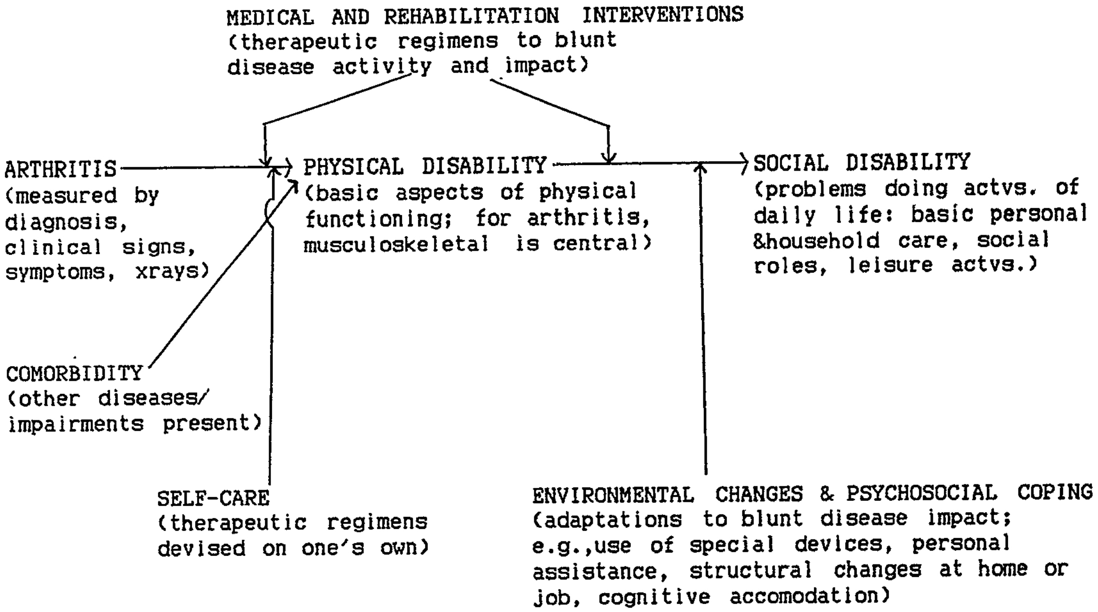
	No	Yes	Instit	Dead
No				
Arth Only	87.3	6.9	()	4.4
Arth Plus	76.3	12.0	2.0	9.5
Other CC	77.4	9.4	2.6	10.5
Yes				
Arth Plus	24.4	43.5	9.1	22.9
Other CC	13.6	37.8	11.2	37.4

Prepare Own Meals Difficulty

1986:	No	Yes	Instit	Dead
1984:				
No Diffic				
Arth	79.5	9.2	2.3	9.0
Nonarth	82.1	5.4	2.4	10.1
Yes Diffic				
Arth	18.6	43.1	10.3	28.0
Nonarth	11.8	39.3	11.9	37.0

	No	Yes	Instit	Dead
No				
Arth Only	88.2	5.8	()	()
Arth Plus	78.3	9.7	2.4	9.6
Other CC	79.8	6.4	2.7	11.1
Yes				
Arth Plus	18.5	42.9	10.4	28.2
Other CC	11.8	39.0	12.0	37.1

Figure 2. A Sociomedical View of Disability



ESTIMATION OF AGED POPULATION DISABILITY LEVELS FROM LIST AND AREA PROBABILITY SAMPLING APPROACHES

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This brief paper compares and contrasts sample survey approaches based on list sample and area probability sample methodology with the aim of examining 1) population coverage, 2) longitudinal survey estimation, and 3) development of data for use in the legislative process covering the aged population. To that end, we begin by generally defining list and area probability approaches in a nontechnical way. First, a list sample requires that each member of a population be maintained on a list of some sort. In our case, nearly all aged people are covered by the Medicare Program (in excess of 96% according to the Actuary at the Health Care Financing Administration) and each person has a unique identifying number. An area probability sample, at least on a national basis, requires selection of areas for sampling based on Census Bureau counts and identification of dwellings within those areas that are to be included in the sample. These two remarkably different sampling approaches and their related methodologies are both available to produce statistics for an aging population. We will, however argue that the list sample approach, as it has been applied in recent survey designs is superior for estimating statistics associated with the Medicare program legislative process.

The choice of a sample survey methodology, e.g., list or area probability should be driven by survey design considerations. For example, good planning dictates that the domains of interest at the appropriate level of variance should be specified as part of the survey preparation process. In our case, the aged population is a small but growing part of the United States population. Most of the aged population is healthy, e.g., in excess of 85% of the aged do not exhibit functional limitation. The aged population itself is less than 15% of the total civilian resident population. It should, therefore, be clear to the uninformed observer that the chronically ill, the institutionalized, and the high medial expenditure aged person represents a rare population event. Indeed, persons of most interest for health insurance legislative purposes are the old, the sick, and the dying, although not necessarily in that order, depending on the purpose at hand. Both the list and area probability approach have recently been employed to estimate statistics for aging an population. Several efforts including the Health Interview Survey (HIS) and the National Medical Expenditure Survey (NMES) use and area probability approach to estimate the civilian noninstitutional population. NMES employs an additional sample of specific institutional types from a list to produce institutional estimates. The National Nursing Home Survey (NNHS) which employs a list of institutions employs a similar approach to estimate characteristics of one general institutional type. Like almost all federal surveys, these studies do not coordinate their content or design in a meaningful way and do not produce statistics that are readily comparable. Further, they are not longitudinal. That is, cross-sectional estimates drive from both the list and area probability driven designs noted above. A longitudinal design follows a cohort of individuals over time regardless of the manner or survey method associated with selecting the cohort. We argue that a longitudinal design combined with use of a list sample of aged persons produces useful statistics on an aging population far more efficiently and effectively than those same statistics could be produced employing an area probability approach. We next present the information and the arguments that have led us to this conclusion. Further, to insure that this discussion is not abstract, we compare and contrast the design, content, and estimates from the National Long Term Care Survey (NLTCS), a list sample product, and the Supplement on Aging—Longitudinal Supplement on Aging (SOA-LSOA), a survey based on the HIS area probability sampling frame which is then used as a frame for more extensive sampling of the aged population (Fitti, 1988). As in most survey efforts, both studies purport to measure the extent of functional limitation in the aged population but employ very different study designs and questionnaire content to accomplish that common end.

The Long Term Care Survey has been conducted periodically since 1982 (1982, 1984, 1989). We plan to complete another cycle in 1992. In 1984 and 1989 both longitudinal and cross-sectional aged population estimates were produced for the aged, disabled population in the community as well as the aged institutionalized population. The list sample of aged Medicare beneficiaries enabled a design which screened very large number of aged persons to locate the functionally limited and institutionalized at low cost. After locating these high risk individuals, a detailed battery of functional status, medical condition, economic, and personal status were collected. Additional limited information remained available for those healthier individuals who did not screen in to the study. Telephone screening, for the most part, was linked to in-person detailed interviews in the LTC Surveys. Further, all screen-ins are followed until they leave the sample universe and an age in sample of 5,000 persons is screened and interviewed in 1984 and 1984 so that cross-sectional estimates may be generated.

The SOA-LSOA was conducted in 1984, 1986 and 1988. Plans for 1990 are indefinite. This survey employed results from the HIS as a frame to insure large numbers of aged persons to draw on. Stratification based on age allowed for adequate representation of both older and younger aged persons. A short telephone interview was employed which assessed functional status, residence and vital status in the follow-up years. Longitudinal estimates as well as cross-sectional estimates may be generated from this study (Kovar, 1987). We present evidence on estimates from the two surveys across three dimensions 1) undercounts of health related events in the area probability format (NCHS, 1966), 2) the ability to accurately estimate very rare events in the aged population (HHS, 1989), 3) estimates of detailed subpopulations at risk as are reflection of both survey and questionnaire design, e.g., the ability to make longitudinal population estimates of 'rare' population characteristics (Manton, 1988; Kovar, 1987). It should be noted that all NCHS data is drawn from published departmental sources as is the LTC survey data with the exception of certain tables drawn from the peer reviewed literature.

In reality, population coverage is our first concern when the two sample surveys representing list and area probability are examined. In brief, work done by or for NCHS over the last three decades illustrates bias associated with employing an area probability approach to estimate health, illness, and related events in a civilian noninstitutionalized population (Series 2, 13; 2, 24 and 2, 54). This bias is a reflection of population undercount in the enrollment of persons in the survey from the established population frame. The very ill, the hospitalized, the dying and the severely functionally limited are simply less likely to respond. This well known nonresponse bias is critical in a survey whose main aim is measurement of health and disability at the population level. In particular, those who are missed, with out consideration of the institutionalized, who are not included in the HIS frame, are at high risk of substantial medical utilization and expenditure and are thus, a highly relevant group for policy and legislative purposes. Were we concerned with consumer expenditures, these high risk, high medical cost groups would be far less important. As it is, an expectation of underestimation of use and consequently expenditure by 10-15% due to nonresponse bias associated with undercounting of the very ill is a condition of employing the area probability approach as it is employed in our example survey (SOA-LSOA) 'Current Estimates from the National Health Interview Survey: United States, 1987' (Series 10, No. 166, pg. 136) notes that "Because hospitalization is common in the period immediately preceding death or institutionalization an older persons are much more likely than younger ones, the data should not be used to estimate the volume of hospitalization of elderly although the data can be used to measure characteristics of elderly people." This observation while framed in the context of reference period bias has clear implications for national estimates of health levels as expressed in functional limitations.

Both the NLTCS and SOA-LSOA employ a subsampling strategy. NLTCS subsamples the aged Medicare population and SOA-LSOA employs the Health Interview Survey to identify aged persons for more extensive interviews. Figures 1 and 2 illustrate the complexity of the LTC Survey design as it has evolved over time. We don't know of a comparable table for SOA-LSOA. The SOA for the 1984 NHIS contained a sample of 11,497 noninstitutionalized persons over age 65 (NCHS, 1987), The 1986 LSOA contacted a 56.2% sample of persons aged 70-79 (99.5% of blacks aged 70-79) and 99.8% of persons and over 5,5158 persons in all (NCHS, 1989). The 1988 LSOA covered all persons aged 70 and above -- nearly 7,000 persons. Though the total samples are large, the SOA/LSOA sample of disabled elderly persons is limited since there was no oversampling of the disabled elderly or of the oldest old. Thus, the primary value of the survey is to examine health transitions in an initially relatively healthy population. On the other hand, the list sample LTC design enables heavy oversampling of the functionally limited and the very ill with economy and ease.

Kovar (1987) reports gross transitions in Figures 3-6 for the 1984-1986 LSOA while Manton reports LTC 1982-1984 transitions in Figure 7. While comparison of published reports shows immediate difficulty in making comparisons between the studies it should be clear that the ability to generate subsamples of the very disabled enable a very detailed large scale presentation of that policy relevant population with acceptable variance.

To further illustrate our comparison and contrast of the two approaches we conclude by employing a table from a report measuring the activities of daily living among the elderly prepared for the Interagency Forum on Aging-Related Statistics. Figure 8 clearly shows the difference between the LTC Surveys and the SOA in estimates of ADLs, their variances, and unweighted counts for uniform years and age groups. The LTC surveys produce uniformly higher estimates of ADL which test as significantly different in several cases.

In conclusion, we have presented evidence and arguments supported by evidence that indicates 1) list sample may be used to produce effective and efficient survey designs for aging related statistics that cannot be easily reproduced with an area probability approach, 2) bias in employing area probability designs in health and disability surveys is a well known phenomenon, 3) longitudinal surveys are easily initiated and have shown with a list sample approach, and 4) clear differences in legislatively relevant statistics have been produced by over two example longitudinal studies; the LTC studies and the SOA-LSOA.

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Figure 1. Component Subpopulations of the 1982 and 1984 National Long Term Care Survey

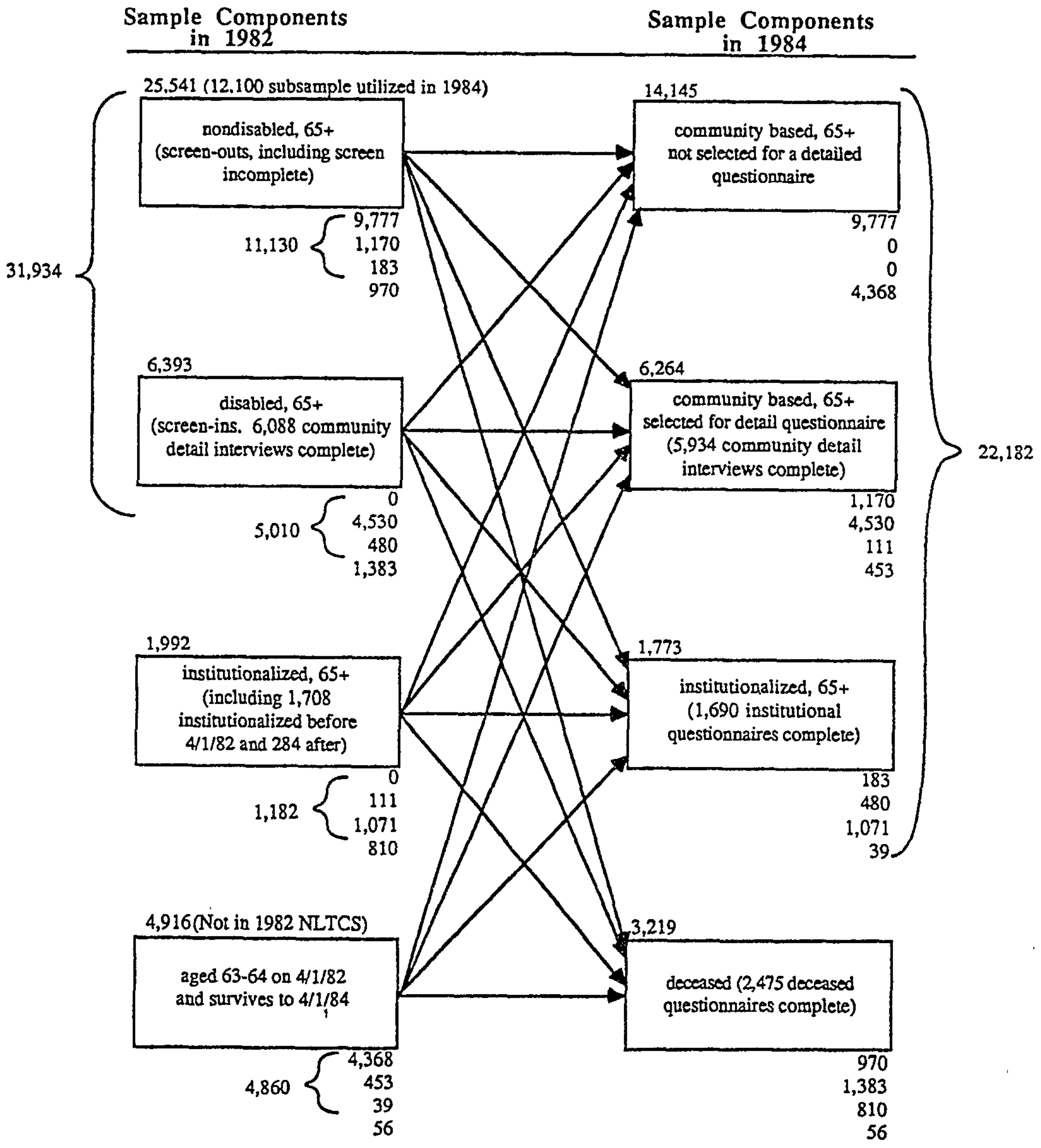
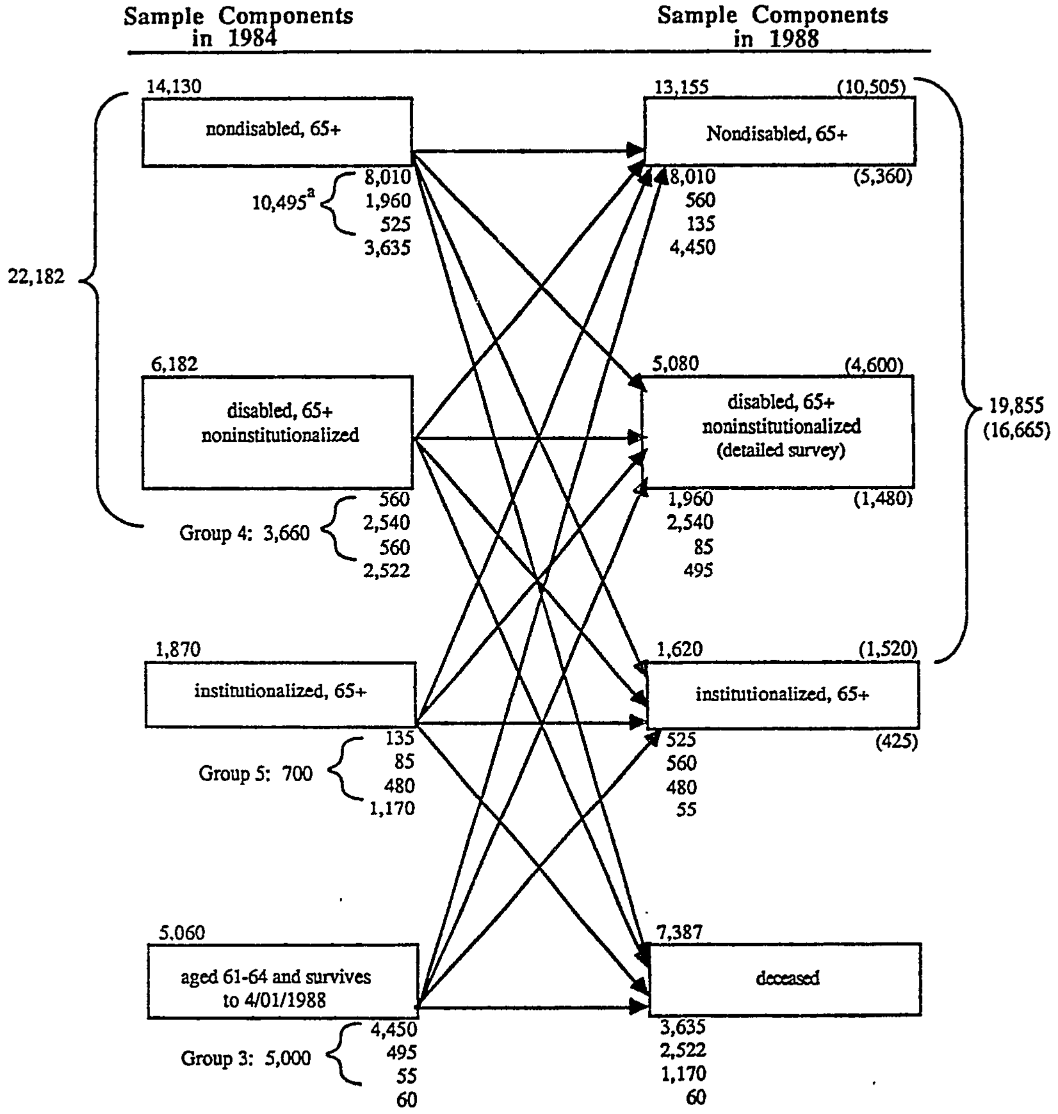


Figure 2. Component Subpopulations of the 1984 and 1984 National Long Term Care Survey



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[a] Groups 1 (N = 5,000) and 2 (N=2,265) formed by sampling 7,265 persons (47.64%) from 10,495 survivors to 1988. Figures in parentheses reflect the adjusted sample size using Groups 1 and 2.

Figure 3: Status in 1986 for People Who Were Age 70 and Over in 1984 by Living Arrangements in 1984

Status in 1986	Total	Living arrangements in 1984				
		Alone	Spouse only	Other than spouse		
				Total	Health reasons	Other reasons
			Population in thousands			
Total	17,335	6,351	6,963	4,021	1,260	2,761
			Percent of population			
Alive	81.5	81.7	83.3	78.0	69.1	82.0
Alone	31.4	70.8	7.6	10.2	6.3	12.0
With others	47.0	6.8	74.0	63.6	53.3	68.3
Institution	3.2	4.2	1.7	4.1	9.5	1.7
Dead	10.9	9.3	10.3	14.5	24.0	10.2
Unknown	7.6	9.0	6.4	7.5	6.9	7.8

SOURCE: NCHS, Longitudinal Study of Aging, 1986

Figure 4: Status in 1986 for People Who Were Age 70 and Over in 1984 by Status in 1986

Status in 1986	Total	Difficulty with		No difficulty
		ADL's	IADL's only	
		Population in thousands		
Total	17,335	4,550	1,856	10,928
		Percent of population		
Alive	81.5	72.3	80.0	85.6
Alone	31.4	27.5	33.2	32.7
With others	47.0	37.3	43.1	51.6
Institution	3.2	7.4	3.8	1.3
Dead	10.9	20.0	11.6	7.0
Unknown	7.6	7.7	8.5	7.4

SOURCE: NCHS, Longitudinal Study of Aging, 1986

Figure 5: Status in 1986 for People Who Were Age 70 and Over in 1984 by Status in 1984

Status in 1986	Total	Status in 1984			
		Difficulty with ADL's or IADL's			No difficulty
		Help with		No help	
		ADL's	IADL's only		
		Population in thousands			
Total	17,335	2,016	2,771	1,619	10,928
		Percent of population			
Alive	81.5	66.1	79.3	76.8	85.6
Alone	31.4	15.5	33.2	39.3	32.7
With others	47.0	40.2	41.3	33.4	51.6
Institution	3.2	10.5	4.7	4.1	1.3
Dead	10.9	26.9	13.9	12.2	7.0
Unknown	7.6	6.9	6.8	11.0	7.4

SOURCE: NCHS, Longitudinal Study of Aging, 1986

Figure 6: Status in 1986 for People Who Were Age 70 and Over in 1984 by Status in 1984

Status in 1986	Total	Status in 1984			
		Difficulty with ADL's or IADL's			No difficulty
		Help with		No help	
		ADL's	IADL's only		
		Population in thousands			
Total	17,335	2.016	2.771	1,619	10.928
		Percent of population			
Community	78.3	55.7	74.6	72.7	84.3
No ADL's	49.9	6.8	29.9	30.6	65.8
One plus ADL's	28.4	48.9	44.7	42.0	18.5
Institution	3.2	10.5	4.7	4.1	1.3
Dead	10.9	26.9	13.9	12.2	7.0
Unknown	7.6	6.9	6.8	11.0	7.4

SOURCE: NCHS, Longitudinal Study of Aging, 1986

Figure 7. Number of Persons (in Thousands) by Transitional Status, 1982 Versus 1984 Disability Status, Weighted Counts, National Long Term Care Surveys (NLTCS)

	1984 Status							1982 Status
1982 Status	Not disabled	IADL only	1 to 2 ADLs	3 to 4 ADLs	5 to 6 ADLs	Institutionalized	Deceased	Population distribution
Not disabled[a]	17,139	845	623	209	180	311	1,701	21,008
IADL only	124	543	265	66	56	76	202	1,330
1 to 2 ADLs	55	220	518	190	97	116	312	1,506
3 to 4 ADLs	12	27	115	148	128	65	156	650
5 to 6 ADLs	5	35	57	65	225	71	272	730
Institutionalized as of 4-1-82	7	9	7	12	11	701	502	1,249
'82 detail nonresponders	12	17	20	15	17	38	109	228
Institutionalized (after 4-1-82)	7	6	7	5	5	89	90	210
Total population in 1984	17,361	1,702	1,606	710	719	1,467	3,344	26,911

[a]Includes those not disabled on screener or detailed interview.

Figure 8. Activity of Daily Living Disability Among the Noninstitutionalized Elderly Age 65 - 74, by Survey and Type of Activity (in Thousands)

	1982 National Long-Term Care Survey	1984 National Long-Term Care Survey	1982-84 National Health and Nutrition Examination Survey Follow-up	1984 Supplement on Aging	1984 Survey on Income and	1987 National Medical Expenditure Survey
Total Age 65-74 Noninstitutionalized Elderly Population/% (Unweighted n)	15,859/100.0% (10,439)	16,682/100.0% (12,687)	14,302/100.0% (980)	16,288/100.0% (7.054)	16,306/100.0% (3,648)	16,886/100.0% (3,489)
One or More ADL Problems	801/ 5.1% (939)	813/ 4.9% (806)	502/ 3.5% (39)	457/ 2.87% (199)	471/ 2.9% (108)	739/ 4.4% (180)
Bathing	634/ 4.0% (742)	639/ 3.8% (642)	303/ 2.1% (21)	404/ 2.5% (175)	432/ 2.6%[b] (99)	625/ 3.7% (150)
Dressing	430/ 2.7% (505)	436/ 2.6% (434)	272/ 1.9% (23)	288/ 1.8% (127)	b	456/ 2.7% (112)
Transferring	443/ 2.8% (515)	404/ 2.4% (405)	302/ 2.1% (22)	242/ 1.5% (104)	204/ 1.3% (47)	c
Toileting	343/ 2.2% (403)	328/ 2.0% (319)	101/ 0.7% (8)	209/ 1.3% (89)	n.a.	c
Eating	225/ 1.4% (260)	209/ 1.3% (200)	170/ 1.2% (17)	63/ 0.4% (27)	b	c

n.a. not asked.
a Excluded toileting.
b Combines bathing, dressing, eating and personal hygiene in one question.
c Cell size too small for reliable estimate.

DISABILITY STATISTICS FOR POLICY ANALYSIS

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Disability statistics are of major interest to policymakers, program managers, and researchers. Reliable and accurate data are needed for policy planning to target public and private programs to meet the needs of disabled persons, to estimate future program needs and costs. Researchers are eager to study the multiple facets of disability and its burden on society, but they are frustrated by the lack of consistency in estimates of prevalence and severity of disability from various surveys. Disabled people and their advocacy and service organizations that have grown in recent years also want more and better data on disability. Compounding the picture is the aging of the population in the 21st century and the growing number of elderly persons who are at higher risk of chronic illness and disability.

The number of disabled persons is growing and creating a greater need for medical, rehabilitation, and social services. We need meaningful yardsticks from which to measure progress and to evaluate programs. Otherwise, policy will be based on guesswork with results that will not meet the needs of the disabled population.

The Committee on National Statistics of the Commission on Behavioral and Social Sciences and Education (CBASSE) of the National Research Council convened a Workshop on Disability Statistics on April 6 and 7, 1989 in Washington, D.C. The purpose of the workshop was to explore and discuss a variety of issues to determine the need for an in-depth panel study to evaluate the current system of disability statistics. Workshop participants include representatives from at least 13 Federal agencies, two senate staff members, academic experts, and private organizations involved in research, service, production, analysis, and the use of disability statistics.

Academic experts in the area of disability included representatives from seven universities. Included were representatives from Brandeis, University of California at San Francisco, Michigan, Ohio State, Pittsburgh, Rutgers, and Yale. Private organizations were also represented, including the World Institute on Disability, National Council on Disability, W.E. Upjohn Institute for Employment Research, American Foundation for the Blind, Child Trends, American Association for the Advancement of Science (AAAS), and the Disability Database Program in Ottawa, Canada.

Discussion Topics

Participants from a multitude of disciplines and interests contributed their expertise to a lively and diverse discussion of many topics:

Concepts and Definitions of Disability. A variety of disability concepts and definitions currently exist that result in a wide range of estimates on the number of disabled persons. The terms disability, illness, disease, sickness, and handicap are used with a great deal of inconsistency, resulting in differing estimates of prevalence. These terms are described briefly below. Public programs providing benefits to the disabled define disability according to their rules for eligibility.

Measurement of Disability. We measure the prevalence and severity of disability in sample surveys, but word questions slightly different. These differences contribute to variations in estimates of the disabled.

Data Needs for Policy Analysis. It is not surprising, therefore, that we end up with different estimates from different surveys that confuse the users of these statistics, including policy analysts and decision makers. Policy analysts also need disaggregated data by subpopulation groups: age, sex, race and ethnicity, and sub-national geographic areas.

Data Needs and Gaps. A variety of gaps in data were identified in the areas of epidemiology, demography, health services use, health insurance coverage, rehabilitation, employment, earnings, social services, benefits, and quality of life.

Coordination. A common theme was the need for better coordination among data producers, more communication among producers and users, and more communication among the users themselves.

Data Dissemination. The view was expressed that there is a considerable amount of information on disability available from a variety of sources, but the data often are not analyzed and disseminated in a timely fashion to be useful for policy analysts.

Special Data Needs. The workshop participants also focused on the special and differing problems of measuring and developing data on children and youth, the working population, and the elderly.

Disability data for children are routinely collected in surveys sponsored by the National Center for Health Statistics (NCHS) and, to a lesser extent, by the Bureau of the Census and other Federal agencies, but there are concerns about the validity and reliability of the data from these surveys. For children, disability is usually measured in terms of a child's ability to perform social roles. For older children, school attendance represents a generally accepted social role. But for children of preschool age, there is much less agreement about what constitutes an appropriate social role. For infants, social roles are even more difficult to define.

For the working population, surveys ask about ability to perform usual activity which is work. But there are many factors that affect the predisposition to disability such as ability to cope with functional limitations, as well as the state of the economy, and the social environment.

For the aged population, surveys measure ability to perform their usual activities and measures of dependency, such as needing assistance in personal care (ADLs) and household care (IADLs). It is not clear that we are getting accurate measures of disability in this manner.

Disability Terms

A variety of disability terms were identified in this discussion and are briefly described below. (These terms are discussed in more detail in Rice and LaPlante, 1988.)

Disease is defined as any bodily disturbance associated with a characteristic set of signs or symptoms. Signs consist of observable health characteristics such as fever, lumps, elevated blood pressure, and laboratory results. Symptoms, however, are not directly observable but are reported by individuals.

Injury refers to damage inflicted on a body by some traumatic, usually external force.

Illness is the perception of disease or injury by the individual. Illness is a psychological state; a person may feel ill in the absence of clinically verified disease or injury.

Sickness is the state of being labeled by oneself or others as having a disease or injury.

Impairment is a chronic physiological, psychological, or anatomical abnormality of bodily structure or function caused by disease or injury.

Chronic illness means the presence of long-term disease or disease symptoms.

Chronic condition is a more general term; it includes impairments not due to disease.

Disability is defined as "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner, or in the range, considered normal," (World Health Organization, 1984). Since human activity is variable, there are many different kinds of disability.

Work disability is a function of the vocation for which a person is trained, which is often selected early in adulthood and may be influenced by impairment existing in youth.

Handicap is the social and economic disadvantage that may result from impairment or disability and may entail loss of income, social status, or social contacts.

NHIS Activity Limitation Terms

Population surveys, such as the National Health Interview Survey (NHIS), often class disabilities by the degree of disruption of activities. A distinction is made between inability to perform one's major activity and limitations in the kind or amount of major activity a person can perform. Thus, the NHIS has four levels of limitation of activity: with activity limitation, limited but not in major activity, limited in amount or kind of major activity, and unable to carry on major activity. In addition, questions are asked of older people relating to functional assistance in activities of daily living (ADLs), such as eating, dressing, bathing, and toileting, and in instrumental activities of daily living (IADLs), including shopping, household chores, preparing meals, managing finances, and using the telephone. Which of these activity limitation terms best describe the disabled population?

Table 1 compares statistics on the prevalence of disability by age from three sources: a) the 1985 National Health Interview Survey; b) The 1985 Survey of Disabled Americans aged 16 years and over conducted by Louis Harris and Associates for the International Center for the Disabled (ICD) in December 1985, and c) the 1982 Long-Term Care Survey conducted by the Health Care Financing Administration (HCFA).

The prevalence of disability from these three data sets differs for the various age groups depending on the questions asked. The NHIS and ICD surveys used similar definitions of disability except for the population group aged 65 years and over. Thus, the two surveys show a 5 percent difference for the 18-44 years age group and only a 2 percent difference for the 45-64 years age group. For the elderly, however, there is a 110 percent difference reported, ranging from 5.1 million from the Long-Term Care Survey to 10.7 million from the NHIS. NHIS and ICD employed the definition of limitation in activity due to chronic conditions and the LTC Survey definition was based entirely on ability to perform daily activities.

Another illustration of differences in the estimated proportion of the population with a work disability is shown in Table 2. The estimates for the total working age population range from 8.8 percent from the Current Population Survey (CPS) to 12.1 percent from the Survey of Income and Program Participation (SIPP). The NHIS reports 9.4 percent of the working population with a work disability. The language of the work disability questions in these three surveys is similar but not identical. In addition, definitions of the working age population differ in these surveys -- NHIS uses 18-64 years, SIPP -- 17-64 years, and CPS -- 16-64 years.

Data Needs

Many data needs were identified in the course of our two-day discussion:

Minimum Data Set. Developing a minimum data of data items to be employed by all surveys was discussed. Current models are minimum data sets for hospital discharges, ambulatory care, and long-term care. The feasibility and need for such a data set for disability statistics should be explored further.

Longitudinal Data. A major gap in disability statistics is the need for longitudinal surveys of disabled persons that would produce information on onset and duration of disability, access to and use and outcomes of rehabilitation services and their impact on individual lives, and transitions of functional ability and status.

Small Area Data. The need for small area data on disability was identified. Program administrators at the state level clearly need reliable and timely data on disabled persons in their states.

International Comparability. International comparisons of disability rates are now difficult, if not impossible. More research should be done on the World Health Organization (WHO) classification system and on comparisons with the U.S. classification system.

Program Needs. The SSI, SSDI, Medicare, and Medicaid programs need more information on service needs and barriers to receipt of services, costs, and the burden borne by individuals and the public. Data are needed on ameliorating the effects of disability and the impact of rehabilitation services.

Policy Analysis. The workshop participants agreed that the needs for disability statistics of policy analysts are not well served by existing programs.

Methodological Needs

A variety of methodological issues were identified:

Measurement of Disability. The differing estimates of the prevalence of disability discussed above indicates clearly that research is needed on many measurement issues. Also discussed was the feasibility of developing disability life tables, a single index of disability, and an index of active life expectancy using the concept of disability-free years.

Use of Administrative Records. Presentations by the Federal agency participants showed clearly that statistics from their programs are available, but are not widely disseminated and used by policy analysts and researchers.

Data Linkages and Matching of Records. Linkages of disability data from surveys to program data could enhance existing databases at a marginal cost. Matching of records is one suggested method of linkage. The underlying barrier is one of confidentiality and this issue needs further exploration as it relates to disability statistics.

Projections. The growing number of elderly and the aging of disabled persons require accurate projections of the disabled population and their medical, social, and rehabilitation needs and costs.

Conclusions

The Workshop participants unanimously agreed that:

- Disability concepts are complex and require further study.
- The present system of collection, analysis, and dissemination of disability statistics lacks cohesion, coordination and direction.

- A variety of methodological and measurement problems exist in the production of disability statistics and these need to be systematically explored and recommendations for improvement are needed.
- A Disability Statistics Panel of Experts is needed to study disability statistics in more depth to improve our current system of disability statistics.

Table 1

Prevalence of Disability from Three Surveys by Age, 1985

Age Group	NHIS	ICD	LTC
	Number (thousands)		
Total	32,726	27,000	-
Under 18	3,221	-	-
18-44	8,391	8,802	-
45-64	10,405	10,179	-
65 and over	10,709	7,992	5,074
	Percent of Population Group		
Total	14.0	14.8	-
Under 18	5.1	-	-
18-44	8.4	8.2	-
45-64	23.4	22.7	-
65 and over	39.6	28.0	19.1

[1] Persons aged 16 and over.

NHIS - 1985 National Health Interview Survey
ICD - 1985 International Center for Disabled Survey
LTC - 1982 Long-Term Care Survey

Source: Rice and LaPlante (1988).

Table 2

Percent with Work Disability from Three Surveys by Sex, 1986

Sex	NHIS	SIPP	CPS
Total	9.4	12.1	8.8
Males	10.0	11.7	9.4
Females	8.9	12.4	8.2

NHIS - 1986 National Health Interview Survey
SIPP - 1984 Survey of Income and Program Participation
CPS - 1986 Current Population Survey

Source: Haber (1989).

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Session V

For Aging

PHCRS

Can the Manitoba Data Base Be A Test Case Or A Case Study?

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Introduction

The policy makers and funders of long-term care programs and services being consumed or demanded by the aging population are increasingly requiring administrators to target these services to "those most in need" of care. Public health statistics available to date have had limited utility in the decision-making processes of policy makers, funders, program administrators and service delivery personnel concerned with long-term care or, indeed, with aging, in general. This disparity between adequately analyzed available data, and decision-making requirements is particularly critical in reference to targeting long-term care services.

The Manitoba Continuing Care Program and the Aging in Manitoba Longitudinal Studies provide a data base suitable for such analyses. Several publications and unpublished reports have specifically addressed the decision-maker's concerns with aging sub-populations to whom services may be or have been targeted. For example, this research has produced findings on geriatric "bed-blockers", risk factors for nursing home placement, the health care costs of aging versus dying, the rates of use of the various types of services, the characteristics of home care clients compared to nursing home residents and to their same age non-consuming peers, and the differential patterns of high versus low users of services.

This presentation will provide a quick review of long-term in Canada. A similarly brief review of the Manitoba Longitudinal Data Bases will be presented in order to address the question of how U.S. researchers and policy makers may be able to exploit the Manitoba Data Bases.

To quote Susan Fletcher (Fletcher, et al, 1987) in a recent publication:

> "Canada has a long-standing commitment to its older citizens, and it offers a variety of programs and services that demonstrate this commitment. Many of these programs address the issue of long term care. Some of these programs and services are provided by the federal government, while most are delivered by the provincial governments. Still others have been developed by volunteer and nonprofit organizations in individual communities." (p. 31)

It is important to recall that the Canadian long-term care system is embedded in the Canadian Health Care System which has established hospital and Medical Care as the minimum insured services across Canada (Rosenfeld, 1984). Essentially, no Canadian can be pauperized by illness, either his or her own or that of a family member, regardless of age, type or duration of disability, or place of residence.

Fletcher notes

> "..... constitutional responsibility for the actual provision of long term care services to the elderly rests with the ten provinces. ...... The federal government retains service delivery responsibility for certain special groups, such as Native Canadians, veterans, and residents of the Territories." (Fletcher et al, 1987 pp. 32-33).

But

> "Canada has essentially ten sovereign states when it comes to long term care programs for the elderly. Each has tailored its programs to meet the quite diverse health and social service needs of its elderly population and to conform to the broader organizational, economic, and political parameters." (Fletcher et al, 1987, p. 39).

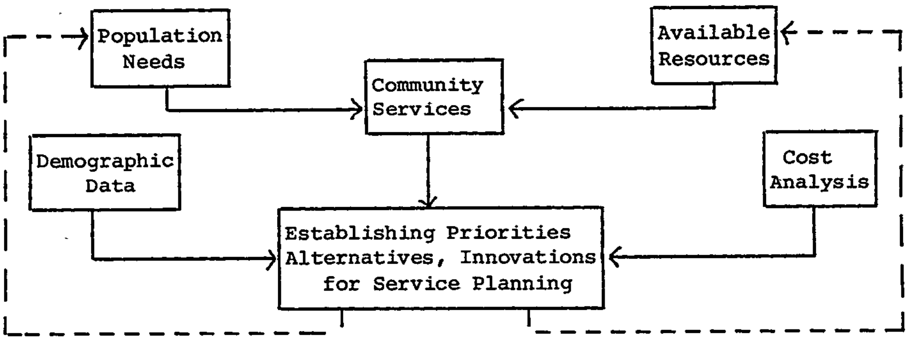
Manitoba has a province-wide, universal, community-based, no-cost-to-consumer long-term care program initiated by the provincial government in 1974 and gradually expanded throughout the province by 1975. The Continuing Care Program assesses persons requiring care, whether for placement in nursing homes which were insured by the province in 1973, or for home care, and delivers services to those who remain at home (Havens, 1988).

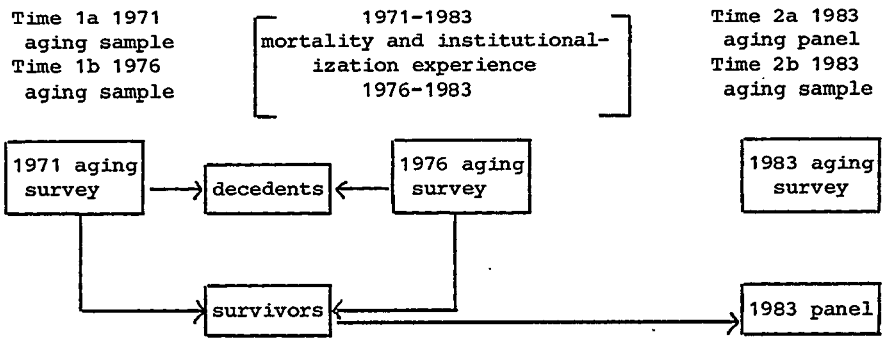
For persons of any age who are referred from any source, determination of need for services is based on a clinical, health functioning, and social functioning assessment. Each referred person is served primarily by one professional staff person, the case coordinator, but assessment and care planning are multidisciplinary.

A common assessment process is used across all sectors of long-term care, and the assessment itself is designed to establish types and amounts of care required. The last step in the process is to determine the most appropriate location for that care. That is, only after all the strengths and needs of the client and the informal support network have been adequately assessed does the assessor begin to consider the site of care.

The 1971, 1976 and 1983 Aging in Manitoba samples and the identification of the panel members, who remained resident in Manitoba, were obtained from the registry of the Manitoba Health Services Commission, which established the registry in 1969. The 1971 sample of 4,803 persons was a random sample of all persons aged 65 years and over, stratified on the basis of age, sex and location (Province of Manitoba, 1973). The top half of Figure 1 presents the original study design while the bottom half displays the longitudinal design.

FIGURE 1





As less funding was available in 1976, both the size and the geographic distribution of the sample were reduced, producing an area probability sample of 1,302 respondents (Hull and Associates, 1979), aged 60 years and over who were resident in the community.

In December, 1982 a new stratified random sample of 2,854 Manitobans aged 60 years and over, resident in the community, was drawn for a third cross-sectional survey (Manitoba Health, 1989). The variables contained within the interviews are listed in Figure 2.

FIGURE 2

Aging in Manitoba Variables

Demographic
Age
Sex
Marital Status

Social Structure
Education
Prior occupation
Retirement status
Ethnicity
Residential status
  - e.g., private home, apartment
Residential location
  - e.g., urban, rural, remote
Religion

Psychosocial
Life satisfaction (LSIA)
Problems with visiting physician
Perceived income satisfaction
Life Space index

Assessed Needs
Economic need
Proximity to family/friends/familiar community
Family/friends as available resources
Shelter needs
Household maintenance, food and clothing needs
Ethnocultural needs
Physical health functioning needs
Mental health functioning needs
Psycho-social needs

Family
Income, Expenses
Perceived adequacy of income
Regular source of care
Adequacy of transportation

Community
Urban-rural-remote character
Resources ability to meet needs

Perceived Health
Disability - Shanas Index of Incapacity
  (Shanas et al, 1968)
Activities of daily living
Recent days in bed due to illness
Self-rated health
Number of conditions

Evaluated Health
Mental status (Kahn, et al., 1961)
Specific Disease Prevalence

In 1983 interviewers surveyed both members of the 1983 cross sectional sample and community resident panel members. During 1984, panel members resident in facilities and those in the community who had not been available for interviews in 1983 were surveyed.

The name, sex, location, birth date and approximate date of death, when known, for the remaining respondents were forwarded to the Manitoba Bureau of Vital Statistics which conducted a manual and computer search of its records. Following this search, the records of the Canadian Mortality Data Base were searched for the remaining respondents. All remaining names were forwarded to the office of Old Age Security, which forwarded a letter from the study to the remaining participants asking them to contact the researchers. Those who responded were interviewed either in person, by telephone or by mail-out questionnaire, and the Mortality Data Base was searched, again.

These processes yielded a final Time 2 Status as shown in Table 1. Death has been confirmed for 3,556 of the respondents including 61 for whom certificates have still not been secured. With the exception of the two European deaths, it is still anticipated that the certificates will be obtained.

TABLE 1

CURRENT STATUS OF 1971 AND 1976 PANEL MEMBERS BY BIRTH YEAR

Status Birth Year	Original*	Death** Information	Interviewed*** 83-88	Refused**** Interview	Lost
1912-1916	405	75 (5)	318 (8)	11	1
1907-1911	353	72 (7)	265 (25)	16 (4)	0
1902-1906	1,517	626 (17)	855 (89)	33 (6)	3
1897-1901	1,315	733 (10)	558 (79)	18 (3)	6
1892-1896	1,044	757 (11)	274 (41)	9 (1)	4
1887-1891	771	661 (4)	102 (22)	1	7
Before 1887	668	632 (7)	29 (6)	1	6
TOTAL	6,073	3,556 (61)	2,401 (270)	89 (14)	27

* 1971 - N = 4803
1976 - N = 1302 including 32 who were also interviewed in 1971.

** Those for whom deaths are confirmed but certificates are not available (N=61).

*** Those who have died since being reinterviewed are noted in (N=270) includes 144 males and 126 females.

**** Includes those who were too ill to be interviewed and for whom no proxy could be located (N=14).

Interviews have been conducted with 2401 surviving panel members. Of the 27 respondents who have been declared lost, 21 were administratively lost due to problematic record linkages prior to the 1983 survey. Therefore, the search procedure since 1983 has been remarkably successful as only six respondents were lost during this process.

The longitudinal utilization portion of the Study includes entirely service-based administrative data. It contains all of the service consumption data based on the total health services system. If any individual has come into contact with the health service sector of Manitoba, and if they were in the original '71, the '76 follow-up or the '83 cross-sectional study, we have all their service consumption data. We also have the service consumption data on the spouses of our interviewees (Mossey, et al, 1981).

Therefore, the utilization data file includes 16,000 individuals covering an 18 year time-frame, from 1970 through 1987. There are potentially as many as 30 separate health service interactions per individual on each of 5,840 days. This can safely be called a very large data set and it is very cumbersome to handle and analyze. One of the immediate problems that we faced was the necessity to put the data into an analytic form to work with without passing through the whole file every time (Havens, 1982).

Jana Mossey has addressed many of the research issues in a recent publication (Mossey, 1987). She speaks of the non-uniform length of utilization records and the development of rate variables for analysis. We have done this within three different categories. One of these arranges the data in three-month summary units; and another in one year summaries. The third category is a locator file.

The locator file maintains each of the 5,840 days as separate file units; but with only one variable per day. This variable indicates whether the individual is: alive and at home; alive in a facility, and if so, the kind of a facility; alive but not in province; and finally dead. In addition to the use of time-framed summaries, we have operationally defined and developed or used summary variables; e.g., an index or a scale.

Sample Analyses

Given, that the residents of personal care homes in Manitoba are extremely frail, without support systems and old on entry, very few return to the community. The average age on entry to a personal care home is 84.3 years of age and in most cases the persons, largely women, have outlived the members of their support network. They tend to be widowed, childless, and largely lacking in other relatives, or others in the household. Therefore, most of the long-term care episodes of care which we have analyzed are episodes of acute care hospitalization within the period of residence in a personal care home (Montgomery et al, 1989).

Further, the major outcome variable which we have studied has been death (Roos, et al, 1986; Roos, et al, 1988; Montgomery, et al, 1989). But, Analysis of surgery as a specific case within acute hospitalization has begun (Roos, et al 1988a; Roos, 1989).

However, with the community samples and the community long term care program in Manitoba, we have also analyzed personal care home placement as an outcome variable among community long term care consumers (Shapiro and Tate, 1985; Roos, et al 1988b). Further, health outcomes of health service non-users are also able to be studied within these combined data bases (Shapiro and Roos, 1985).

Based strictly on the interview responses, we have analyzed the impact of discretionary income on a sense of financial security and other quality of life variables (Havens, 1988). We have also compared changes in social isolation over time (Havens, 1985) and among survivors versus decedents (Havens, 1989).

We have begun to initiate discussion with Laurence Branch relative to both active life expectancy and distance from death concepts.

Research Potential Relative to Long-Term Care

Based on the foregoing, perhaps it is obvious that the Manitoba longitudinal data bases contain a rich source of information on older community residents who consume long-term care as well as residents of long-term care institutions. Our analyses have included those using institutional long-term care as opposed to, or following, community long-term care. We have been able to look at a broad range of long-term care settings. The use of a common assessment in both institutional and community long-term care enables us to compare those persons requiring the same levels of care across settings.

This latter research strategy is especially important in policy considerations. That is, who will be able to use community long-term care services and for how long and how do they differ from those who use institutional long-term care services? This information enables policy makers to develop more appropriate bases for fiscal decisions relative to targeting long-term care over the next several years.

Conclusion

In Mossey's article, she reviews several of the efforts to conduct similar analyses from data contained in a variety of U.S. data bases, arguing for linking existent data bases. This is based on her experience in our Manitoba Studies of linking interview, utilization and mortality data bases. She concludes:

> "Although not entirely free of potential problems, our experiences have demonstrated the advantages and usefulness of linking existing data files for research purposes. Several characteristics have emerged as particularly relevant in assessing whether linkage of several data files would be productive:
>
> "1. The source data bases should be reliable, valid and complete.
> 2. The reference population should be completely enumerated (with) a unique identifier.
> 3. The registration system should be independent of any specific activity.
> 4. Mechanisms for resolution of issues related to confidentiality and to the linkage of data from surveys must have been established." (Mossey, 1987, p. 298-301)

In this case, Dr. Mossey is suggesting that the Manitoba Studies be used as a Case Study to assist U.S. researchers (or others) to develop data bases linking data sets from multiple sources. If her suggestions were pursued, then our U.S. colleagues would be able to perform analyses similar to ours using U.S. data. Hence, the concepts, designs, techniques and expertise of the Manitoba Longitudinal Studies on Aging would be exploited.

Based on the richness of these data, it would appear that another policy relevant research strategy could be pursued. While Manitobans continue to analyze these data, the data base is appropriate to a much broader range of questions than have been posed to date. Researchers from other jurisdictions might test hypotheses with these data before embarking on primary data collection or linking of secondary data in order to increase the effectiveness of studies in their own locations. This strategy could be used to respond to or inform policies, programs and services which may have to be targeted to aging sub-populations such as those who are "most in need".

Given this latter suggestion, the Manitoba data base should, in fact, be capable of performing as a Test Case. In summary, then, the Manitoba data base presents researchers with an option for either a case study or test cases in health policy developments especially relative to long-term care.

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COMMUNITY HEALTH CARE COSTS OF DISABLED ELDERLY: IMPLICATIONS FOR POLICY OPTIONS

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(Not available for publication)

TARGETING RESOURCES TO ELDERS:
PROJECTIONS OF NEED UNDER THREE SCENARIOS

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Jessyna McDonald and Laura Wilson

A recurring theme in planning is the need to quantify levels of unmet need for services in order to effectively target resources. This year has seen a Congressional mandate to state units on aging to produce scientifically valid estimates of unmet need for various types of services covered under the Older Americans Act. And, even when not under a mandate to produce such estimates, state units are required to produce long range state plans for future service delivery based on the best available evidence of need for services.

Methods for determining unmet need are debated among the academic community. Preferred methods often require fiscal resources which are out of reach for many state units on aging attempting to develop an accurate, scientifically valid needs assessment. Among academics, limitations in functional abilities are generally accepted as the most appropriate measures for service needs (Kane and Kane, 1986), yet variations exist among federal agencies as well as state governments concerning how presence of an impairment should be translated into a measure of need/demand for service. The definition selected for planning purposes will have a decided impact on the resource allocation decisions faced by each state. A lack of consistent measures across agencies further complicates the data environment and impairs a state's ability to develop initiatives in health, income support, long term care and social services appropriate to the unique characteristics of a state's environment.

Certainly, the needs assessment literature has confirmed the weakness of an approach which simply asks an individual if they "need" a particular service. A primary limitation in this approach is the lack of familiarity with service taxonomies and the "jargon" of service provision. Further, an understanding of the array of factors which interact with perceptions of need to produce utilization is, at best, limited. The linkage of predisposing, enabling and "need" concepts to utilization is an important first step. However, these enabling conditions which have been linked to utilization explain a relatively small amount of the variance in prediction. In other words, there are many unexplained influences which cannot yet be identified.

In this uncertain environment, many social service agencies and state governments of all types are guilty of an incremental planning process which simply reinforces the status quo in service delivery. Agencies following this planning protocol appear to support the idea that "expressed need" or receipt of assistance is a more reliable basis for planning than "felt" need, presence of a difficulty, which can be determined in community based needs assessments. Reliance upon existing patterns of service consumption where small incremental changes are made based on increases or decreases in demand result in an acceptance of the status quo--existing services are defined as the appropriate ones and the important question of whether new services need to be developed and other phased out never really arises.

The definition of unmet need becomes politicized when attempting to determine which measure of impairment to use in national, state or local data bases. Should one rely upon a self report of difficulty performing some activity of daily living, or must one rely solely upon figures which indicate that an individual with a difficulty is receiving help for that problem--again focusing on need versus demand as a tool for planning? Inconsistencies among federal agencies exist in terms of which figure--actual prevalence of difficulty or use of assistance to perform an activity where difficulty is experienced--is reported. Heartland has performed several different analyses using these two scenarios and has added a new dimension which has resulted from recent discussions and court cases. That dimension focuses on the idea that an individual may need to be impaired in two or three areas before he/she could be defined as disabled. This question carries enormous import for states given the recent emphasis on determining levels of disability as a component in the intrastate funding formula as exemplified in the current Florida court case.

This paper presents three different approaches to the use of existing data bases to estimate the range of need and/or demand for services. Although Heartland provides estimates using these various approaches for "low tech" support services, this discussion will focus on ADL limitations only and the kinds of projections which might result from use of the 1984 Supplement on Aging to project need for services.

Table 1 demonstrates several prevalence rates identified in the weighted sample of elders 65 and older. No tests of significance are applied since corrections for the complex sample design have not been incorporated in these figures. NCHS experts have indicated that for many variables the complex design has little impact since elderly with specific conditions do not tend to cluster (Kovar, 1989). The SOA contains probes about seven difficulties in activities of daily living (ADLs) as well as information about bowel and bladder incontinence. One projection scenario simply involves reporting these prevalence levels and applying either the national or appropriate regional figures to a state's population to determine how many people may be in need of a particular service. In the SOA, the identification of a difficulty with a particular ADL is followed up by a probe determining whether or not the individual receives assistance from another person for this problem. The second row under each ADL in Table 1 reports this response. For the difficulties bathing, dressing or eating, assistance is used by three fifths to three quarters of the elders. For difficulties involving physical mobility such as ability to get in or out of bed or chair or walking without assistance, the level of assistance is far lower, ranging from one-quarter for assistance walking to about one-third for assistance getting in or out of a bed or chair. One projection scenario would have us assume that we should look only at the lower adjusted prevalence rate which controls for whether or not an individual is receiving assistance. That adjusted prevalence rate is presented in the third row under each ADL limitation. One can see that application of the requirement that an individual receive assistance would result in substantially lower prevalence rates and projection multipliers than the more liberal unadjusted prevalence rate. Services which are designed to assist elders with mobility problems would in particular be planning for a far lower number of potential clients than the prevalence figure would indicate.

The decision about which figure to use is guided both by methodological and political concerns. First, what we are perhaps most comfortable with is a set of arguments indicating that not everyone who indicates they have a difficulty is impaired enough to ask for help either from an informal source or from the service system. Although some would argue that the individuals not receiving assistance should be identified as the targeted number of individuals with unmet needs, others argue that those not receiving assistance are the elders who do not have the "enabling" or predisposing characteristics which predict utilization of services. What we would like is a method by which we could tease out "unmet demand" for services. How many of those individuals not receiving assistance would actually utilize assistance if it were available either within their family structure or in the formal system? How many of those not receiving assistance are doing so because no services or support systems exist for them? The ability to accurately determine this more valuable figure for planning would require far better data than we have concerning **accessibility and availability** of services in any particular area.

What we as academicians are perhaps less comfortable with is the idea that the choice of a multiplier for planning purposes will be a political, not a research decision. Depending upon the support for social/health services in a state legislature, a planner may be willing to use a more liberal prevalence figure unadjusted by receipt of assistance to justify funding levels for various program. In other political environments, a planner may choose the adjusted prevalence level to project future needs to avoid creating the image of an ever burgeoning elderly population who will deplete valuable state resources and redirect them from other deserving groups. In differing environments, either choice has its merits and its drawbacks. The more liberal, unadjusted prevalence figures might represent a "worst case scenario" for planning while the adjusted prevalence rates certainly represent information which will lead to a maintenance of the status quo. The first figure probably overstates the level of need, and the second ignores the fact that receipt of assistance is mediated by problems in accessibility and availability of services both in the formal sector and in the home and family environments of many elders.

Let us look briefly at a third possible scenario which is hovering on the horizon for planners. Several federal agencies have participated in discussions concerning the appropriate ways to measure disability in a population. Some very interesting work has been done with the National Medical Expenditure Survey projecting the disabled population using various definitions. One of the suggested definitions involves requiring an individual to be impaired in several activities of daily living before they can be defined as disabled. Table 2 presents the comparison for total number of ADLs with the number of problems for which an individual receives assistance. Less than one-fifth of the individuals with one ADL limitation receive assistance. Three-fifths of the individuals with two ADLs do not receive any assistance. However, when an individual reports three or more ADL limitations, he/she is more likely to be receiving at least some assistance. Less than one-third of these individuals receive no help, and slightly more than two-fifths are receiving assistance with all three problems. This simple comparison does not begin to address the concept of adequacy or appropriateness of assistance. Figure 1 graphically describes the impact requiring the receipt of assistance to define a problem as a need would have on the calculation of number of individuals who are disabled. Using a more liberal prevalence level, 9.4% of the elders 65 or older would be considered disabled (3+ ADLs). Using the adjusted levels, less than 4% would meet this criterion.

Again, the importance of the political environment of the planning process is evident. Planning for service delivery using these more conservative estimates would drastically reduce the requests for support to develop services. Serious questions might also exist about the wisdom of waiting until an individual develops three or more problems to intervene with assistance. Indeed, our own work with the 1986 Longitudinal Supplement on Aging which looks at outcomes for various groups over time indicates particularly for minority elders that intervention is most helpful before three ADLs develop. Once three ADLs are reported, the mortality rate increases dramatically, but prior to reaching that level of disability, the chances of improving or maintaining status quo are greater. Any policy which requires presence of three or more ADLs to qualify for assistance will actually mediate against minority elders who report a higher mortality rate and less chances of improvement than do nonminority elders (McDonald, Harlow, and Ludwin, 1989).

What stance should we as a national resource center take in assisting state units in the development of their state plans. First, we are committed to making multiple indicators for planning available to the state units. In practical terms, this means that our products will contain several measures of need and suggestions for the use of various indicators or multipliers. Center reports will profile prevalence levels and an analysis of how many are receiving help and how many are not. None of these measures can be used out of context with the others since they are inextricably tied to issues of availability and next to appropriateness of services. If a planner elected to rely upon an adjusted prevalence rate to determine the potential demand for services in his/her community, the immediate assumption would be that existing assistance is appropriate. We know from many caregiver studies that more than 80% of all assistance is supplied in the informal service sector. Therefore, 80% of the adjusted prevalence figure are probably not in the formal sector at all. No standards of quality control exist for the provision of services within families. Many of those individuals who are receiving services may be receiving inappropriate or inadequate services from an overburdened or inappropriately skilled caregiver (Harlow, Wilson, Rosentraub, 1987; Harlow, Wilson, Pickard, 1987; Harlow, Rosentraub, Pickard, and Wilson, 1988). How, then, do we calculate what unmet need is among that group?. Further, we have no way of knowing whether or not **enough** help is being offered or received.

A second pitfall exists for states who want to apply these national or regional figures as their state level multipliers. An adjusted prevalence rate is influenced by the number and availability of services which can respond to a particular problem. For example, looking at the number of people with disabilities who are receiving regular (daily) help, Maryland fares best among three of the state specific studies from the National Panel Study on Health and Aging. Almost three-fourths of those with one ADL do not receive help, but just under half of those with 3 ADLs are receiving help, and approximately 80% of those with 5-6 ADLs receive assistance. Arkansas figures are substantially lower for receipt of assistance for up to 4 ADLs, but two-thirds and three-fourths receive assistance for 5 and 6 ADLs, respectively. Montana rates are even lower. Approximately half those with 5-6 ADLs receive assistance.

Heartland will continue to provide several types of measures from which state planners can identify levels of unmet need in their own states. One emphasis will continue to be on identifying who is receiving help and who is not. These individuals who are not receiving help are those which appear to receive less attention in the national data sets. The assumption appears to be that receiving assistance is a better measure of an impaired individual, and that by using this measure, one can weed out the mostly health or only marginally impaired who are not likely to need service at the present time. However, an examination of state level data sets does not confirm that picture of the people who are not receiving help. In the state and local samples, an average of more than 60% of those individuals who are not receiving services report perceptions of poor or fair health. Very few describe themselves as in excellent or good health.

As for the requirement that a individual be impaired in three areas before being defined as disabled, the center will continue to provide all information about impairments in a format which identifies individuals who none, one, two, or three or more. When asked for policy recommendations rather than data analysis assistance alone, the center will advocate against such a stringent definition of eligibility for assistance. While this definition may be appealing when focusing on cost control and may even be necessary if facing a triage situation in planning for service delivery, longitudinal data indicate that this move in eligibility determination would have long run negative impact on the survivability and quality of life of many elders, most particularly those of minority elders. And this definition actually takes on enormous importance in the face of recent court decisions concerning the legality of various intrastate funding formulas. If the patterns which appears to be emerging in the Florida case is reenacted in other states, the figures for disability levels among males and females may begin to substitute for previous figures focusing on percentage of elderly over 75 or "frail." In terms of a better basis for a funding formula, reliance on figures of disability should be preferable since the over 75 population will become increasingly heterogeneous in its health characteristics. The selection of a "cut-off" point in the definition politicizes the framework unnecessarily. What remains to be determined and what is critically important is what the accepted definition of disability and the related political and service impacts of the selection of any particular definition will be.

TABLE 1

REPORTED DIFFICULTIES IN SELECTED ACTIVITIES OF DAILY LIVING AND ADJUSTED PREVALENCE RATES

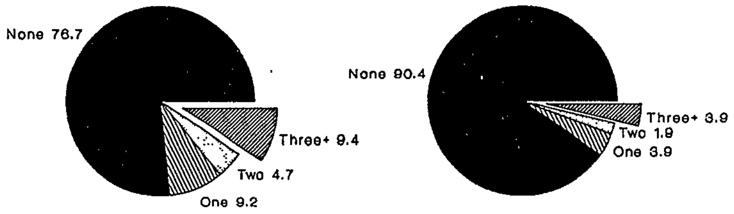
ADLS	NATIONAL	N'EAST	N'CENTRAL	SOUTH	WEST
Bathing					
% Reporting Prob.	9.8	8.7	9.5	11.1	8.9
% Getting Help	60.9	65.1	54.1	61.9	63.3
Adj. Prevalence	6.0	5.1	5.1	6.9	5.6
Dressing					
% Reporting Prob.	6.2	5.1	5.3	7.9	5.7
% Getting Help	69.9	77.3	66.4	70.4	64.9
Adj. Prevalence	4.3	3.9	3.5	5.6	3.7
Eating					
% Reporting Prob.	1.8	1.3	1.6	2.3	1.9
% Getting Help	58.6	76.2	45.9	57.9	59.3
Adj. Prevalence	1.1	1.0	0.7	1.3	1.1
In/Out Bed					
% Reporting Prob.	8.0	6.7	7.8	10.1	6.0
% Getting Help	35.4	42.6	30.2	37.1	29.3
Adj. Prevalence	2.8	2.9	2.3	3.7	1.8
Walking					
% Reporting Prob.	18.7	16.5	18.2	22.1	15.8
% Getting Help	24.8	29.5	21.2	25.2	23.5
Adj. Prevalence	4.6	4.9	3.9	5.6	3.7

TABLE 2

RECEIPT OF ASSISTANCE AND NUMBER OF ADL/IADL LIMITATIONS AMONG ELDERS 65 OR OLDER IN THE 1984 SOA

ADLs	RECEIVE HELP FOR:			
Number	None	One	Two	Three or more
None	100.0			
One	83.7	16.3		
Two	60.6	21.1	18.2	
Three or more	32.9	14.8	10.6	41.6
IADLS				
None	100.0			
One	28.8	71.2		
Two	9.5	22.2	68.4	
Three or more	9.4	3.2	7.0	80.3

Reported Problems and Adjusted Prevalence of Multiple ADL Impairments



Reported

Adjusted

1984 SOA Elders 65+

OBSERVATIONS ON THE RURAL ELDERLY AS A SPECIAL CHALLENGE TO OUR SYSTEM OF HEALTH STATISTICS AND HEALTH DELIVERY

James P. Cooney, University of Kansas Medical Center

BACKGROUND

Purpose of the Study. The study of Kansas health services, health statistics, and the elderly (#1) has two objectives:

1. to examine the changing relationship between the elderly and the health delivery system; and---

2. to test the sufficiency of secondary source data (#2) as primary source information for defining the changing relationship.

The study is basically an interplay between method and subject which evolved from pragmatic opportunities at the University of Kansas Medical Center (KUMC): the emergence of a health services research agenda and the development of the Center on Aging.

For the health services research agenda, we are identifying and evaluating secondary source health statistics available within the state. The importance of secondary source data has been well documented and supported in the development of the Cooperative Health Statistics System of the National Center for Health Statistics. Suffice to say here that, given assurance of validity and reliability, secondary source data offer significant economies of scale for certain types of studies.

For the Center on Aging, the construction of socio-demographic and health profiles of the elderly will be increasingly relevant for program development.

The Rural Elderly. Almost 94% of the state of Kansas is rural (#3) and contains almost fifty percent of the resident population. The population of the state continues to grow; however, since 1985, the rural areas have consistently shown a loss of residents.

The elderly represent a small but growing proportion of the state's population-- estimated to be slightly more than 14% by 1990. Approximately 2/3s of elderly Kansans live in rural areas. Because of outmigration of the younger rural population to the urban areas, the elderly rural proportions are growing. The proportion of the rural elderly in the state is greater than comparable proportions at both the regional and national levels (Figure #1) (#4). If the current trend continues, the elderly will constitute twenty percent of the Kansas rural population by the early part of the 1990s.

In brief, the Kansas rural elderly represent the greatest majority of the state's elderly and a growing proportion of the state's declining rural population per se.

Rural areas nationally have tended to be underserved in terms of health services. Also, the elderly per capita tend to exhibit a greater need/demand for health services that any other age segment of the population. While beyond the scope of this paper, the rural vs urban elderly growth patterns have major significance both in terms of health economics as well as rural economics.

Kansas Rural Community Hospitals (#5). The Kansas community hospital universe mirrors the rural distribution of the population. Over 75% of all the state's community hospitals are located in rural areas. The proportion of rural hospitals in the state is also greater than similar distributions at both the regional and national levels (Figure #2).

Hospitals with less than 100 acute care inpatient beds appear to be the ones most threatened in terms of future financial survival. These small (#6) hospitals constitute almost 90% of the state's rural hospitals.

Admission trends for Kansas rural hospitals of all bed sizes in the current decade reflect both those of our geographic region-- West North Central and the United States. The trend in rural hospitals of all bed sizes among the three areas has been a drop in admissions of at least 35 to 40% (Figure #3).

---

(1) Elderly - persons sixty-five years and older;

(2) Secondary source data - all data used in the study are secondary in that they were not collected for purposes of the study. These data, subject to editing for confidentiality, are routinely and readily available from governmental and nongovernmental data system sources within the state of Kansas. Several of the secondary data systems had their origins in terms of concept and content (if not fiscal support) in the Cooperative Health Statistics System of the National Center for Health Statistics.

(3) Figures cited appear at the end of article.

(4) As defined by the US Office of Management and Budget, in cooperation with the Federal Committee on Metropolitan Statistical Areas, metropolitan statistical areas (MSA) within Kansas include: Butler, Douglas, Johnson, Leavenworth, Miami, Sedgewick, Shawnee, and Wyandotte counties. All other counties within the state are considered "rural" for the purposes of the study.

(5) Community hospitals - nonfederal, short-term, general and other special hospitals.

(6) Small hospitals - community hospital of less than 100 beds.

Occupancy trends are also down (Figure #4). In 1980 occupancy rates in the three geographic areas ranged between sixty and seventy percent. In 1987 (the last year of available data), the comparable rates had dropped to between fifty-five to forty-five percent, with Kansas rural hospitals on the low end of the occupancy scale.

In brief, as health care institutional forms and services, rural hospitals predominate in the state of Kansas. They like all other community hospitals nationwide, have experienced a downward trend in both admissions and occupancy.

The current occupancy levels per se would make the long-term survival of small rural hospitals doubtful, at least in their present form. This has obvious and detrimental health services implications for the total rural population, but especially for the rural elderly. The urban elderly while at risk, are comparatively less so as their community hospital service supply is not as threatened as the rural.

Study Parameters. Because of time and space constraints, only a portion of the ongoing study will be presented. Specifically, we will limit observations to rural community hospital use by the rural elderly.

The principal secondary data resource for the study's community hospital use information base is the Kansas Health Data System (KHDS). KHDS was established in 1975 under the auspice of Kansas Blue Cross/Blue Shield. It is a monthly hospital discharge abstract system. The majority of its core data base, centers around the Uniform Hospital Discharge Data System (UHDDS).

Using the DRG Grouper software system, KHDS encoded DRGs into the data source base for the year 1980 forward. KHDS therefore is a particularly useful secondary data resource in terms of pre-Prospective Payment System vs post-Prospective Payment System performance comparisons.

In the study the KHDS data base over a nine year period ---1980 thru 1988 was used. Specifically, discharges from the years 1980, 1982, 1984, 1986, and 1988 were selected from this time period for reasons of economy and based on the fact that discharge patterns do not change significantly from year to year.

The study universe parameters and data resulted in an information base of over one-half million discharges (535,316) for 107 hospitals.

For the time period of the study, ALL observed hospitals remained in the System.

RURAL HOSPITAL USE BY THE ELDERLY.

Numerical Trends and Their Implications. In terms of discharges from the small rural hospitals studied, there has been a steady downward trend in the nineteen-eighties. The decline for these hospitals is more extreme than the one previously observed (see Figure #3) for all rural community hospital bed sizes. As illustrated in (Figure #5), the downward trend is found in BOTH the under and over 65 years of age patient population.

Inpatient day patterns also mirror the same downward trends (Figure #6). It should be noted that the UNDER 65 patient population accounts for the majority of DISCHARGES in every year of observation whereas the OVER 65 group account for the majority of DAYS. This difference, as is generally known is a result of the greater medical complexity (on the average) of the over sixty-five year old patient compared to the under 65 patient.

The net outcome of the downward discharge and inpatient day trend for both age groups is a decline in the average length of stay. This negative adjustment is most noticeable in the elderly with a drop of close to five full days on the average stay since 1980 (Figure #7).

The nonelderly change in days was less dramatic since they were at an average of more than four days less than the elderly at the start of the study period. At the lowest point of average stay (1984), the under 65 had lost almost one-half day. HOWEVER, subsequent to 1984, the average stay for the nonelderly has increased almost a quarter of a day. This shift explored more in depth through DRG analyses, tends to reflect a more medically complex under 65 patient towards the end of the decade than at the beginning.

In summary in terms of numbers, all three traditional measures of community hospital inpatient use (discharges, days, and stay) are downward through the current decade for both the over 65 and under 65 patient groups. It should be noted that the trend originates at the beginning of the decade. It does not appear to have been significantly impacted per se by the implementation of either the Federal Prospective Payment System (circa 1985) or the Kansas Blue Cross/Blue Shield system of DRG-based prospective payment (1984).

Implications of Proportional Utilization Trends. In terms of discharges, the over 65 proportion is increasing at the expense of the under 65 patient population. By 1988, the elderly component of the hospital discharge population had increased by more than 20% (Figure #8).

Perhaps more significant is the changing ratio between elderly and nonelderly patients. In 1980 the ratio was approximately four elderly patients for every 6 nonelderly. By 1988 that ratio was approaching 50:50.

In order to further compare change between the elderly and nonelderly patients, the discharge and inpatient day information has been translated into an index with the year 1980 equalling 100 (Figure #9). These standardized comparisons underscore the nature of the utilization changes between the two age clusters of patients. Analyses indicate that in terms of discharges, there has been over a 50% decrease in NONelderly discharges; the comparable figure for the ELDERLY is slightly more than a 1/3 decrease. The proportional loss for both in terms of DAYS is approximately 60%

While there has been a loss for both age groups, the proportional and numerical decrease for the younger patients has been greater. This has potentially critical economic implications for the small hospitals by increasing their revenue dependency on federal programs. The elderly who are almost exclusively Title XVIII as a primary payment source, are becoming a greater proportion of the institutions revenue sources. This is occurring at the same time the Federal reimbursement formula and perhaps others are tightening for the rural hospital AND total admissions are significantly decreasing especially in terms of the nonelderly who traditionally have been sources of more liberal reimbursement options.

Prospective Payment Systems and Change in Small Rural Hospital Use Patterns. Prospective payment systems were in part at least designed to encourage appropriate use of acute hospital services. Analysis of hospital use patterns before and after program implementation could possibly indicate the effect of such programs.

1984-1986 were the pivotal years in Kansas both for implementation of the federal and state Blue Cross PPS programs. It was observed, but not quantified by individuals monitoring hospital use prior to the implementation period that there was some buildup of utilization prior to program implementations. (Figures #10 and #11) comparatively illustrate trends in discharges and days before and after PPS implementation. In general the trends indicate that:

1. there was a decrease in both discharges and days beginning at least four to five years prior to PPS program implementation;

2. the rate of decrease in discharges increases subsequent to program initiation whereas--

3. the rate of decrease in patient days slows subsequent to program implementation.

It appears there has been some effect of PPS on hospital use patterns. However, the exact nature of such effects are not measurable at this level of analysis. Further, multiple factors in the decade of the eighties including but not limited to changes in medical technology and shifts in population socio-demographics were contributing to the downward use trends. PPS was not the sole change factor.

Irrespective of causes, the most significant effects of the change patterns appears to be the growing predominance of the elderly proportion of patients together with the overall decline in total numbers of patients of both age groups.

A tightening of reimbursement formulae under these circumstances especially of the Medicare program, has negative potential for future fiscal stability of the small rural hospital. Prospective payment methods may not be a causative agent for downward trends, but they may be tarred as an ultimate villain in institutional survival.

DRG Patterns of Change. DRG analyses among the study group of rural small hospitals was initially conducted by identifying the top twenty DRGs in the elderly and the nonelderly patient populations. This was done for each of the five observational years. The top 20 for both age groups in all observational years generally accounted for fifty percent of the discharges.

If a DRG dropped out of or entered into the top twenty in any one observation year it was monitored throughout the study. For the elderly population, this resulted in a total of thirty-one DRGs appearing in the top 20 for at least one year.

Preliminary analyses were then conducted on the movement/nonmovement of the individual top 20 DRG's rank positions. To date these have indicated the following for the elderly population:

1. Five DRGs remained in approximately the same rank order position throughout the study. However, their lengths of stay decreased.

DRG NOMENCLATURE	RANGE: RANK ORDER POSITION
SIMPLE PNEUMONIA AND PLEURISY AGE >69 AND/O CC	1 - 2
HEART FAILURE AND SHOCK	2 - 3
SPECIFIC CEREBROVASCULAR DISORDERS EXCEPT TIA	4 - 5
BRONCHITIS AND ASTHMA AGE >69 AND/OR CC	6 - 8
CIRCULATORY DISORDER W AMI W/O C.V. COMP DIS ALIVE	13 - 14

2. Six DRGs dropped out of the top 20 and remained out during for the remainder of the study. The lengths of stay for all declined. Three of these were at the low end of the top 20 (17TH-20TH rank position). However, three held considerably higher positions:

DRG NOMENCLATURE	RANK ORDER BY YEAR				
	80	82	84	86	88
CHRONIC OBSTRUCTIVE PULMONARY DISEASE:	5	4	12	20<	20<
ATHEROSCLEROSIS AGE >69 AND/OR CC:	4	7	19	20<	20<
HYPERTENSION	13	15	20<	20<	20<

3. Eleven DRGs moved into the top 20 at least for one year during the study. Only four of these remained over several years and/or held a high rank order in the last year of the study:

SIMPLE PNEUMONIA AND PLEURISY AGE 16-69 W/O CC - This DRG had been rank ordered between 65-70th position for the first four observational years of the study. The number of discharges had been declining, but ranged from between 250-100. The average length of stay had also been steadily declining. However, in 1988 there were 668 discharges for this DRG, a threefold increase from the previous observational year (1986).

CIRCULATORY DISORDERS W AMI & C.V. COMP DIS ALIVE - This DRG was not in the "top 20" until 1986 when it appeared in 14 position; in 1988 it went to 13th.

G.I. HEMORRHAGE AGE >69 AND/OR CC - This DRG was not in the "top 20" until 1982 when it appeared in 17th position; in 1984, it was in 13th; 11th in 1986; and 8th in 1988.

NUTRITIONAL AND MISC METABOLIC DISORDERS AGE >69 CC - This DRG appeared in the "top 20" in 16th position in 1982; in 1984 it was in 9th position; 8th in 1986; and 11th in 1988.

4. Six DRGs remained in the top 20 throughout the study period, but shifted their rank order position considerably over the nine year period.

DRG NOMENCLATURE	RANK ORDER POSITION SHIFT
CARDIAC ARRYTHMIA & CONDUCTOR DISORDERS AGE>69 AND/OR CC	11TH TO 7TH
ANGINA PECTORIS	12TH TO 3RD
ESOPHAGITIS, GASTROENT & MISC DIGEST DISORDERS AGE >69	1ST TO 5TH
MEDICAL BACK PROBLEMS	6TH TO 10TH
DIABETES AGE >35	9TH TO 19TH
KIDNEY AND URINARY TRACT INFECTIONS AGE >69	10TH TO 16TH

Analyses of these four types of changes while still ongoing have indicated several causative factors. These include, but are not limited to:

A. artifacts of alterations in the DRG system. As an example of these, deletion in 1987 of the "greater than age 69 and/or comorbidity, complications" probably produced the "epidemic" of pneumonia and pleurisy noted in (#3).

B. medical technology and/or medical management. As example, the decline in rank order of Diabetes (#4) greater than age 35 was probably the result of increasing management of such patients on an ambulatory rather than hospitalized basis;

C. movement to greater specificity of acute condition and/or heavier weighted DRG. This group would include several examples of "DRG creep" as well as change in medical management resulting in non-hospitalized treatment. An exchange of Atherosclerosis for Circulatory Disorder with AMI is a possible example of this pattern.(#'s 1 & 2)

D. certain changes at the moment are without explanation. Angina Pectoris (#4) is such an example in its movement from 12th position to 3rd.

While close to but not in the "top 20" the following two DRGs are of interest because of their relevance to health needs of the elderly and their marked decline both numerically and in terms of average length of stay over the study period.

DRG NOMENCLATURE	STUDY YEAR 80	82	84	86	88
FRACTURES OF HIP AND PELVIS					
# CASES	561	548	377	276	216
RANK ORDER #	22	24	26	34	37
ALOS	12.6	13.3	9.0	7.5	5.9

DRG NOMENCLATURE	STUDY YEAR 80	82	84	86	88
HIP & FEMUR PROCEDURES EXCEPT MAJOR JOINT AGE >69 C					
# CASES	360	395	397	325	215
RANK ORDER #	34	33	24	27	38
ALOS	25.2	22.0	15.1	11.5	9.9

In both DRGs, the average length of stay has decreased markedly. This change is a reflection of medical technology/medical management. However, the DRGs are probably subject to PPS pressure and the option to transfer rehabilitation of such patients to less intensive (and expensive) care institutions than hospitals with the possibility of reimbursement.

The change in days of stay also implies the need for medical and supportive resources external to the hospital required to support rehabilitation post-hospitalization.

The significant decline in the number of Hip/Pelvis fracture discharges remains to be explained. Some of the change possibly could be the result of admission of such cases to larger hospitals as smaller hospital services become restricted. However, this is only a possible and partial explanation.

CONCLUDING NOTES. The intent of our observations was not to conclude but to illustrate and hopefully to interest.

--to illustrate that secondary sources of data, many of which evolved from the Cooperative Health Statistics System continue to exist and in many cases appear to have matured. Maturity is most noticeable in the discharge abstract area where former problems of validity and reliability appear to have been significantly reduced under the twin impact of improved education and more sophisticated computer technology. The economy of scale of the systems' data products remains.

--to illustrate the implications of our population aging trends both in terms of need and delivery of health services, with special emphasis on the rural elderly as a very specialized population in terms of need and risk.

--to interest in the applied study of this specialized population and their health and social needs complicated by the facts of rural environment and economy.

--to interest also in the exploration of the informational and intelligence potential of secondary source data towards understanding and effecting productive change in delivery and financing of care.

ACKNOWLEDGEMENTS

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Carrie Hildenbrand, RRA and Instructor, Department of Medical Record Administration Education, University of Kansas Medical Center;

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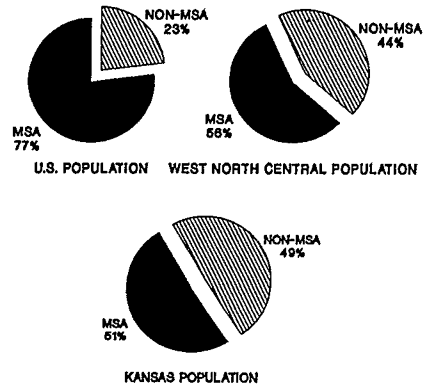
Dr. Morton Creditor, M.D., Professor and Director, Center on Aging, University of Kansas Medical Center;

Ronald A. Morley, Vice President, Cost Control Programs, Blue Cross and Blue Shield of Kansas, Inc;

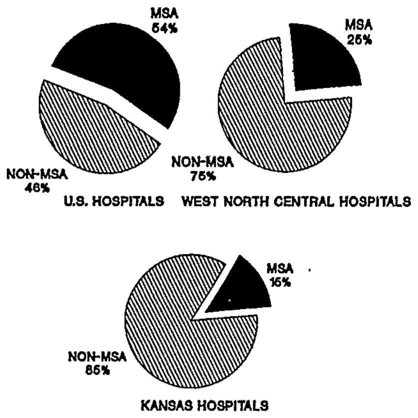
RURAL AND URBAN POPULATION PROPORTIONS FOR THE UNITED STATES, WEST NORTH CENTRAL REGION, AND KANSAS IN 1987



Source: U.S. Bureau of the Census Estimates

Figure #1

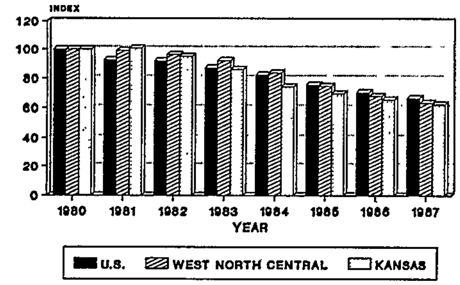
RURAL AND URBAN COMMUNITY HOSPITAL PROPORTIONS IN THE UNITED STATES, WEST NORTH CENTRAL REGION, AND KANSAS IN 1987



Source: Hospital Statistics 1988

Figure #2

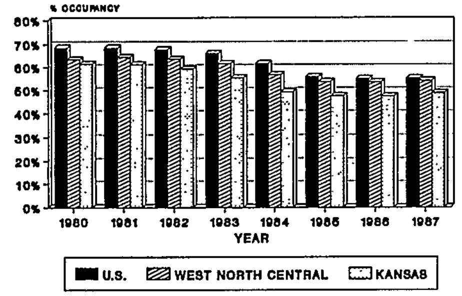
ADMISSIONS TO NON-MSA COMMUNITY HOSPITALS INDEX (1980 - 1987)



1980 = 100
Source: AHA, Hospital Statistics

Figure #3

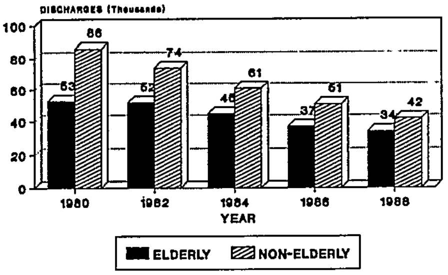
PERCENT OCCUPANCY IN NON-MSA COMMUNITY HOSPITALS (1980 - 1987)



Source: AHA, Hospital Statistics

Figure #4

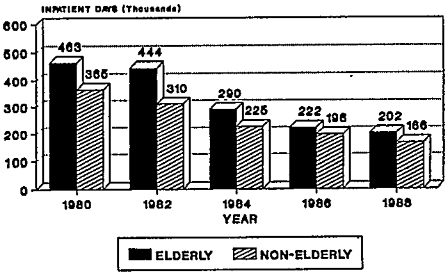
KANSAS NON-MSA COMMUNITY HOSPITAL DISCHARGES BY AGE CATEGORY IN SELECTED YEARS (1980 - 1988)



Source: Kansas Health Data System

Figure #5

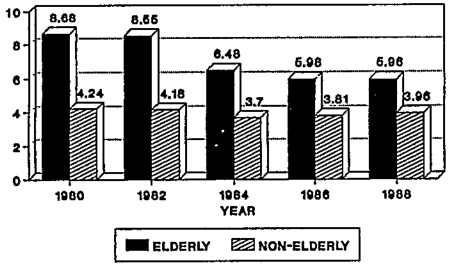
KANSAS NON-MSA COMMUNITY HOSPITAL INPATIENT DAYS BY AGE CATEGORY IN SELECTED YEARS (1980 - 1988)



Source: Kansas Health Data System

Figure #6

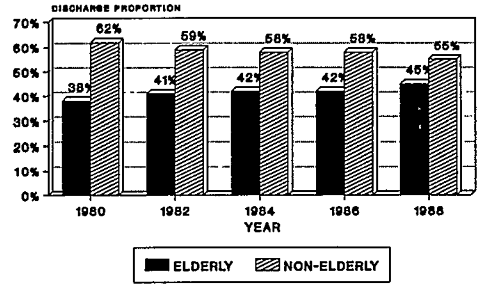
KANSAS NON-MSA COMMUNITY HOSPITAL AVERAGE LENGTH OF STAY BY AGE CATEGORY IN SELECTED YEARS (1980 - 1988)



Source: Kansas Health Data System

Figure #7

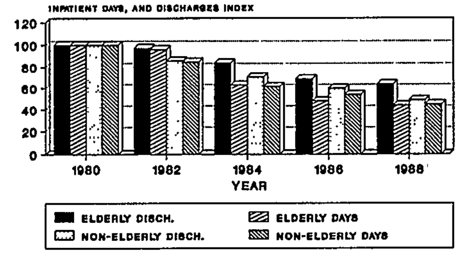
KANSAS NON-MSA COMMUNITY HOSPITAL DISCHARGE PROPORTIONS BY AGE CATEGORY IN SELECTED YEARS (1980 - 1988)



Source: Kansas Health Data System

Figure #8

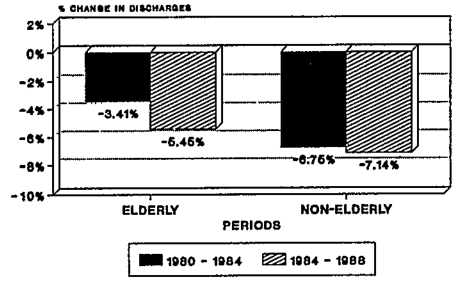
KANSAS NON-MSA COMMUNITY HOSPITAL INPATIENT DAY AND DISCHARGE INDEX BY AGE CATEGORY IN SELECTED YEARS (1980 - 1988)



1980 = 100
Source: Kansas Health Data System

Figure #9

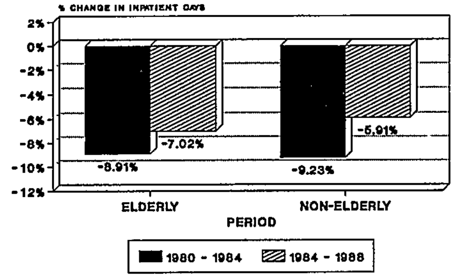
KANSAS NON-MSA COMMUNITY HOSPITAL DISCHARGE MEAN ANNUAL PERCENT CHANGE BY AGE CATEGORY (1980 - 1984, 1984 - 1988)



Source: Kansas Health Data System

Figure #10

KANSAS NON-MSA COMMUNITY HOSPITAL INPATIENT DAY MEAN ANNUAL PERCENT CHANGE BY AGE CATEGORY (1980 - '84, 1984 - '88)



Source: Kansas Health Data System

Figure #11

THE POWER OF FUNCTIONAL ASSESSMENTS: DISCUSSION

Rosalie A. Kane, University of Minnesota

The papers presented in this session raised many salient points about measuring an older person's functional status and need for care. As discussant, I found myself ready to enthusiastically echo many of the arguments.

Particularly, I would say "amen" to Karen Harlowe's comment that the service taxonomies that professionals invent and present to respondent's often bear little relationship to the categories in which people think. We tend to present older people and their families with lists of services such as "respite care" and "homemaking services" and ask them whether they use or need such a service. Based on detailed interviews we are doing at Minnesota with older people and their families, I seriously doubt that most respondents know what is meant by many of the terms.

The set of presentations began with Betty Haven's discussion of the rich Manitoba data set, developed as a result of case manager's periodic assessments of clients of the Continuing Care Program. I am struck that a great deal of information is available about social aspects of the client, including the family. It does not seem that the assessment information is used in any arbitrary way to force a decision about who gets what services. I have the impression that in Manitoba professional judgment rather than a fixed algorithm is still used to tie all the information together and reach a care plan. This is somewhat in contrast to the rules of eligibility being suggested for home care services in the United States.

But the Manitoba data could be analyzed to learn something about differing family constellations, and different mixes of family and professional help, how these are related to functional status and cognitive status, and what outcomes can be expected over time. Indeed, a data set such as Manitoba's should enable fine-tuning the work of case managers. Perhaps comparisons with data from states that provide comparable information (such as Oregon) would also be feasible.

I will concentrate the rest of my remarks on the challenges of measuring functional abilities and need for service (either of people or communities) in today's policy climate. As these presentations suggest, functional assessment has more than come of age. One's score on measures of abilities to perform activities of daily living (ADL) or instrumental activities of daily living (IADL) may now be worth money, either to the object of the assessment or to some service provider. The score can also be used to confer an entitlement, to make a person eligible for a service they wish, or, perhaps, to render them ineligible for a service they wish (for example, if the assessment indicated they were "too disabled" for home care.

Once a measure is used to confer a status, it is never quite the same as an objective measure of the phenomenon. One has only to think of the Grade Point Average or, to take an example closer to today's subject, some of the scales used by states to determine eligibility for skilled or intermediate levels of nursing home care. Both these examples illustrate how readily a measure can be corrupted when it is used to confer a status.

Indeed, functional status as measured by ADL and IADL scales has been proposed in most federal and state long-term care legislation as the eligibility criterion for the new services. As Corbin Lui's paper illustrates, whether one sets the eligibility at 2 ADL impairments, or 3 or 4 has great cost implications. And as Karen Harlowe's paper illustrates, one can get quite different answers depending on how one casts one's questions.

ADL measures are more objective than many psychometric tools, and they have perhaps a deceptive simplicity. But, in fact, there are many variations in the way information can be collected on the 5 or 6 simple items usually included on ADL scales (that is, bathing, dressing, toileting, transferring from bed or chair, feeding, and perhaps continence.)

For example, an ADL scale can vary according to:

- o <u>the source of the information:</u> report of the older person himself or herself; report a family member; report of a professional; or demonstration.
- o <u>the time frame:</u> right now; in the last few weeks; in the last six months.
- o <u>the place;</u> a key issue is whether assessments done in hospitals are valid.
- o <u>standard for determining independence:</u> for example, how well must the activities be performed before the subject is judged capable; how quickly must they be performed; does the amount of pain and discomfort accompanying the activity count; if a person needs to be reminded to do the activity but is otherwise capable, is this viewed as independence or dependence?
- o <u>capability versus performance:</u> will the measurement focus on the subject's capability to perform a task, or the habitual performance?

The latter takes into account the motivation of the subject and the opportunity afforded by the environment.

Each of these variations has practical significance. There are studies suggesting that functionally-impaired people, their family caregivers, and professionals are incongruent on the way they rate the impaired person's functioning. Often the professional is mistakenly taken as the gold-standard against which the validity of the others is measured. But in fact the professional may not be in a good position to judge. Often, too, a professional's standard for competent performance may be unreasonably high. (For example, a person may be said to be unable to dress independently if unable to manage various buttons, zippers, and fasteners, yet Velcro can improve functional for all practical purposes. Similarly, adequacy in bathing and housekeeping is a matter of value judgement.)

If a person needs to be reminded to perform various activities (for example, eating) and needs considerable supervision for safety's sake, is that person independent or dependent in ADL and IADL functions? This issue is attaining practical significance. Some states have adopted decision rules for their Medicaid-waiver programs where the they count the person as dependent if they need reminders, whereas other programs rate on physical abilities alone. Advocates for persons with Alzheimer's disease are afraid that their group will be left out of eligibility if strict ADL criteria are used. On the other hand, some proposed state and federal legislation would use a physician's diagnosis of dementia as an eligibility criterion, and surely this is too loose a definition, given the possibility of early diagnosis.

The relationship between measurable cognitive impairment and measurable functional impairment is an empirical question. A challenge for this group is to identify or develop data sets that have independent measures of ADL and IADL functioning, cognitive functioning, and need for daily supervision, and to determine how well they are correlated.

Corbin Lui's paper provides a vivid example of how ADL impairment can be "costed out." I have only a few quibbles about this very interesting work. First, I could wish that health services researchers abandon the insurance term "moral hazard" to refer to the additional demand that occurs when benefits are offered in attractive forms. Language is powerful, and the term seems to connote that persons eligible for new benefits by dint of their ADL impairment would be acting immorally by using those benefits.

Second, in using the Channeling Demonstration utilization information to project likely users of new long-term care benefits depending on eligibility criteria and the associated costs, we should remember that the specific personnel utilized and the costs are somewhat artificial. They are a result of the public policies in place that govern home health agencies. Under a different set of operational rules (more analogous, say, to the Canadian provinces), the cost of paraprofessional care would go up much more and the costs of professional care less than under Dr. Lui's projections. Finally, because these data will be used for political purposes, it seems insufficient just to remark as an aside that not all the projected costs of the benefit are new costs, but in fact some of these costs will replace existing costs under Medicaid and other public programs. The eyes of funders are likely to remain fixed on the cost columns. Therefore, it would be much more helpful, if it is possible, to present estimates of the new costs.

Whether ADL impairments should be measured by "unmet need" or by "inability to perform," the issue touched on by Harlowe's paper is a knotty question. ADL functions are so basic that there is unlikely to be much unmet need. The need to be fed, toileted, and cleaned is usually met to some extent, but perhaps at unusual sacrifice on the part of the impaired person and the family. Taken together, the papers of this session suggest to me that the measurement of functioning is more than a technical exercise, and that social values are buried in the measures and the rules for their use. Just as important as deciding whether 1 or 2 or 3 ADL deficiencies will be the magic passport to home care services is deciding how those deficiencies will be operationally defined.

Session W

For Minorities

PHCRS

ALCOHOL USE AMONG BLACK WOMEN: USING EPIDEMIOLOGIC DATA TO IMPROVE POLICY AND PROGRAM PLANNING DECISIONS

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Empirical data on the nature and extent of alcohol problems among black women is limited.1 The available data, however, suggest that alcohol use is of more serious consequence among black than white women. Data analyzed by the Secretary's Task Force on Black and Minority Health2 provide one indication that black women suffer disproportionately from alcohol-related causes of death. The Task Force found that age-adjusted mortality rates for chronic liver disease and cirrhosis, indicators of prolonged and heavy alcohol use, were twice as high among black (13.5 per 100,000) compared to white women (6.9 per 100,000) in 1979-81.

Factors contributing to the greater prevalence of alcohol-related illness and death among black women are not well understood. Little is known about the extent to which poorer outcomes are a function of differences in the quantity of alcohol consumed, the use of health services, or some combination of these factors. The data most frequently cited on racial differences in alcohol use are now more than 20 years old and are from a survey that included a small number of black women.3 To more precisely characterize the nature of the problem and the possible interventions that could reduce racial disparities in alcohol-related health outcomes, more recent and reliable information on the drinking and utilization patterns of black women is needed.

PURPOSE/METHODS

This study compares patterns of alcohol use among black and white women in order to assess the extent to which racial differences in alcohol-related illnesses and causes of death are a result of racial differences in drinking. It is a descriptive analytic study designed to test the hypothesis that patterns of alcohol consumption differ for black and white women. Specifically, the study answers two questions: (1) Are black women more likely than whites to be non-drinkers, heavier drinkers, or have a disorder of alcohol abuse and/or dependence; and (2) What factors are associated with alcohol use and abuse among black and white women?

To answer these questions, the study conducts secondary analysis of the responses of the Baltimore Epidemiologic Catchment Area (ECA) household survey. The ECA program was initiated by the National Institute of Mental Health (NIMH) and conducted within five U.S. geographic areas.4 The Baltimore ECA study design included a multi-stage probability sampling of households in the eastern region of Baltimore, Maryland. Household screening information was obtained on 95 percent of the 3,817 households initially selected for the sample. Personal interviews were conducted in 1981 and 1982 using a survey instrument that included the NIMH developed Diagnostic Interview Schedule (DIS). The DIS is a standardized interview schedule designed to make mental disorder diagnosis according to criteria of the Diagnostic and Statistical Manual, Third Edition (DSM III).

Alcohol use and abuse is measured using a quantity-frequency (Q-F) scale5 and the DIS questionnaire items. The Q-F scale requests information on the amount of alcohol consumed, how often alcohol was consumed in the past month, and the type of beverage consumed. With this information, an estimate of the average amount of alcohol consumed per day is computed using a scoring procedure which multiplies the number of drinks consumed by an estimate of the alcohol content of the beverage. The drinking groups are operationally defined to coincide with the definitions used by Clark and Midanik6 when comparing results of the 1967 and 1979 national surveys of adult drinking practices. Heavier drinking is defined as consuming 1.0 or more ounces of absolute alcohol per day.

The DIS questionnaire items are used to assess the presence of a disorder of alcohol abuse or dependence. Alcohol abuse is defined according to DSM III criteria as (a) a pattern of pathological alcohol use or (b) impairment in social and occupational functioning due to alcohol use. Alcohol dependence is also defined according to DSM III criteria as the presence of criteria (a) or (b) accompanied by either tolerance or withdrawal.

Current and lifetime alcohol use disorder prevalence rates are presented in this study. Lifetime rates represent the percentage of respondents who ever met symptom criteria for a DIS alcohol disorder. After a disorder is diagnosed as present within an individual's lifetime, the recenty of the symptoms is determined. Current rates represent the percentage of respondents with symptoms present within the 2 weeks, 1 month, or 6 month period prior to the interview. For the purpose of this study, a current alcohol use disorder is defined as the presence of abuse or dependence within the past 6 months.

As a first step in the analysis, racial differences are assessed in the percentages of non-drinkers, heavier drinkers, or women with an alcohol use disorder ever in their lifetime or currently. In this analysis, population estimates are weighted to represent the age-sex-race composition of the Baltimore ECA.7 Linear and logistic regression models are used to examine the extent to which race is associated with alcohol use while controlling for and studying the effects of socio-demographic characteristics (i.e., age, education, income, employment, marital status, and household size). To statistically test hypotheses regarding racial differences in alcohol use, interaction terms for race by each of the socio-demographic characteristics were included in the regression models. The interaction terms enable an assessment of the combined effects of race and the socio-demographic variable on alcohol use.

RESULTS

The study population consisted of 2,100 women or 60 percent of the 3,481 respondents interviewed by the Baltimore ECA survey. All male respondents and respondents who reported their racial backgrounds as American Indian, Alaskan Native, Asian and Pacific Islanders or Hispanic were excluded from the analysis. Of the 2,100 women remaining in the study population, 39 percent (N=809) were black and 65 percent (N=1374) were age 18-59.

Overall, the drinking patterns of black and white women were similar (see Table 1). About three-fifths of the women surveyed reported alcohol use in the month prior to the interview, with black and white women consuming on average less than one drink per day. Statistically significant racial differences were detected for the measure alcohol abuse or dependence ever within the lifetime; but the percentage of black and white women heavier drinkers or women with a current alcohol use disorder did not differ significantly.

To assess the combined effects of race and the socio-demographic characteristics on drinking, multivariate techniques were used. The major findings from this analysis are presented in Figures 1-6. Racial differences in the likelihood of being a non-drinker were found by age and marital status (see Figure 1 and 2). Adjusted estimates, computed for the significant interaction terms, indicate that black women were more likely than whites to be non-drinkers if they were young, i.e., 18-24 (43 percent vs. 29 percent), of older age, i.e., 60 or more (84 percent vs. 55 percent) or married with spouse (65 percent vs. 39 percent). Additionally, correlates of non-drinking identified for both black and white women were age of 60 or more years and/or education of fewer than 12 years.

Significant racial differences in heavier drinking were found by years of education. Data presented in Figure 3 show that education was inversely related to heavier drinking among black women, but had little influence on heavier drinking among whites. As a consequence, a similar percentage of black and white women with less than 12 years of education were heavier drinkers (4 percent vs. 5 percent) but black women who had completed high school and those with some college education were less likely than whites to be heavier drinkers (2 percent vs. 4 percent; 1 percent vs. 4 percent). This finding applied to all women and to the subset of women drinkers (see Figure 4). For both black and white women, factors strongly correlated with heavier drinking were middle age (i.e., age 25-44, 45-59) and/or limited household income (i.e., less than $6,000).

Figures 5 and 6 provide estimates of alcohol abuse or dependence by age groups. After adjusting for differences in socio-economic characteristics, black and white women were equally as likely to have ever met criteria for abuse or dependence or to meet criteria for a current disorder. Non-significant interaction terms for race by each of the socio-demographic characteristics confirmed that patterns of abuse did not differ for black and white women in these sub-groups. Factors found to be strongly correlated with abuse or dependence among black and white women were age of 18-59 and/or marital status of separated, divorced, or widowed.

To assess the extent to which the two measures of alcohol use were related, a new classification scheme integrated data on the DIS alcohol use disorder with data on the quantity-frequency alcohol use measure. Respondents were assigned to 1 of 4 groups: non-drinkers, light/moderate drinkers; heavier drinkers; or DIS alcohol use disorder. All women with a diagnosis of alcohol abuse or dependence were grouped together, irrespective of their classification based on the quantity-frequency measure of alcohol use. Interestingly, while more than half (24/42) of the women with an alcohol use disorder were heavier drinkers, only one-fourth (24/90) of the heavier drinkers were diagnosed with a current alcohol use disorder.

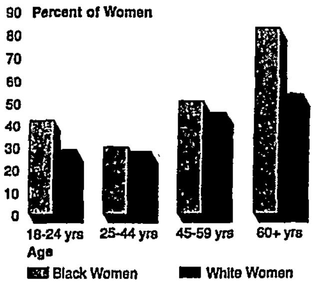
TABLE 1. GAO Alcohol Use and Abuse Among Women in the Baltimore ECA Survey

	Blacks (N = 786)	Whites (N = 1221)
Non-Drinkers	47.7%	39.7%
Heavier Drinkers	5.1	4.2
Alcohol Abuse/ Dependence Ever in Lifetime	6.3	3.0[a]
Current Alcohol Abuse/Dependence	3.1	1.6

[a] Statistically significant difference at the 95 percent confidence level

FIGURE 1

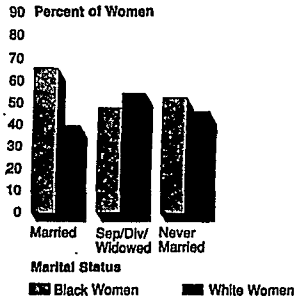
GAO Adjusted Percent Women Non-Drinkers By Race and Age



Source: Baltimore ECA Survey Data, 1982

FIGURE 2

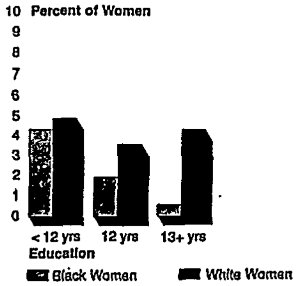
GAO Adjusted Percent Women Non-Drinkers By Race and Marital Status



Source: Baltimore ECA Survey Data

FIGURE 3

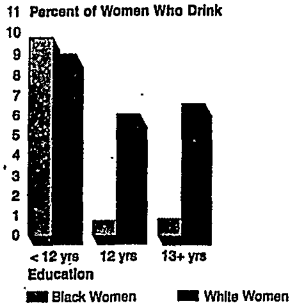
GAO Adjusted Percent Heavier Drinkers By Years of Education: All Women



Source: Baltimore ECA Survey Data, 1982

FIGURE 4

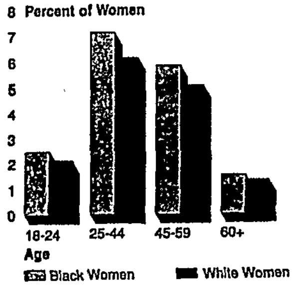
GAO Adjusted Percent Heavier Drinkers By Education: Drinkers Only



Source: Baltimore ECA Survey Data, 1982

FIGURE 5

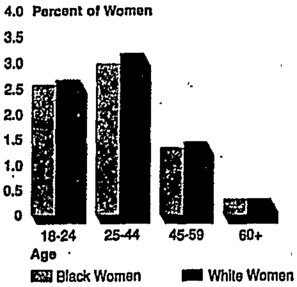
GAO Adjusted Rates of Alcohol Abuse/Dependence Among Women Within Lifetime



Source: Baltimore ECA Survey Data, 1982

FIGURE 6

GAO Adjusted Rates of Current Alcohol Abuse/Dependence Among Women



Source: Baltimore ECA Survey Data, 1982

Table 2, presenting the combined alcohol use or abuse measure by two summary age groups, shows that about 8% of black women and 5 % of white women age 18-59 were heavier drinkers or had an alcohol use disorder. While black and white women age 18-59 differed only modestly within drinking groups, racial differences among women age 60 and older were considerable.

TABLE 2.

GAO Distribution of Women By the Combined Alcohol Use or Abuse Measure

	N	Non-Drinker (%)	Light/ Moderate (%)	Heavier (%)	Alcohol Abuse/ Dependence (%)
Women 18-59					
Black	645	41.9	50.4	4.4	3.3
White	710	31.4	63.3	3.3	2.0
Women 60+					
Black	144	82.4	16.4	0.0	1.2
White	511	55.8	40.7	3.0	0.5

Source: Baltimore ECA Survey Data, 1982

RELEVANCE OF FINDINGS TO POLICY AND PROGRAM PLANNING

This study provides epidemiologic data which are useful for policy and planning purposes. First, the information is helpful in developing estimates of the need for alcohol treatment services for women. Second, the knowledge gained improves our understanding of the factors that contribute to racial disparities in alcohol-related illness and causes of death among women. And finally, the study findings can assist in developing preventive interventions which target black and white women.

Knowledge of the proportion of black and white women who abuse or are dependent on alcohol is important in deriving estimates of the need for alcohol treatment services that target women from both racial groups. Decisions to maintain or expand resources (i.e., financial, physical, or human resources) to address a problem are contingent upon our knowledge of the extent of the problem confronting a population group or geographic area. Applying estimates from this study to the Baltimore population would suggest that at any given point in time about 4,800 black and 2,200 white women have an alcohol use disorder and thus could benefit from treatment. Since it is known that only a fraction of the persons in need of care actually seek care, this study provides only part of the knowledge base needed to derive health service resource requirements for the treatment of alcohol-related problems among black and white women. The findings, however, provide the essential framework of information needed to evaluate the adequacy of resource allocation decisions.

This study has several implications for the planning of research designed to inform policy decisions. The fact that the study findings differ from national survey results raises questions about the generalizability of the national findings to the Baltimore area and shows the importance of local as well as national surveys. The varying survey results serve as a reminder that since most national surveys include only a small number of observations from a geographic area or population subgroup, findings must be applied cautiously for local policy decisions.

Beyond this general message, however, is the relevance of the ECA findings to our understanding of the factors that contribute to racial disparities in alcohol-related health outcomes. National survey estimates have provided support for the belief that racial differences in alcohol-related illness and causes of death were a consequence of a greater prevalence of alcohol abuse among black women. The finding that black women were at no greater risk of heavier drinking or of an alcohol use disorder raises questions about the extent to which racial differences in drinking contribute to the vastly different alcohol-related health outcomes of women in Baltimore. The findings of this study suggest that explanations other than drinking (e.g., later detection of symptoms, less effective treatment modalities, or the presence of other illnesses) should be investigated as possible factors accounting for racial differences in alcohol-related morbidity and mortality.

Finally, this study identified factors associated with alcohol use which were common to black and white women and other factors which were unique to black women. Identifying factors associated with drinking is important for planning alcohol abuse prevention, intervention, and treatment services which are most likely to be effective. For both racial groups, middle age (i.e., 25-59) and/or limited income (i.e., less than $6,000) were correlates of heavier drinking. Age of 25-59 and/or being separated, divorced, or widowed were correlates of alcohol abuse or dependence. Thus, prevention efforts should similarly target black and white women with these characteristics. However, while the at-risk group may be similar, the intervention approach for each racial group may very well differ. It is this difference which may necessitate distinct allocations of funds for white women and for black and other ethnic minority women.

The finding that education was inversely related to heavier alcohol use among black women is potentially important in the development of alcohol abuse prevention strategies. How or why education functions to reduce the likelihood of heavier drinking is unclear. Perhaps educational achievement among black women results in less motivation for heavier drinking, i.e., less need for mood altering substances to either reduce feelings of inadequacy or augment feelings of excitement. It is also possible that the education variable merely serves as a proxy for an upwardly mobile population of black women that has less of a willingness to engage in behavior that could pose a risk to their accomplishments. Another plausible explanation is that black women college graduates have fewer opportunities to drink than their white counterparts given differences in employment patterns.

Admittedly, much remains to be learned about the association between education and drinking among black women. While it could be premature to alter intervention efforts based on the results of a single local study, this study provides sufficiently strong evidence to encourage research to assess whether an alcohol abuse prevention/intervention strategy that promotes educational achievement has greater relative merit for black women than white women. To systematically test the benefits of such an approach, a prevention/intervention trial that evaluates the effectiveness of programs that have elected or not elected to include educational attainment efforts in their approach could be undertaken. The programs could target women who have not completed high school or are at risk of not completing high school. Women could be identified in a number of ways including for example, through programs providing services to teenage mothers, by reviewing school truancy and disciplinary records, and through job training programs.

Alcohol treatment programs should also be sensitive to the possible influence of education on the drinking behavior of black women and even consider developing programmatic efforts that assist women in completing high school or passing a high school equivalency test. Many alcohol treatment programs already include vocational and educational service components designed to enhance treatment efforts. The findings of this study provide evidence that while these efforts may have only marginal benefits for whites, they may be essential components for black women.

In summary, this study provides strong evidence that black women in the Baltimore ECA were at no greater risk of heavier drinking or alcohol abuse and/or dependence than whites. This finding raises questions about the generalizability of national alcohol use survey estimates to the Baltimore ECA and provides evidence to suggest that racial differences in alcohol-related mortality may not be a consequence of greater alcohol use among black women. Additionally, findings on correlates of alcohol use identified at least one factor which may be helpful in shaping alcohol prevention programs which target black women.

+ This work was done while the author was a doctoral student at The Johns Hopkins University School of Hygiene and Public Health and does not necessarily reflect the views of the U.S. General Accounting Office.

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RACE DIFFERENCES IN HYPERTENSION: IDENTIFYING THE DETERMINANTS

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Epidemiologic research has long identified an association between race and hypertension (1,2). Blacks are twice as likely as whites to have high blood pressure (3). As a major risk factor for coronary heart disease (CHD) and the major risk factor for cerebrovascular disease, hypertension is an important contributor to excess morbidity and mortality in the black population. CHD is the most common cause of death among blacks, and contrary to popular perception, it occurs more frequently among blacks than whites (4). With regard to stroke and kidney disease, the excess deaths for blacks are out of proportion to the higher prevalence of hypertension among blacks. Mortality rates from stroke and end-stage renal disease are 7 to 19 times higher for blacks than whites (3,5).

Identifying the mechanisms responsible for race differences in elevated levels of blood pressure can facilitate attempts to control hypertension among blacks, and reduce death rates from CHD and stroke. Decades of research have provided important information about the existence and magnitude of race differences in hypertension, but how and why these differences occur is not well understood. Racial differences in socioeconomic and other environmental factors as well as black-white differences in renal physiology and other genetic mechanisms have been proposed as the causes of race differences in blood pressure (3,6).

Marital status (7), medical care (8), exercise (9), obesity (10), salt intake (11), alcohol (12), caffeine (13), and cigarette smoking (14) have all been identified as possible risk factors for elevated levels of blood pressure. In this paper we explore the extent to which these risk factors can account for race differences in blood pressure levels. First, we examine race differences in the distribution of these risk factors, and then we investigate the extent to which these health behaviors and lifestyle characteristics, both singly and in combination, can explain observed race differences in blood pressure.

Data and Methods

Study Population

This study uses data from the second National Health and Nutrition Examination Survey (NHANES II) to analyze the relationship between race and hypertension. A detailed description of the survey design has been reported earlier (15). Conducted between 1976 and 1980, NHANES II is a cross-sectional sample survey selected to be representative of the civilian, noninstitutional population in the United States. The overall response rate was 73 percent. Children and persons living below the poverty line were oversampled. Analyses for this study are restricted to adult respondents between the ages of 20 and 74. Complete data on all of our measures is available for 10,669 adult respondents. One thousand and twenty-eight of these adults are Black.

Measures

Each respondent's blood pressure was measured three times, using standardized procedures (15). The measures of systolic (SBP) and diastolic blood pressure (DBP) utilized are based on the mean of the second and third blood pressure readings. Respondents currently taking high blood pressure medication or who have SBP greater than 159 or DBP greater than 94 are defined as hypertensive. In addition to this dichotomous measure of hypertension, SBP and DBP are also used as dependent variables. However, whenever SBP and DBP are utilized, we attempted to eliminate a potential source of bias. Since the diagnosis of hypertension could change some of the health behaviors examined here, for all analyses using SBP and DBP as dependent variables, we excluded all respondents (n=3,082) who reported that they had ever been told by a doctor that they had high blood pressure or hypertension.

Table 1 lists the independent variables used in examining the relationship between race and hypertension. Race is measured as (Black=1, White/other=omitted). Age in years is used as a demographic control in all analyses. Years of formal education and total family income (in dollars) are two indicators of socioeconomic status utilized. Marital status is the measure of social integration (married=1, unmarried=omitted). Medical care is measured by the number of times in the past 12 months that a respondent's blood pressure was measured. Blood pressure measurements when a respondent was an in-patient were not included. The number of reported blood pressure measures range from none to 75.

Measures for six health practices assess traditional risk factors for hypertension. The body mass index (BMI) is used to measure obesity. The BMI is created by dividing weight in kilograms by the square of height in meters. Smoking status is divided into four categories: heavy smokers, light smokers, former smokers and persons who have never smoked cigarettes. Two indicators of exercise, both based on self-report, are employed. The first measures physical activity obtained from recreational activities and

Table 1. Variables Used In Analyses of Race Differences In Blood Pressure Levels, NHANES II (1976-1980).

Variable	Measurement
1. Age	Years
2. Race	Black/all other (omitted)
3. Socioeconomic Status	
A. Income	Total household earnings (dollars)
B. Education	Years
4. Marital Status	Married/unmarried (omitted)
5. Medical care	Number of times blood pressure checked in past year
6. Obesity	Body mass index: weight (kg) divided by square of height (m)
7. Smoking	Heavy (greater 1 pack/day), light (less 1 pack/day), former, never (omitted)
8. Physical Activity	
A. Recreation	1=much exercise, 2=moderate exercise, 3=little or no exercise
B. Usual Day	1=very active, 2=moderately active, 3=quite inactive
9. Salt	
A. Salt Shaker	Frequency of using the salt shaker at the table. 0=rarely or never, 1=occasionally, 2=frequently
B. Salty Snacks	Frequency of eating salty snacks. 0=never,05=less than once a week, 10-60=one to six times per week, 1010-1100=one to 10 times per day
10. Alcohol	Index based on the consumption of beer, wine and alcoholic beverages. 0=never, 5=less than once a week, 10-60=one to six times per week, 1010-1050=one to 20 times per day
11. Caffeine	Amount of coffee or tea a person drinks. 0=never, 05=one to six times per week, 1010-1300=one thirty times per day

the second assesses the level of activity in the respondent's usual day. Alcohol is a summary measure based on the consumption of beer, wine and hard liquor. Two indicators of salt intake are utilized: frequency of salty snacks and frequency of using the salt shaker at the table. Finally, caffeine intake is measured by the frequency of drinking coffee or tea.

Statistical analysis

Simple descriptive analyses are used to present mean differences by race in the distribution of risk factors for elevated levels of blood pressure. However, this report relies primarily on multiple regression analyses to estimate the magnitude and statistical significance of the relationships among race, risk factors and blood pressure. When hypertension is the dependent variable, multiple logistic function analyses using maximum likelihood -estimation procedures (16) are employed. To facilitate interpretation approximate relative risk ratios are presented. The relative risk is the ratio of the expected hypertension rates for blacks compared to whites. Ordinary least square regression analyses are used when SBP and DBP are the dependent variables. All analyses are reported separately for men and women. The data are weighted for individual selection probability and nonresponse. Post-stratification procedures are employed to adjust the data by age, sex and race to be representative of the civilian, noninstitutionalized U.S. population.

RESULTS

Table 2 presents the distribution of the risk factors by race. There are no significant race differences, for either sex, in physical activity, salt intake and alcohol consumption. Moreover, the observed differences are not consistently in the direction of elevated blood pressure levels for blacks. In keeping with the expectation of higher rates of hypertension, blacks are less likely to be married, more likely to smoke, and black females are more likely to be obese than their white counterparts. At the same time, blacks report higher levels of

Table 2. Distribution Of Risk Factors By Race (Means And Proportions), For Males And Females, Aged 20-74, NHANES II (1976-1980).

	Men		Women	
	White (n=4558)	Black (n=512)	White (n=4980)	Black (n=619)
Marital Status	.78	.59*	.66	.40*
Medical Care	3.12	3.91*	3.78	5.20*
Physical Activity				
Recreation	1.47	1.41	1.46	1.35
Usual Activity	1.48	1.46	1.58	1.47
Obesity	24.74	24.81	24.03	26.38*
Salt				
Salty Snacks	86.25	71.33	57.80	49.74
Salt Shaker	1.13	1.07	.83	.76
Total Alcohol	79.33	76.65	25.36	19.28
Caffeine	838.80	571.04*	854.26	593.51*
Smoking				
Never	.27	.25	.53	.56
Ex-smoker	.35	.25	.16	.11*
Light	.23	.43*	.24	.30
Heavy	.14	.07*	.07	.03*

*=p<.05

medical care and lower levels of caffeine consumption than whites. Moreover, the association between race and health practices is sometimes complex. In the case of smoking, for example, although blacks have a higher rate of smoking, white males and females are twice as likely to be heavy smokers than their black peers.

Table 3 shows the relationship between race and hypertension. Estimated relative risk for blacks compared to whites and their associated 95 percent confidence intervals are presented. Each entry in the table represents a separate logistic regression analysis. The first model presents results of the relationship between race and hypertension adjusted for age. The second model shows how the age-adjusted association is altered when controls are introduced for the two socio-economic status (SES) indicators. In subsequent models, risk factors are added singly to a base model that includes the coefficients for race, age and SES. A final model includes all the covariates of the previous models. The primary interest here is in assessing change in the association between race and hypertension when adjusted for other risk factors. If differential exposure to risk factors is partly responsible for race differences in

Table 3. Estimated Relative Risk[1] And 95% Confidence Intervals For The Association Between Race And Hypertension, For Males And Females, Aged 20-74, NHANES II (1976-1980)

Adjusted For	Men		Women	
	Rel. Risk[1]	95 Percent Confidence Interval	Rel. Risk[1]	95 Percent Confidence Interval
Age	1.42	(1.09-1.86)	3.16	(2.55-3.91)
Income, Education	1.42	(1.08-1.87)	3.03	(2.43-3.79)
Marital Status	1.40	(1.06-1.84)	3.19	(2.55-4.00)
Medical Care	1.36	(1.03-1.80)	2.71	(2.15-3.42)
Physical Activity	1.42	(1.08-1.86)	2.97	(2.37-3.73)
Obesity	1.35	(1.02-1.78)	2.43	(1.93-3.06)
Salt	1.38	(1.05-1.81)	3.00	(2.40-3.76)
Alcohol	1.44	(1.09-1.88)	3.03	(2.43-3.79)
Caffeine	1.35	(1.02-1.78)	2.89	(2.30-3.63)
Smoking	1.50	(1.13-1.98)	3.10	(2.47-3.88)
All Variables	1.25	(0.93-1.68)	2.29	(1.79-2.94)

[1] Multiple logistic regression model.

hypertension, there should be reductions in the magnitude of the race effect when these risk factors are entered into the regression equation.

Several points are noteworthy in Table 3. First, the association between race and hypertension is markedly larger among females than among males. While black females are three times more likely than their white peers to be hypertensive, the estimated relative risk for black males is only 1.4 times that of white males. Second, controlling for income and education results in virtually no reduction in the association between race and hypertension. This is instructive because it is generally believed that socioeconomic factors account for a substantial part of the elevated risk of hypertension among blacks.

Third, the risk factors considered here have minimal impact on the racial differences in blood pressure. For males, none of the adjustment variables markedly reduce the association between race and blood pressure. Among females, medical care and obesity are responsible for the largest reduction in the effect of race, but even these variables make only a minimal contribution. Obesity reduces the association between race and hypertension by 20% while medical care accounts for 11%. In sum, the socioeconomic and behavioral risk factors explored here do not play a critical role in explaining race differences in hypertension.

As noted earlier, the diagnosis of hypertension is often accompanied by recommendations for change in at least some of the risk factors considered here. To avoid this source of bias, we explored race differences in the mean levels of diastolic and systolic pressure in a subpopulation that excluded all respondents who had ever been told by a physician that they had high blood pressure. Our plan of procedure for these analyses were similar to those described for Table 3. We first examined the association between race and mean levels of blood pressure adjusted first for age and then for age and SES. The other covariates were then entered one at a time with all subsequent models, including controls for the socioeconomic indicators and age.

Table 4 presents the results of these analyses for diastolic blood pressure. The metric regression coefficient for race and the net R^2 associated with the introduction of each new covariate is presented. Table 4 reveals that only obesity makes a meaningful contribution to explaining variations in diastolic blood pressure. For both men and women, obesity explains nine percent of the variance in blood pressure. Not surprisingly, it is only when adjusted for obesity that the association between race and diastolic blood pressure is reduced. This reduction is small for males (18% from the model that includes controls for age and SES) but dramatic for women (74%). In fact, the association between race and diastolic blood pressure is reduced to non-significance when adjusted for obesity.

Similar analyses, not shown, explored race differences in systolic blood pressure. An identical pattern was observed for females. The significant association between race and systolic blood pressure ceased to exist when adjusted for obesity. Among males, there were no significant race differences in systolic blood pressure. In sum, higher levels of obesity among black females

Table 4. Association Between Race And Diastolic Blood Pressure, Males and Females, Aged 20-74, NHANES II (1976-1980).

Adjusted For	Men			Women		
	Race	R^2	Net R^2	Race	R^2	Net R^2
Age	1.36+	.039	---	1.76**	.103	---
Income, Education	1.30+	.047	.008a	1.70**	.108	.005a
Marital Status	1.45*	.053	.005b	1.79**	.109	.001b
Medical Care	1.34+	.048	.001b	1.77**	.108	.000b
Physical Activity	1.30+	.046	-.001b	1.75**	.107	-.001b
Obesity	1.07+	.139	.092b	0.44	.201	.093b
Salt	1.29+	.047	.000b	1.68**	.111	.003b
Alcohol	1.30+	.049	.002b	1.70**	.108	.000b
Caffeine	1.40+	.048	.001b	1.73**	.108	.000b
Smoking	1.49*	.052	.005b	1.59**	.112	.004b
All Variables	1.35+	.144	.097b	0.67	.207	.099b

a=Incremental contribution to R^2 from the age adjusted regression model. b=Incremental contribution from the model that includes age and SES variables.
+=p<.05; *p=<.01; **=p<.001

compared to their white peers, can completely account for race differences in diastolic and systolic blood pressure. Researchers have long noted that black females are twice as likely to be obese as white females (17). Our findings here suggest that this higher level of obesity may be a critical determinant of hypertensive disease among black females.

DISCUSSION

Our results are consistent with other data that indicate that obesity may play an important role in the development of hypertension (18, 19). Accordingly, weight loss is a potent strategy to reduce elevated levels of blood pressure. Studies reveal that weight loss is associated with reduced levels of blood pressure, independent of pharmacological treatment (20) or sodium restriction (21). In fact, the MRFIT data reveal that men who did not receive pharmacologic treatment for blood pressure but who experienced a given level of weight loss, had greater reductions in systolic and diastolic blood pressure than men on antihypertensive medication who achieved the same level of weight loss (20).

There is thus clearly a need for greater emphasis on nonpharmacological approaches to control hypertension in the black community. The urgency of such action is suggested by several factors. First, only a minority of adults in the U.S. have optimal levels of blood pressure; that is, diastolic and systolic pressures less than 80 and 120 mm Hg, respectively (22). Persons in the high normal range of blood pressure readings (e.g., DBP between 80 and 89 mm Hg) have reduced life expectancy and higher rates of hypertension-related diseases (11, 22). Accordingly, efforts to control blood pressure should focus not only on persons arbitrarily defined as hypertensive but should attempt to move the entire population distribution of blood pressure downwards.

Such attempts at hypertension control should not use the standard stepped-care pharmacological approach. There is renewed concern in the medical community about the use of pharmacology as the sole or primary strategy to control hypertension, especially mild hypertension (23-25). Some 70% of persons with essential hypertension have mild hypertension (DBP 90 to 104 mm Hg [11]), and the available evidence from clinical trials suggest that the benefits of giving such patients antihypertensive medications may not exceed the risks (23-25). Nonpharmacologic approaches emphasizing weight control and changes in health behavior appears to be more appropriate than antihypertensive therapy for persons with mild hypertension and high-normal levels of blood pressure (22).

The identification of obesity as a major risk factor for elevated levels of blood pressure in the black population creates both an important opportunity and a major challenge. Attempts to control obesity are notoriously ineffective over the long term. Physicians now regard obesity as a relatively incurable disorder and sociologists indicate that the medicalization of weight is an example of the extension of medicine into an area where it does not possess the expertise to effect a cure (26).

A recent report from New Zealand (27) suggests a possible model for weight control efforts in the black community. This study showed that inexpensive, community based, behaviorally oriented weight control programs can produce long term weight loss among low SES women. These programs were based within local natural communities and were led by lay leaders who had received training from professionals. Given the central role that the church continues to play in the black community and the high level of public religious participation among black females, it appears that the black church is a natural community that could be targeted for intervention efforts. Health providers should attempt to build linkages with the black church that would facilitate the empowerment of black females to make changes to improve their health status.

More generally, the primary prevention of high blood pressure requires population based approaches targeted at whole communities (28). Stunkard (29) has recently reviewed the community approaches, such as the Stanford Community Studies project, that have focused on reducing heart disease risk. He argues, correctly, that more systematic efforts must be made to apply the "technology" of these community studies to the control of obesity.

Stunkard (29) also indicates that, to a large degree, obesity is under the control of the social environment. Larger social institutions and processes create conditions that can initiate and maintain obesity. Accordingly, in the long run, the primary prevention of obesity, hypertension and the all of the lifestyle related chronic diseases, may require changes not only in the behavior of individuals but in the socioeconomic conditions under which they work and live. An individual's position in society is linked to larger social structures and processes that constrain and limit his/her behavior in ways that can promote either health or illness. There is need of greater recognition that the lifestyles of the poor are adaptive to the realities and constraints of the external environment. Accordingly, McKinlay (30, p. 257) warns that "attempts to alter lifestyles without also altering social structure and life chances may do more harm than good."

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EXTRAPOLATING THE NEED FOR CARE AMONG MINORITY ELDERS: IMPLICATIONS FOR ALTERNATIVE SERVICE DELIVERY SYSTEMS

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The "appropriate provision of care" to an increasingly aging society is, perhaps, among the most pivotal public policy issues on the National Health Agenda. Confronted with this "new geriatric mandate", many public health and long-term care providers have begun to utilize various forecasting models, in order to extrapolate the future long-term care supply and demand needs. Given the rising costs of health care, coupled with the rapid increase of the older population, there is a recognized need to develop "alternative service delivery systems", as a mechanism to promote quality and access, while concurrently containing costs.

Recent studies have shown correlations between advancing age and the increased incidence and prevalence of functional limitations and co-morbidity (Branch and Jette, 1982; Guralnik, 1988; Manton, 1988). Predictors of institutionalization include: age, ADL dependencies, race, living alone, marital status, income, mental status, and lack of social supports (Kane and Kane, 1986).

In 1985, there were an estimated 6.2 to 6.5 million elders who depended on others for assistance in activities of daily living and instrumental activities of daily living. By the year 2000, that number is expected to increase to 14.3 million. In a recent report by the General Accounting Office (1988), it was concluded that the "very dependent" elderly were less likely to obtain nursing home care and more likely to remain in the community with a myriad of unmet needs.

Recently, there has been increased concern relative to racial differentials in health status and access to medical care. These disparities in the excess of unmet needs (Blendon et al, 1988) and the excess deaths (U.S. Department of Health and Human Services, 1985) between whites and nonwhites appear to be widening. Among the most vulnerable are minority elders, who are more likely to be "multipally disadvantaged" due to the cumulative effects of disadvantage imposed by various socio-structural constraints throughout the life course.

While there has been a proliferation of research conducted in order to explicate various social, structural and biologic determinants of health among the aged, there is only a paucity of information relative to the health status and behaviors of minority elders. Moreover, some ethnogerontologists claim that the existing body of knowledge is "fragmented" and "inconclusive" and based, for the most part, on cross-sectional, as opposed to longitudinal data. Kane and Kane (1986) are among those who caution against the use of cross-sectional studies as the sole basis for policy development. In addition, those studies often assume the notion of homogeneity within races, which refutes the current perspectives of heterogeneity and diversity in aging.

Intra-cohort and inter-cohort diversity in the trajectories of functioning among various minority populations has a wide-range of methodological and policy implications. Since the aged, like racial and ethnic minorities are not homogeneous groups, the notion of divergence is salient to any discussion of determinants of long-term care needs or service utilization patterns. It is within this framework, that population estimates of the unmet needs and need for care among various elderly minority groups should be conducted.

The purpose of this paper is to discuss the use of longitudinal studies, namely, the Longitudinal Study on Aging (LSOA) in targeting "alternative service delivery systems" for minority elders. Although cross-sectional studies may be useful in describing variations in health status and health utilization patterns among various populations, caution should be exercised in forecasting service delivery needs, based only on these data. Longitudinal studies may be more useful to health policy analysts and planners in, not only, quantifying services, but also examining and estimating changes over time.

It is within this framework that a secondary analysis of the LSOA was conducted. As you may know, the LSOA was a follow-up to the 1984 Supplement on Aging and part of the National Health Interview Survey. The purpose of the LSOA was to provide statistical measures of changes in functional status and living arrangements of older adults, in order to determine points of intervention which may delay or prevent institutionalization. Data were collected on the incidence and prevalence of various conditions, demographic characteristics, health utilization patterns, community and social supports, as well as, health opinions and behaviors. The LSOA was designed to provide national estimates of the noninstitutionalized 70 years of age and older population. Preliminary analysis of the LSOA was conducted in order to determine the extent to which various factors influenced changes in the trajectories of ADL functioning or self-care activities. Variables included: race, age, marital status, education, income, perceived health, availability of assistance from others and the number of ADL difficulties in 1984. Multi-variate models were utilized to determine the extent to which various interactions affected changes in ADL functional status. Intra-cohort differences in the rates of morbidity and mortality were found by age and gender. However, due to unequal cell sizes, racial comparisons could not be made.

Findings from this study are similar to recent studies which have shown increased intra-cohort divergence in the trajectories of ADL functioning, with advancing age (Manton, 1988). Minority elders are heterogeneous populations, showing divergence in functioning by age and gender. While some groups declined in functioning, others remained stable or improved during, the two year period.

Determining the Need for Alternative Service Delivery Systems

While the majority of National Health Objectives for the Year 2000 are applicable to all minority groups, several appeal to be more salient to the emerging needs of various elderly minority populations, these include:

a) to prevent, detect and control other chronic conditions and disorders;

b) to maintain and improve the quality of life of older people; and

c) to improve health education and access to preventive health services and to improve surveillance and data systems.

Recent trends toward structural changes in, and the corporatization of, health and long-term care services are major challenges which will affect the extent to which health objectives targeted toward minority elderly populations will be attained, particularly, among those characterized as having at-risk lifestyles. The questions of fiscal and moral responsibility for sharing the burden and costs of care, while concurrently ensuring quality, continuity and access will continue to be major challenges to public health.

Among the highest priorities of the public health agenda is increasing the demand for health promotion/primary prevention services among black and other minority populations, at all stages of the life course. Since there are various predisposing and enabling factors which may influence the "perceived" and/or "evaluated" need for care (Aday and Anderson, 1980), a redistribution of public health systems resources toward health promotion and primary prevention targeted toward minorities, at earlier stages of the life course, should be considered. At the same time, quantification of the extent to which various interventions are effective is also important. Thus, development of various surveillance systems is critical to monitoring the cost effectiveness and efficiency of various formal and informal systems in meeting the service needs of targeted special populations.

It is within this framework, that the "Special Populations Alternative Service Delivery Systems Model for Long-Term Care" is presented. It is based on the notion of a coordinated continuum of care, which is designed to promote the increased access to, and utilization of community-based health promotion services and resources. The organization and availability of alternative service delivery systems targeted toward minority populations should be community-based and managed in collaboration with families, neighborhood groups, civic organizations, churches and the private sector. Health promotion activities, however, must be "life course initiatives", as well as, "age-based." These activities should be intergenerational, as well as, multi-systems approaches to improving health-related quality of life. Greater emphasis should be placed on cultivating family and informal social networks within the minority community, as well as, providing resources and incentives to family caregivers.

As we approach the year 2000, there are many challenges in the area of minority health and aging. We are confronted with one of the major challenges of the century--"the challenge of change"--lifestyle changes, values and systems changes. While the doors to the past traditional health service delivery systems may appear to be closing, the future may hold various "windows of opportunity."

SPECIAL POPULATIONS

ALTERNATIVE SERVICE DELIVERY

SYSTEMS MODEL FOR LONG TERM CARE

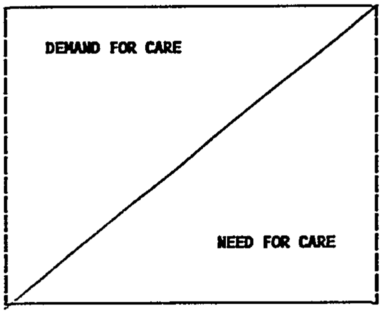
(McDonald, Harlow and Ludwin, 1989)

CONSUMER CHARACTERISTICS

Predisposing
  o Mutable
  o Immutable

Enabling
  o Mutable
  o Immutable

Need
  o Perceived
  o Evaluated



SYSTEM CHARACTERISTICS

Availability
o Volume
o Distribution

Organization
o Entry
o Structure

CONTINUUM OF CARE

Self-Help Informal	Supports	Institutional Help Formal Supports
PRIMARY PREVENTION	SECONDARY PREVENTION	TERTIARY PREVENTION
Preventive Interventions Community Services	Screening & Early Detection Ambulatory Care Acute Care	Rehabilitation Home Care Extended Care

*Adapted from Aday, L, Anderson, R., and Fleming, G., (1980). Health Care in the U.S. Equitable for Whom. Beverly Hills, CA: Sage Publications

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Session X

For Homeless

PHCRS

BEYOND PRIMARY CARE: SPECIAL NEEDS OF HOMELESS CHILDREN

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The New York Children's Health Project (NYCHP) provides pediatric services to homeless children via mobile medical units as an outreach activity of the New York Hospital-Cornell Medical Center. Begun in November of 1987 the project was developed in response to substantial health care needs of a growing population of homeless children in New York City. The number of children living with homeless families in 1980 was estimated to be approximately 1,400. By 1986-87 this number had grown to approximately 12,000. It was further estimated that at least another 100,000 children were living with "near homeless" families; that is to say, those who were living in poverty doubled up with friends or relatives but unable to identify a fixed address. Although the problems associated with a lack of stable housing are exacerbated in New York City, this is clearly a national problem of substantial proportions. Many authorities estimate that as many as 3 million Americans may fall into the homeless designation.[1]

With nearly 60% of its 2 million child population living with families below the poverty guidelines, economic and medical deprivations are common problems for families in New York City. An overburdened and underfunded indigent health care system is continually stressed by the concomitant problems of pervasive substance abuse (particularly crack), and AIDS as well as the growth of poverty in general. Homelessness has added an additional dimension which imposes yet another enormous challenge to the system.

The Shelter System in New York

In New York City, homeless families are maintained in public and private shelters pending the availability of low income permanent housing for homeless families. While some of these transitional facilities are run by city and private agencies the majority of families, particularly in 1986 through 1988, were housed in privately owned "welfare hotels" where profound squalor, deprivation and endangerment were staples of daily living. Families remained in the homeless shelter system for an average of 15 to 18 months. Many families were housed far from their original neighborhoods so that whatever relationships existed with ongoing health care providers were effectively severed. By and large, health care needs could not be met effectively in the new transitional neighborhoods.

Health Care Needs of Homeless Children

Children living with homeless families have a number of identifiable problems which can be attributed to the working combination of poverty, lack of access to health care, and conditions in the shelters themselves. Severely affected children might be considered to have the "Homeless Child Syndrome" which is described elsewhere.[2]

In general, to deal with the medical problems of homeless children, primary health care is the essential focus of new programs. However, secondary and tertiary health care needs are an important and often neglected concern of program planners. Data from the New York Children's Health Project indicates the need for including backup and hospital-based health care services as an integral part of the health care planning process for homeless children.

Methods

During 1988 the New York Children's Health Project had 6,452 primary health care encounters and 7,665 overall program encounters involving 3,057 children.

The vast majority of these encounters took place on one of the two mobile medical units (MMU) operated by the NYCHP. The MMUs are custom-designed, self-contained health stations containing two examining rooms each as well as registration, waiting and laboratory areas. The MMUs are driven on a scheduled basis to hotels and shelter facilities where large numbers of families with children reside. The medical teams are led by pediatricians from the Department of Pediatrics of The New York Hospital-Cornell Medical Center. The teams also include nurse practitioner or pediatric resident, nurse, registrar, and driver. Since the goal is primary health care, the same team is usually scheduled to visit a particular site on a regular basis. Families and providers see the MMUs and the NYCHP as their child health provider and are able to schedule appointments, rechecks and preventive care interventions on the basis of the weekly schedule.

Data recorded for each encounter and each patient in the system is extensive. Complete medical histories, physical examinations, demographic and socio-environmental information is obtained by the primary care teams and recorded on data forms for entry into the NYCHP Children's Health Network. This network is a table-driven relational database management application serving a UNIXbased user community. (Software developed by John Snow, Inc.)

When children are identified as having problems not amenable to management by a primary health care team, appropriate referrals are made at a designated back-up facility, usually The New York Hospital. An elaborate and highly structured follow-up program has been designed to ensure maximum compliance with fulfillment of secondary and tertiary health care needs. The follow-up team is coordinated by an experienced pediatric nurse who works closely with other members of the project and serves as a liaison to the services of the back-up hospitals and medical centers.

Communications with families include telephone calls, mailings and actual visits to the shelter sites. Children and their parents are greeted at the hospital by Project staff and are escorted to the specialty clinic or other special service.

As of December 1, 1988 the project has employed a car service to bring patients to the hospital. This was done in response to the significant difficulties experienced by many of the families in accessing the back-up facilities.

Results

In the 12 months of 1988, 3,057 children between the ages of 0 and 21 years were seen in 6,452 separate encounters, with an average of 2.1 encounters per registered patient. Of the 7,523 different diagnoses recorded, 2,581 or 40% were "well child" with the remaining being illness diagnoses. These latter included acute illness problems as well as a variety of chronic or even congenital medical concerns.

In 1988, 306 children required a total of 319 follow-up or special services referrals.

Although some referrals were required by acute or emergent situations, most were on the basis of neglected or undertreated chronic illnesses. Some children needed surgical procedures for congenital problems which were not formerly recognized or not appropriately managed. Following is a summary of referrals made in 1988:

NYCHP: 1988
319 Referrals

Emergency Service Eval	- 55 (17.2%)
Speech & Hearing Eval	- 33 (10.4%)
Ped Subspecialties	- 231 (72.4%)

NEW YORK CHILDREN'S HEALTH PROJECT
DISTRIBUTION OF DIAGNOSES
January - December 1988

Number Diagnoses 7523
Number Encounters 6452

Diagnosis	Total N=7523	Percentage of total encounters N=6452
Well Child	2,581	40%
Upper Respiratory Illness	1,059	16.4%
Dermatologic Conditions	999	15.5%
Otitis Media	876	13.6%
Gastroenteritis	289	4.5%
Iron Deficiency Anemia	209	3.2%
Pharyngitis	178	2.8%
Asthma	153	2.4%
Conjunctivitis	147	2.3%
Bronchitis/Bronchiolitis	125	1.9%
Thrush	103	1.6%
Ceruman Impaction	84	1.3%
Allergy	70	1.1%
Trauma	69	1.1%
Strabismus/Other Ophth	65	1.0%
Caries	60	.9%
Inguinal Hernia	45	.7%
Pneumonia	36	.6%
Speech Delay	28	.4%
Failure to Thrive	25	.4%
Other	322	5.0%
Total Diagnoses	7,523	

* **Note**: Percentages do not reflect a total of 100% as patients are not limited to a single diagnosis.

NYCHP: 1988

Pediatric Subspecialty Referrals

Ophthalmology	48	20.8%
Ped Surgery	33	14.3
Dermatology	22	9.5
ENT	17	7.4
Cardiology	13	5.6
Adol/Gyn	12	5.2
Child Dev/Beh	12	5.2
Neurology	11	4.8
Other	63	27.2
Total	231	100.0%

It was found that 47 of 55 (85.5%) emergency services referrals were completed. On the other hand, only 142 of 264 (53.8%) non-emergent specialty referrals kept at least one appointment.

Specific intervention activities seemed to have an observable impact on compliance. For example, following introduction of the car service on a regular basis for patients requiring treatment at the hospital, a positive change in compliance was noted.

NYCHP

Addition of Car Service - 12/1/88

	#Appts	%Compliance
Nov. 1988	38	27
Dec. 1988	37	63

Conclusions

The NYCHP is a unique, mobile-unit based health care program providing medical services to homeless and economically disadvantaged children in New York City. Although its predominant mission is to provide primary health services, it is clear that the patient population has substantial secondary and tertiary referral needs. An appropriate system to handle the organization and implementation of the referrals was developed and has resulted in excellent appointment compliance rates. It should be recognized that populations with unmet primary health needs may also experience important secondary and tertiary needs requiring specific program development.

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IMPACT STUDY-OUTCOMES OF SERVICES TO HOMELESS FAMILIES: REPORT OF RESEARCH IN PROGRESS

John J. Stretch, St. Louis University;Larry W. Kreuger, University of Missouri-Columbia

CONTEXT

The development of homeless services in St. Louis is on the cutting edge of what is being done nationwide. St. Louis is one of only three cities, the others being New York and Washington, D.C., in which a court-honored consent decree is in effect to provide services to the homeless.

The St. Louis decree is unique, however, in that it requires services designed to move the individual out of homelessness. Rather than warehousing the homeless as New York's public shelters do (they currently house more than 7,800 families in 61 welfare hotels), the contract for services model between the City of St. Louis and private social service agencies facilitates community networking.

PROBLEM STATEMENT

Current research on the homeless can be divided into three categories: 1) attempts to count the homeless, 2) descriptive studies of shelter populations and 3) clinical assessments of health and mental health (Bassuk and Lauriat, 1986). Research to date has been primarily exploratory or descriptive with a major gap in the area of program evaluation.

Unexplored areas include systematic investigation of 1) the origins of homelessness, 2) geographic patterns of mobility, 3) courses and outcomes of homelessness, 4) characteristics of some of the new homeless such as families, or 5) the impact of service provision programs on the likelihood of reintegration into society (Bassuk, 1985:32).

It is the immediacy of crisis and impending need for shelter that causes many private philanthropic funders to choose to place their resources into bricks and mortar programs rather than engaging in research related to long-term planning.

Current research efforts in process indicate this emphasis. One project will focus on how poor welfare families who are vulnerable to becoming homeless manage not to become homeless (Rank and Hirschl, in process). Another will examine families living in overcrowded conditions to investigate what causes some families to fall into homelessness while others do not (McChesney, in process).

The successful programs already undertaken in St. Louis and the state of national research point to a rare opportunity to contribute to that larger policy database through further study of homelessness in St. Louis. The impact study was designed as a joint-venture of the Midland Division of the Salvation Army, the United Way of Greater St. Louis, the Missouri Department of Social Services, and the Department of Housing and Urban Development (HUD) and is targeted to fill this policy data gap.

POLICY AND PROGRAMMATIC SIGNIFICANCE OF THE IMPACT RESEARCH PROJECT

Over the last eight years in St. Louis, there has been a significant investment in poor families who have suffered from the uprootedness and attendant crisis of homelessness. There is little empirical data on or justification for the amount of investment made in these families. Moreover, there is 1) no clear picture of what types of families have been helped, 2) how long this help has sustained them, and 3) what their current family situation and status is.

These largely poor families, now homeless, have benefited from concerted efforts by a network of public and private agencies to deal with their many crises; stabilize them; place them as functioning families in the community; support their rerooting by a community networked process of case management and follow-up. Other than anecdotal evidence, there are no systematic data (Milburn and Watts, 1986) to-date which chart the outcomes and impacts of community networked resources directed to insure their continual functioning in the community after the initial homeless crisis has been resolved.

It is unknown what happens to homeless families once programmatic support ends. Do they become displaced again? If not, what sustains them in their new found environment? What elements account for their ability to reroot themselves back into the larger community? Can we get a beginning estimate of what costs are associated with these desirable benefits?

What was required is relevant data over time, to approach the cost-to-benefit justification for community investment in these families. This research proposes to address this missing database needed for both programmatic justification and for policy support purposes at the local, regional, and national level.

The study, through its networked service provision component, is targeted to describe in detail formerly homeless families who are currently functioning in the community as well as provide linkage through the Homeless Services Network for additional services to those families reentering or about to reenter the homelessness cycle.

Furthermore, the research should

prove timely in shaping the forces now gathering on the national level for significant welfare reform. The major service and support that have gone into providing for these poor families who additionally have become homeless are some of the proposed major components surrounding the welfare reform debate. Major components are: (1) better income maintenance strategies; (2) targeted educational services; (3) child care services; (4) basic health care; (5) life skill training; (6) jobs. Life skill training encompasses, but is not necessarily limited to money management, parenting, home maintenance, employment, and landlord-tenant relations.

Thus, the products of this first ever descriptive research effort to discover impact characteristics should have initial utility for determining the value of substantial and sustained investments on the part of the human services community in poor families rendered dysfunctional by homelessness; as well as, provide a tenable, testable model of key elements in the welfare reform movement relevant to state and federal policy options for the new homeless poor.

Since the opening of a new 54-bed Salvation Army Family Haven in June 1979, this 60-day program has aimed at preventing, ameliorating, and correcting the undesirable effects of displacement on homeless families through an intensive casemanagement approach. The City administration has committed itself to a partnership with the Family Haven in providing program operating funds.

For nearly half a century, the Salvation Army has provided crisis shelter in St. Louis. Because of this long-term involvement in the plight of homeless individuals and families, Salvation Army staff recognize the need to provide more than basic food and shelter to homeless persons. Families require a case management approach combined with longer period of temporary shelter. Consequently, the leadership of The Midland Division of The Salvation Army has worked diligently with the members of the research team to develop the Homeless Continuum Model (HCM), a five-stage, casemanagement treatment plan: 1) Prevention, 2) Crisis Intervention, 3) Stabilization, 4) Resettlement and Transitional Housing, and 5) Follow-Up. The model is nationally recognized as a successful program for homeless families (The War Cry, 1987; Whitman, 1988). Figure 1 presents the model as it is operative in program year 1988.

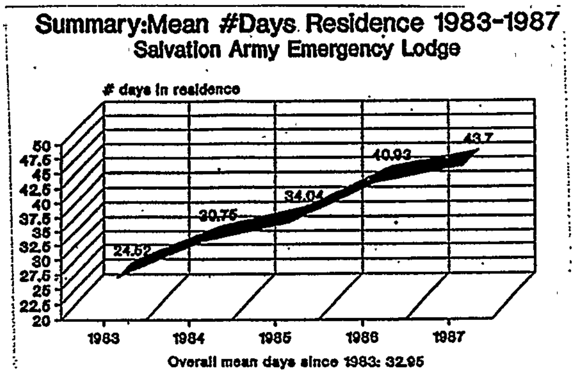
The per diem cost of $35.00 for residents of the Family Haven is extremely reasonable when considering the full range of services and intensive case management provided to each family. Traditional shelter programs, which have very limited services and few staff, have correspondingly lower per diem rates. An analyses of cost differentials between casemanaged programs and bed-and-board shelters in St. Louis is available . Specific information on job classifications and job descriptions for the program is also available from the Administrator of The Salvation Army Family Haven.

It is clearly evident that additional data is required to support and justify the increased amount of governmental and community resources devoted to homeless families served by the Salvation Army full Homeless Continuum Model (HCM).

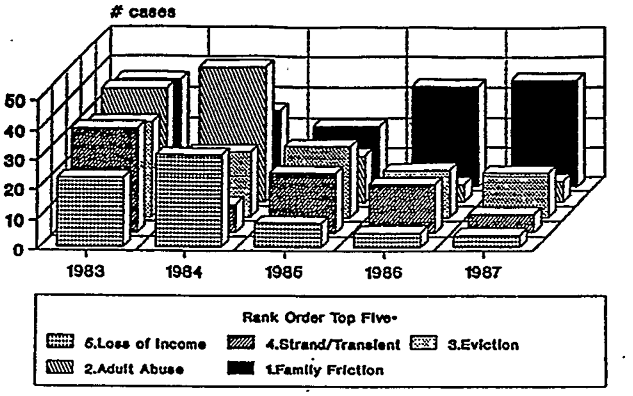
PRELIMINARY FINDINGS FROM SECONDARY DATA ANALYSIS AND FROM INITIAL FIELD DATA

Existing Family Haven data indicate that families served between 1983 and 1987 were found to be primarily comprised of young children and infants headed by young females. The education level of Family Haven families decreased between 1983 and 1987, and AFDC remained the principle source of income. The young females heading Family Haven families were primarily black and presented family friction and overcrowding as the most important reasons for being without residence. The mean length of service at the Lodge increased from 24.5 days in 1983 to 43.7 days in 1987 (overall mean length of stay 1983-1987 was 32.9 days).

Upon termination of stay at the Family Haven, approximately 51% of families received housing placements in relatively permanent settings (Section 8, Other Public Housing, Private Rented or Purchased, Live-in Arrangements, and Sharing with Friends). The other 49% of Family Haven families were placed either in temporary housing, they moved to other shelters, or left the Family Haven without specifying housing arrangements. The 431 cases which received permanent placements were selected as the sampling frame for field interviews. In 1987 The Salvation Army Family Haven developed a microcomputer based information system

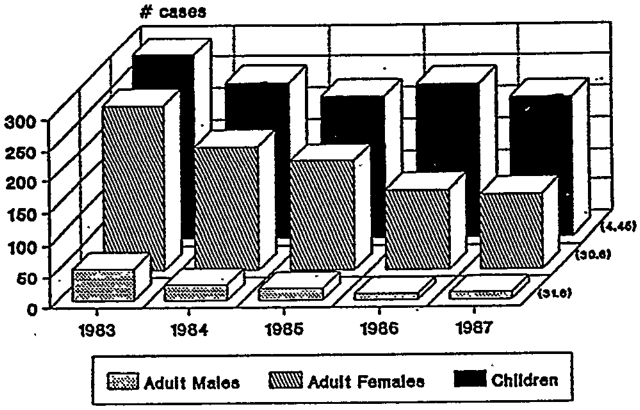


Top Five Reasons for Emergency 1983-1987
Salvation Army Emergency Lodge



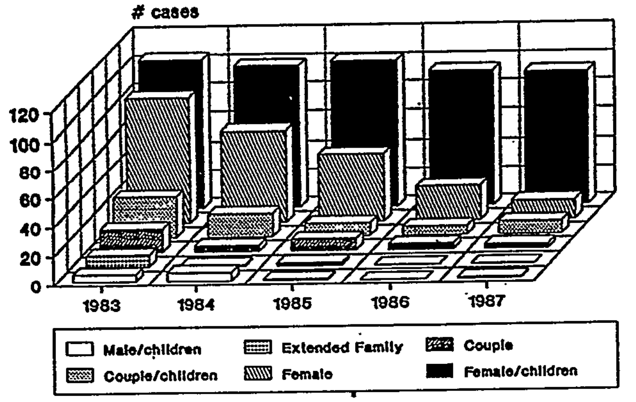
• Excludes reasons not in Top Five

Summary of Adults and Children 1983-1987
Salvation Army Emergency Lodge



(with average age since 1983)

Summary of Family Composition 1983-1987
Salvation Army Emergency Lodge



which has been described elsewhere (Unified Homeless Database System, Kreuger, et. al., 1987).

DATA FROM SECONDARY SOURCES

The Missouri Department of Social Services database searches based on 1002 SSNs located 539 cases (53.8%) in Food Stamp files, 573 cases (57.1%) in Income Maintenance files, and a maximum of 288 cases (28.7%) in selected Wages and Contributions files. There was a significant amount of overlap in these databases. For example approximately 90% of the Food Stamp cases were found in the Income Maintenance files. Data (which are not reviewed here) from these three sources include demographic characteristics, length of time receiving assistance, addresses and telephone numbers, and related information. The addresses from these files provided an important data source for locating families to be interviewed.

The St. Louis County Housing Authority database search yielded 119 cases of former Family Haven residents who were located in County sponsored public housing and Section 8 housing. Addresses from this source were also used to locate families to interview.

One of the key interests in this research project is whether or not families served by the Family Haven between 1983 and 1987 became homeless again. One indicator of post-Family Haven homelessness is whether former Family Haven residents have called the St. Louis Reception Center after leaving the Family Haven. The St. Louis City Reception Center search produced 109 matches from the base of 1002 SSNs. Of these matches, 58 (53%) were eligible for field interviews. Further analysis indicated that only 14 of these cases, however, involved calls to the Reception Center at a time after Family Haven residence. That is, most of the calls (44) where made by former Family Haven families before they lived in the Family Haven. Therefore, only the 14 post-Family Haven calls would indicate possible homelessness among families after leaving the Family Haven. The St. Louis Reception Center data search was by no means exhaustive as former Family Haven families may have sought shelter without using the Reception Center facility. In addition, questions remain about the reliability of Reception Center data for persons who may have called more than once.

DATA FROM FIELD INTERVIEWS

Field interviews began on June 15, 1989 in an effort to locate and interview 300 former Family Haven families out of a pool of 431 cases served between 1983 and 1987. The pool of 431 cases consists of families who received a housing placement considered to be relatively permanent (Section 8, Other Public Housing, Rented/Purchased Housing, Other). These 431 cases reflect, to a large extent, those formerly homeless families who had the most opportunity to benefit from the extensive Family Haven services.

Planned comparisons center on the status and stability of permanently placed families since leaving the Family Haven. Primary interest includes amount and type of service while residing at the Family Haven, length of stay, and length of time since Family Haven residence. Covariates considered at present include family size, number of children, age and education of family head.

Outcome measures, which are being developed as the research unfolds, include employment and income source history, dependence upon extended family, multiple family occupancy housing, additional homeless episodes, and a number of self-reported ratings about neighborhood, current and past residences, and family well being.

As of July 10, 1989 over 60 interviews had been completed and 55 were available for preliminary analysis. The following data refer only to these 55 cases and are preliminary.

These data show a mean time since Family Haven residence of 1230 days (median 1201 days), or about 3.4 years. Approximately 60% (34) of the former Family Haven families are currently residing in Section 8 housing, 8% were found in private rental or purchased units, 3.6% (2) were found in shelters in St. Louis, and the remainder where located in other public assistance settings. The mean length of time in current residence was 22 months (median of 12 months). Approximately 43% reported that they were living in residences which the Salvation Army had located for them upon termination of Family Haven residence. About one third of those interviewed report living in only one residence since staying at the Family Haven, with a mean of 1.9 residences since Family Haven stay.

Of those interviewed 85.7% (48) were black, the mean number of children per residence is 2.6, with a mean number of adults at 1.2, and a mean number of total occupants of 3.66. Approximately 69% (39) indicate having extended family within 100 miles of their current residence, and 46% (26) report turning to extended family for financial/residential assistance since leaving the Family Haven.

Only 16% (9) report being currently employed, and 57% (32) indicate that AFDC is the principle source of income. The mean monthly income was $293 (median of $282), and about 25% (14) of the former Family Haven families report losing a major income source since leaving the Family Haven.

The most stated neighborhood problems reported to date include crime in general at 55% (31), drug problems at 21% (12), and minor problems with neighbors at 2%. Approximately 28% report a major illness since leaving the Family Haven, 33% report having needed prenatal care, 21% report having needed psychiatric services, and 5% report needing treatment for alcohol use.

Of those with children, 71% (40) report that children are in school, 23% (13) indicate that the children have been involved in St. Louis's desegregation and busing program. Approximately 18% indicate that their children have needed special education, about 20% (11) report run-in's with the police, and approximately 3% (2) indicate problems with a divorce or separation. Regarding victimization, 21% (12) report being a victim of crime since leaving the Family Haven, 11% (6) indicate they were victims of adult abuse, and 11% (6) report that child neglect/abuse investigations had been undertaken.

POLICY IMPLICATIONS OF THE DATA

The trauma of living without a permanent residence poses unique difficulties for homeless persons, and attempts by human service providers to relieve suffering and ameliorate problems often require herculean efforts. Human service managers and administrators would do well to sensitize themselves to data monitoring deferential needs of homeless populations and tracking service delivery to them in order to assess the effectiveness of innovative programs for both traditional and emerging policy efforts. Such policy based program evaluations, derived from relevant and timely empirical data, increase the legitimacy and acceptance of traditional and newly emerging programmatic responses to help the homeless. Such data also provides additional bases of support for increased funding at local, state, regional and federal levels of responsibility.

Accurate data about homeless populations, which focus attention on homeless families, have a continuing functional role to play in the shaping of public policy issues affecting governmental and private agency responses to the homeless. Public policy requires an enlightened community and informed public officials. Data need to be systematically collected, integrated, transmitted and shared at various levels of public and private policy aggregation. Policy makers at the federal, regional, state, and local community levels need to be constantly reminded of the numbers and distribution of the homeless in their various jurisdictions. It has been demonstrated in other policy studies that lack of relevant and timely data retards responsible policy development and action. When this reality is recognized a reasonable response is the harnessing of current data processing capabilities to meet the demands of sound policy development. This is one strategy in this project.

The findings about homeless children and their parents within the context of identifying and meeting their specialized needs emerging in this research may be indicative of the overall patterns of homelessness among families in most urban areas in the United States. Regardless of whether the St. Louis data reflect special problems of the homeless, or whether they reflect more general problems of low income black and white urban families, the patterns described here point to the ever-present need for human service providers and policy makers to be informed about the demographic characteristics of those they serve and seek to serve. Only when human service professionals and policy makers are adequately familiar with the problems of their clientele can they make appropriate choices for program development, implementation, evaluation, and change.

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THE SALVATION ARMY
ST. LOUIS CITY & COUNTY
HOMELESS CONTINUUM MODEL
SERVING HOMELESS FAMILIES
Total Beds - 167 Nightly

PREVENTIVE STAGE	CRISIS INTERVENTION STAGE	STABILIZATION STAGE	RESETTLEMENT/ TRANSITIONAL HOUSING	COMMUNITY RE-INTREGRATION			
FAMILY SUPPORT CENTER	RECEPTION CENTER (10 Total Beds)	FAMILY HAVEN (54 Total Beds)	TRANSITIONAL HOUSING PROGRAM (48 Total Beds)	FAMILY SUPPORT CENTER			
Mortgage Assistance Rent Counseling Tenant/Landlord Mediation Relocation Services	City-Wide Intake & Referral Center for the Homeless HOSPITALITY HOUSE (25 Total Beds) The Salvation Army Emergency Shelter for Families & Individuals	COMMUNITY IN PARTNERSHIP FAMILY CENTER (30 Total Beds) TREATMENT SERVICES Training Sessions: (Building Self Esteem) Budgeting (Rent on Time) Parenting (Non Violent Child Care) Home Care (Cleaning Techniques) Substance Abuse (Drug and Alcoholism) Housing Search and Landlord Relationships Additional Services: Health Care Nutritional Planning MRDD/Development Screening School Program for Children Legal Services Counseling Women's Groups Assertiveness Training Short & Long Term Life Goals Setting	12 Units - Cluster Housing Authority St. Louis City/County Housing Solutions PERMANENT PLACEMENT Private and Market Rate Landlords Informal Support Groups Voucher/Section 8 Housing City/County Ecumenical Housing Production Corp. Household Goods Network Housing Trust Fund (In Process)	Living in the Community as a Responsible Tenant		Living in the Community as a Responsible Employee	Living in the Community as a Nurturing Family
				First Year 30-40 Families	Second Year 30-40 Families	Third Year 25 Families	Fourth Year 25 Families
				Stabilization and Monitor of Tenant Responsibilities Rent (On Time) Child Care Home Care Substance Abuse Good Neighbor	Educational Programs Employment Training Health Care Participation in Church Activities and Neighborhood Groups	Employment Placement Public/Private Partnership Accessible Transportation Employment Expectation Productive Assertive Punctual Employment Benefits Health Care Child Care	Housing Opportunities Community Involvement Achievement of Self-Sufficiency and Independent Life Style

BUILDING SELF ESTEEM AND SELF-SUFFICIENCY

[This continuum was developed by The Salvation Army and was partially funded by a grant from the Department of Housing and Urban Development and the Community Development Agency of St. Louis under provision of Title I of the Housing and Community Development Act of 1980 (P.L. 96-399).]

Figure 1

TUBERCULOSIS IN A NEW YORK CITY SHELTER FOR HOMELESS MEN

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and Lawrence L. Scharer, M.D.

(Not available for publication)

Session Y

HIV Infection

PHCRS

TRENDS IN MEDICAID UTILIZATION AND EXPENDITURES FOR PERSONS WITH AIDS IN CALIFORNIA

Penelope Pine, Health Care Financing Administration

An estimated 40 percent of the nations 100,000 persons with acquired immunodeficiency syndrome (AIDS) have received care under the Medicaid program. The proportion of AIDS patients served by Medicaid varies by geographic area with estimates as high as 65 to 70 percent of AIDS patients enrolled in New Jersey and New York Medicaid programs. Most AIDS patients become eligible for Medicaid by meeting the disability requirement under the Supplemental Security Income (SSI) Program, which provides benefits to disabled persons with low incomes and few or no assets. Patients with AIDS who do not qualify for SSI may still receive Medicaid in those states with medically needy programs or by qualifying for AID to Families with Dependent Children (AFDC).

Several states have suggested that the percent of persons with AIDS enrolled in Medicaid is increasing over time. It is estimated that the proportion of AIDS cases in California enrolled in Medicaid rose from 19 percent in 1983 to 33 percent in 1988 (Kizer, 1988). As the proportion of AIDS cases grows among intraveneous drug abusers, their sexual partners and their children, the proportion enrolled in Medicaid may likewise increase. Because of the major role of Medicaid in financing the care for patients with AIDS, a better understanding of program utilization and expenditures is important. Therefore, the Health Care Financing Administration (HCFA) has sponsored several studies of Medicaid enrollees with AIDS. This study uses Tape-to-Tape data and death certificates for AIDS patients in California for the period 1982-1986. The Tape-to-Tape data base contains enrollment, claims and provider data from the Medicaid Management Information System (MMIS) for several states including California.

A major barrier to health care financing research on AIDS is the lack of definitive ways to accurately identify AIDS patients in claims data. Prior to October 1986, there were no unique diagnostic codes for AIDS in the International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM). Although the use of unique codes for AIDS has been implemented, there is still concern that these codes may not be used with any degree of consistency and not all cases are identified by these codes. Because the study period is prior to 1987, we developed a clinical algorithm to overcome the lack of AIDS specific codes.

Using ICD-9-CM codes that include immunodeficiencies and other AIDS manifestations, we developed an algorithm to identify a group of Medicaid recipients suspected of have AIDS. This group was restricted to males, age 18 and older. The algorithm was not extended to females and children as they accounted for less than 5 percent of the cumulative AIDS cases in California during the study period. The study population was also restricted to persons who were continuously enrolled in Medicaid after the first AIDS related claim. Also, persons eligible for both Medicaid and Medicare and persons enrolled in HMO's or other capitated plans were excluded.

This paper presents study results for two cohorts of patients in the Medicaid program in California. Cohort I consists of enrollees whose year of entry into the study was 1984 and cohort II consists of enrollees who died in 1986. The distribution of age and Medicaid eligibility characteristics is presented in Table 1. The greatest percentage of enrollees in both cohorts are in the 30-39 year age group (Table 1). This age group represented 55 percent of all enrollees in cohort I and 48 percent in cohort II.

As expected the majority of AIDS patients are enrolled in the disability eligibility group since women and children who are mostly AFDC enrollees have been excluded. However, the distribution by maintenance assistance status varies between the two cohorts. In cohort I, only 27 percent were categorically needy and 71 percent were medically needy while cohort II was 46 percent categorically needy and 53 percent medically needy. Perhaps, since cohort II consisted of persons who died in 1986 and it is known that expenditures for health services are high in the last year of life, it was more likely that this group became categorically eligible for Medicaid.

Table 2 presents the length of enrollment for the two cohorts. The average length of eligibility for cohort I was 10 months and for cohort II was 7 months. The distribution of number of months of enrollment for cohort I ranged from 24 percent with enrollment of 1-3 months to 13 percent with enrollment of 13-18 months. Cohort II had a higher proportion of persons with a very short length of enrollment, 33 percent and the distribution decreased to only 4 percent with enrollment of 18 months or more. These variations can be explained somewhat by the fact that cohort I consisted of persons who were continuously enrolled in 1984 while cohort II consists of persons who died in 1986 and were in their last months of life.

The Medicaid expenditures distribution for several categories of health services is presented in Table 3. Total expenditures for Cohort I were $20,768 and $19,227 for cohort II. The majority of expenditures were for inpatient hospital care, 86 percent for cohort I and 84 percent for cohort II. Ambulatory visits were included in the other category which represented 11 percent for cohort I and 15 percent for cohort II.

Expenditures per month of enrollment were highest for those enrolled for the shortest amount of time (1 to 3 months) - $5,846 for cohort I and $4,753 for cohort II (table 4). The expenditures per month generally decreased as length of enrollment increased, with enrollees who had the longest length of enrollment (19 months and over) having the lowest expenditures rate, $876 for cohort I and $1,607 for cohort II. Because persons enrolled for less than three months during the year were either newly enrolled or became disenrolled, their high expenditures per month indicate that enrollees with AIDS have heavy use of services at the beginning or end of their stays on Medicaid. To confirm this result, average monthly expenditures are shown in figure 1 for the first 12 months of enrollment and in figure 2 for the last 12 months of life for the study population. The higher expenditures during the first few months of enrollment and during the last months of life are consistent with the view that expenditures for health services for persons with AIDS generally has two peaks one at the beginning of the illness and one prior to death.

The data highlight utilization patterns of persons with AIDS over a period of several years. Utilization patterns will continue to change with increased knowledge for treatment regimens, development of new therapies such as AZT, the continued emphasis on case management, and increasing use of ambulatory services for AIDS patients. Further development of this longitudinal data base will allow us to investigate enrollment patterns, severity of illness and differences in program utilization and expenditures by various demographic and risk behavior groups.

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Table 1

Demographic and Medicaid Eligibility

Characteristics of California AIDS Study Cohorts

Characteristic	Cohort I*	Cohort II**
Total Number Enrollees***	180	489
	Percent Distribution	
<u>Age</u>		
19 or less	0.6	0.5
20 - 29	16.7	17.5
30 - 39	55.0	47.8
40 - 49	22.2	26.4
50 - 59	5.0	7.5
60 or more	0.6	0.2
<u>Eligibility Group</u>		
Disabled - Categorically Needy	27.2	45.8
Disabled - Medically Needy	70.6	52.8
AFDC - Categorically Needy	0.6	0.2
AFDC - Medically Needy	0	0
Other	1.7	1.1

---

* 1984 characteristics of enrollees whose year of entry in study was 1984

** 1986 characteristics of enrollees who died in 1986

*** Excludes females, males under 18, HMO enrollees, and persons enrolled in both Medicaid and Medicare

Table 2

Length of Medicaid Enrollment of California AIDS Study Cohorts

Characteristic	Cohort I*	Cohort II*
	Percent Distribution***	
<u>Length of Enrollment</u>		
1 - 3 Months	23.9	33.0
4 - 6 Months	18.9	21.7
7 - 9 Months	16.1	20.5
10 - 12 Months	13.9	10.2
13 - 18 Months	12.8	11.0
18 Months or more	14.4	3.6
Mean number of <u>months enrolled</u>	10.1	7.1

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* Enrollees whose year of entry in study was 1984

** Enrollees who died in 1986

*** Excludes females, males under age 18, HMO enrollees, and persons enrolled in both Medicaid and Medicare

Table 3

California Medicaid Expenditures per Person for Entire Time in AIDS Study

Service Category	Cohort I*	Cohort II**
Total Expenditures***	$20,768	$19,227
	Percent Distribution	
Hospital	86.0	83.5
Nursing Home	1.8	0.2
Drugs	0.9	1.8
Other	11.4	14.5

---

* Enrollees whose year of entry in study was 1984. In this cohort 6 percent were enrolled in Medicaid at the end of the study period (December 1986). Because it is likely that they would incur expenditures after the study period the expenditure rates are an underestimate of the total expenditures of this cohort.

** Enrollees who died in 1986

*** Excludes females, males under 18, HMO enrollees and persons enrolled in both Medicaid and Medicare

Table 4

California Medicaid Expenditure per Month Enrolled by Enrollment Length For Enrollees with AIDS*

Enrollment length during study period	Cohort I**	Cohort II***
1 - 3 months	$5,846	$4,753
4 - 6 months	3,452	3,573
7 - 9 months	2,940	2,635
10 - 12 months	2,655	2,510
13 - 18 months	1,721	2,279
19+ months	876	1,607

---

* Excludes females, males under 18, HMO enrollees, and persons enrolled in both Medicaid and Medicare

** Enrollees who year of entry in study was 1984

*** Enrollees who died in 1986

FIGURE 1
1984 CALIFORNIA MEDICAID AIDS COHORT

AVERAGE MONTHLY EXPENDITURES
FOR THE FIRST 12 MONTHS OF ENROLLMENT

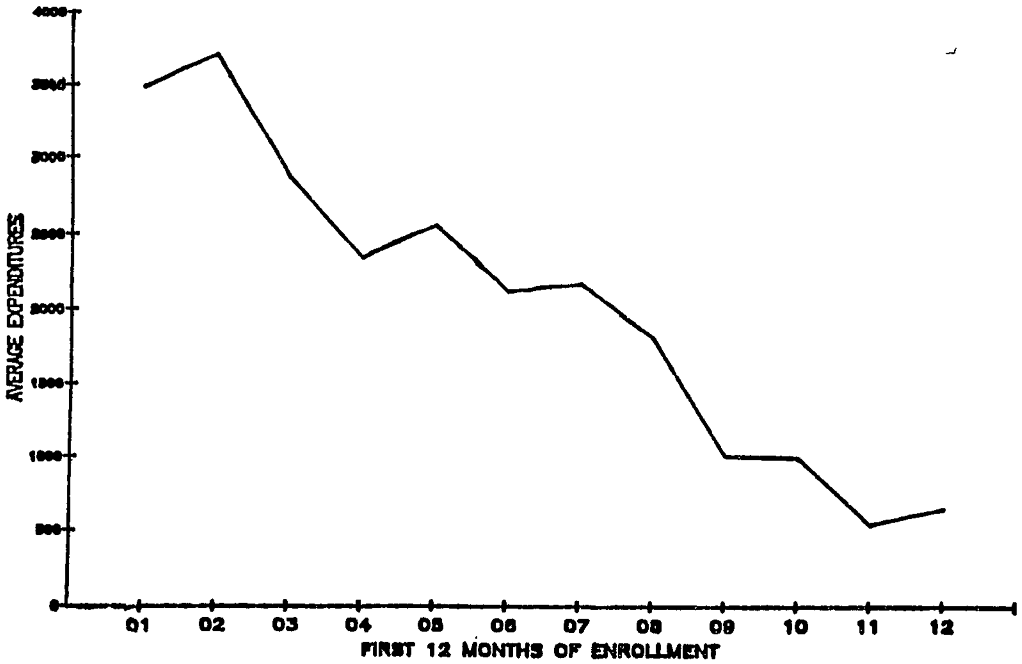
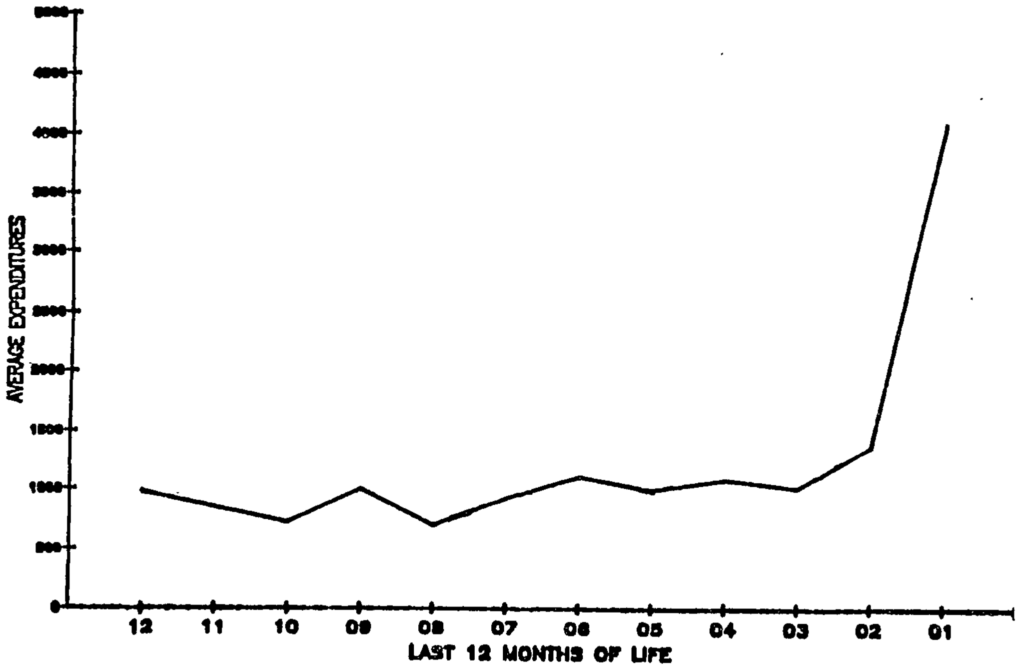


FIGURE 2
1986 CALIFORNIA MEDICAID AIDS COHORT

AVERAGE MONTHLY EXPENDITURES
FOR THE LAST 12 MONTHS OF LIFE



COST AND UTILIZATION OF INPATIENT SERVICES FOR PEDIATRIC AIDS

Sherry Allison-Cooke, National Perinatal Information Center

A. Overview

While the total number of AIDS infected children is still relatively small, infants and children with AIDS are probably the most tragic aspect of the AIDS epidemic, and their numbers are growing at an alarming rate. The Centers for Disease Control reported the year-end 1988 AIDS population for persons under 13 years of age to be 1,347, a dramatic 83% increase over the 737 cases reported for 1987.(2) Over half of these children have died already.(9)

Alarmingly, the CDC statistics on Pediatric AIDS cases underrepresent the total problem. As the Surgeon General's office points out:

> *"an additional undetermined number of children with evidence of HIV-infection are not included in the numbers because they do not fit the CDC definition for AIDS. These children are defined as having AIDS-related complex (ARC), not a reportable syndrome at this time. Many, if not all, will progress to AIDS."(3)*

This uncounted but potentially AIDS-afflicted population was estimated at 2,000 in 1987.

In addition, the occurrence of Pediatric AIDS is spreading geographically. While a mere year ago the bulk of Pediatric AIDS was confined to only four cities - New York, Newark, Miami, Los Angeles (7) - these locations now account for just over 40% of reported cases. In fact, the top 15 cities now account for just over 60% of all cases, with the remainder spread across a very large number of locations.(10) Since the appearance of a few cases of Pediatric AIDS in an area generally represents only the "tip of the iceberg," more and more cities can expect to witness an explosion of infants and children with the disease in the near future.

Nearly 80% of children with reported AIDS are between the ages of one and five.(9) Perinatal transmission is the predominate modality through which the infection is transferred to children, approaching 80% of known cases.(2, 7, 9) It is difficult to pinpoint at which stage during the prenatal period the vertical transfer of the infection occurs, which infants born to infected or exposed mothers will manifest the disease, or how long the dormant period will be for different children.(5) Recent estimates project that 30%-60% of all children born to women with AIDS eventually manifest symptoms of the disease themselves,(6) although for many of these the gestation period may be close to five years.(8)

Blood transfusions are another etiologic risk factor linked to the current demographic profile of identified Pediatric AIDS cases: 13% of known cases. Other risk factors - coagulation disorders such as hemophilia (6%) and undetermined transmission (3%-4%) - account for the remaining cases.(9)

The overall number of women with AIDS has also increased dramatically. According to CDC reports over the past three years, the number of female AIDS cases has grown from 1900 identified cases in December 1986 to 3,497 cases in 1987, to nearly 7,000 cases as of December 1988. This represents an increase of nearly 85%-100% per year, and CDC projects that the increases will continue. Well over two-thirds of these women are Black or Hispanic.(2, 9) As the population of women with AIDS continues to increase, so will the prevalence of Pediatric AIDS.

While the human costs of AIDS are paramount, the economic factors are not inconsiderable. Estimates of the economic impact of AIDS as it relates to medical costs range from the Andrulis et al projection of $23,000 per case over a lifetime, (12) to Hardy's estimate of $168,000.(11) Current forecasts of aggregate medical costs as presented by Hellinger cite a middle range expense of $57,000 per case in 1988.(4)

While the length of hospital stay for adults is decreasing, this may not be the situation for the pediatric population.(6) The expected expense of pediatric care is compounded for AIDS children when issues such as the inability of families to cope at home with the sophisticated care required, the expense of this care, "Boarder Babies," and problems inherent with a parent also being AIDS infected are factored in.

Throughout the literature the variation in cost estimates is striking, and the need for additional work is clear. Also, these estimates have been based predominantly on adult AIDS cases and do not take into account the additional problems inherent in treating the pediatric population.(4) This paper is an initial attempt to look at least at the inpatient utilization patterns and medical costs associated with hospital episodes of persons under 13 with AIDS.

B. Data and Methods

This analysis was based on hospital inpatient data collected by the National Perinatal Information Center (NPIC), a non-profit hospital membership organization and health services research center. The major missions of the NPIC are health services research in maternal and child health; perinatal health care policy analysis; and the dissemination of information to member institutions, government agencies, perinatal professionals and the general public. Recent research areas include financing and reimbursement, specifically DRG modeling efforts; policy implications of changes in the organization and delivery of regional perinatal programs; neonatal consequences of maternal substance abuse; investigation of a prototype Pediatric AIDS registry; neonatal infections; cesarean section rates in perinatal centers; and development of quality of care analyses for obstetrical and newborn care.

NPIC's primary membership constituency consists of major urban hospitals providing high risk obstetrical/neonatal care. Over 50 such hospitals are now NPIC members. These institutions provide NPIC with patient specific discharge, billing and cost data which are merged into a national Perinatal Center Data Base (PCDB) which has become a major resource to researchers in maternal and child health. The PCDB now spans the years 1985-1987, and includes items abstracted from patient medical and billing records, plus information gleaned from each hospital's Medicare Cost Report. These data are collected annually from NPIC member institutions and merged into a unique clinical-financial information base.

The PCDB data are patient-specific and allow for utilization and financial analyses along a variety of parameters, including but not limited to: demographics (age, sex, race, payor); infant birthweight; diagnoses, procedures and DRGs; hospital service; level of care; and geographic area. The PCDB currently encompasses nearly four million merged discharge-billing records, of which over 600,000 are newborns. Perinatal care (maternal, newborn and neonatal) represents 35% of inpatient activity in member hospitals; pediatrics (< 13 years of age) is about 20%. NPIC hospitals average over 500 beds, 3,500-4,000 births, and over 20,000 total discharges per year. They span 38 states.

The following analysis of Pediatric AIDS is based on data from the most recent year collected by the PCDB: 1987. The 1987 database includes 48 hospitals, five of which could not be included in this analysis due to a lack of pediatric data. (They either were maternity specialty hospitals or else submitted data for mothers and infants only.) Patient abstract files from the 43 remaining hospitals revealed 1,540 discharges for patients aged 0-12 with any of the following diagnostic conditions:

1. HIV Infection	(ICD-9-CM 42-44)
2. HIV Positive	(ICD-9-CM 795.8)
3. Other Immune Deficiencies	(ICD-9-CM 279)
4. Other Reticuloendothelial and Immunity Disorders	(DRG 398 and 399)

NPIC collects up to 15 diagnoses per patient, and many of these 1,540 discharge abstracts included diagnosis codes which spanned more than one of the four categories indicated above. To avoid double counts, discharges were assigned to diagnostic categories on a prioritized basis according to #1 through #4 above. That is, if a given case included any DX code in the 42.00-44.99 ICD-9-CM range, it was categorized under HIV infections, regardless of whether other AIDS-related codes also were present.

As is indicated by Table 1 below, over half of our original group of 1,540 discharges were coded as HIV infected. Most of the remainder were other immunity disorders or other cases in DRG 398 or 399.

****

Table 1

Pediatric Discharges by Prioritized AIDS-Related Diagnostic Categories: Select NPIC Hospitals, 1987

DX CATEGORY	#	%
DX 42-44	802	52.1%
DX 795.8	71	4.6%
DX 279	257	16.7%
DRGs 398-399	410	26.6%
TOTAL	1540	100.0%

****

For purposes of this analysis, the most strict definition of AIDS was employed, i.e. only cases of HIV infection (codes 42.00-44.99). This relatively narrow definition of the population to be studied eliminated 738, or 48%, of the original 1,540 discharges. While greatly reducing the number of discharges under investigation, this decision seemed appropriate for an initial look at the data in which we wanted to focus on the most clearly defined cases. Hopefully, later analyses will be able to encompass other diagnostic categories and investigate such issues as the costs and utilization patterns associated with HIV infected vs. HIV positive vs. "suspected" or "possible" AIDS cases.

C. Findings

It should be emphasized that this is a purely descriptive analysis and should be viewed only as a first step in investigating costs and utilization patterns associated with Pediatric AIDS. Given the relative dirth of information in this area, such an approach seems totally appropriate.

An unexpected characteristic of the patient care patterns for these children with AIDS emerged very early in the analysis. Of the 802 discharges for HIV infection under age 13, over three-quarters (627 cases) were one day stays. (Table 2) Further investigation revealed that the vast majority of these were admitted and discharged on the same day, i.e. they were less than 24 hours in duration and did not involve an overnight stay.

****

Table 2

Lengths of Stay for All HIV Infection Discharges: Select NPIC Hospitals, 1987

LOS	#	%
Same Day	603	75.2%
One Day	24	3.0%
2-7 Days	86	10.7%
≥ 8 Days	89	11.1%
TOTAL	802	100%

****

Calls to selected hospitals disclosed that these patients were generally on monthly gamma globulin treatment regimens or research protocols which were administered and charged as *"same day"* admission-discharges rather than on an outpatient basis. However, the care rendered appears to fall more in the outpatient than inpatient sphere.

While the majority of these *"same day"* cases occurred in the one hospital which had by far the largest volume of Pediatric AIDS discharges, this phenomenon was observed in some other hospitals as well. This produced very skewed distributions for length of stay (LOS) and costs and greatly depressed mean values for these measures. Consequently, these *"same day"* cases were also eliminated from the analysis, primarily because we wished this initial analysis to focus not only on the strictest diagnostic definition of AIDS but also on the strictest definition of inpatient utilization and costs.

Omitting *"same day"* stays resulted in the elimination of 603 more discharges. The final 199 discharges all represented cases with an ICD-9-CM code for HIV infection and all were in the hospital for at least 24 hours as part of their hospital stay (unless the discharge disposition indicated that the patient died). This final population under study was arrived at as follows:

Discharges	Type
1540	HIV Infection or Related DX
-738	Related DX
802	HIV Infection
-603	Same-Day Stays
199	Inpatient HIV Infection Discharges

All subsequent tables are based on these 199 discharges which were distributed across 14 hospitals.

A reinvestigation of length of stay with same-day stays eliminated from the analysis shows that 24 or 12.1% are legitimate one day stays, with the remainder split fairly evenly between 2-7 days and ≥ 8 day stays. (Table 3) The average LOS for Pediatric AIDS discharges was 12.5 days.

****

Table 3

Lengths of Stay for Pediatric HIV Infection Discharges: Selected NPIC Hospitals, 1987

LOS	#	%
One Day	24	12.1%
2-7 Days	86	43.3%
≥ 8 Days	89	44.7%
TOTAL	199	100.0%

****

Nearly two thirds of these discharges included ICD-9-CM code 42 - *"HIV Infection with Specified Conditions."* (This code was assigned priority over 43 or 44 for cases with multiple codes.) Code 43 - *"HIV Infection Causing Other Specified Conditions"* - the second priority code, accounted for most of the remaining cases (28.1%). Code 44 - *"Other HIV Infection"* - included only 7% of the 199 discharges. (Table 4)

****

Table 4

Diagnostic Distribution of Pediatric HIV Infection Discharges: Select NPIC Hospitals, 1987

DX	#	%
42	129	64.8%
43	56	28.1%
44	14	7.0%
TOTAL	199	100.0%

****

As depicted in Table 5, over 70% of these discharges were for children under five years of age. Twelve percent died, and five percent were transferred to another institution.

****

Table 5

Age and Discharge Disposition of Pediatric HIV Infection Discharges: Select NPIC Hospitals, 1987:

AGE	#	%
0-4	143	71.9%
5-12	56	28.1%
DISCHARGE DISP.		
Home	165	82.9%
Died	24	12.1%
Transferred	10	5.0%
TOTAL	199	100.0%

****

Turning to the financial characteristics of these discharges, they incurred $2,375,065 in aggregate hospital bills during 1987 for an average charge of $11,935 (Table 6). It should be noted, however, that this average is greatly affected by the presence of a few particularly expensive cases. Omitting such cases would reduce the average by as much as 30%-40%.

Nearly two-fifths (38.7%) of all bills exceeded $6,000 per hospital stay. Significantly, over half of the total charges were for ancillary services, while most of the rest were for routine room and board. Less than 10% of all charges were for ICU stays.

****

Table 6

Distribution of Charges for Pediatric HIV Infection Discharges: Select NPIC Hospitals, 1987

Total Charges	$2,375,065
Average Charge	$11,935
Percent > $6,000	31.7%
Room & Board	37.7%
ICU	9.7%
Ancillary	52.6%

****

Also of obvious interest is who pays for the inpatient care of children with AIDS. The NPIC data for 1987 indicate that over three quarters of the funds come from public sources, primarily Medicaid. (Table 7) Contrary to our expectations, only two percent was unreimbursed care.

****

Table 7

Payment Source for Pediatric HIV Infection Discharges: Select NPIC Hospitals, 1987

PAYOR	#	%
Public*	151	75.9%
Private**	42	21.1%
Free/Self	4	2.0%
Missing	2	1.0%
TOTAL	199	100.0%

* Medicaid, Medicare, Workman's Compensation, CHAMPUS, Other Government

**Commercial Insurance, Blue Cross, Other

****

D. Summary

The findings from this analysis, as described in the preceding sections, can be summarized as follows:

1) A total of 1,540 pediatric discharges during 1987 from 43 urban tertiary centers were identified with definitive, related or suspected AIDS diagnositc categories: ICD-9-CM codes 42.00-44.99, 795.8, or 279.00-279.99 and DRGs 398 or 399. Of these, 802 were coded as HIV infected; other discharges were eliminated from the analysis.

2) Nearly 80% of all hospital stays for children with HIV infection were ≤ one day, and three quarters of these were *"same day"* admission-discharges

receiving regular treatment or therapy. Most of these 603 cases were part of ongoing treatment protocols and were also omitted from the analysis.

3) The average LOS of the 199 remaining inpatient discharges for pediatric HIV infection from 14 hospitals was 12.5 days, but over half of all stays were ≤ one week.

4) Over 70% were for children under age five.

5) Twelve percent died, and five percent were transferred to another site for care.

6) The average hospital bill per discharge was nearly $12,000. However, if a few extremely high cost cases were to be dropped from the analysis, this figure would decline by as much as 30%-40%.

7) Ancillary services account for over half of the $2.4 million in total charges for these 199 discharges during 1989. Room and board approaches 40%, and ICU is less than 10%.

8) Public payment sources, primarily Medicaid, paid for over three quarters of these hospital bills. Blue Cross and private insurance covered another 21%. Unreimbursed care was only two percent of the total.

E. Future Research

This very preliminary analysis of hospital discharges for children with AIDS generated some interesting findings. Not surprisingly, however, it has lead to even more questions and pointed out a number of areas where further research is needed. Obvious next steps include:

1) Duplicate the above analysis based on patients, not discharges. This will involve linking patient records and tracking readmissions.

2) Factor the *"same day"* admissions into the overall cost figures.

3) Include HIV positive cases as part of a comparative analysis with HIV infected cases.

4) Conduct indepth reviews of the "suspected" or "related" diagnostic categories.

5) Delineate hospital variations in utilization patterns, charges, resource allocations and patient outcomes, especially for high vs. low volume hospitals.

6) Investigate the possibility of variable coding practices among hospitals, especially as regards designations of cases as HIV infection vs. "other immune deficiencies."

7) Complete each of the preceding analyses for multiple years of data. This would allow both for trend analysis and for linkage of patient episodes of care across discharge years.

Rudimentary as this initial analysis may be, it clearly indicates that the NPIC Perinatal Center Data Base has considerable potential for adding to our base of knowledge concerning hospital based care of children with AIDS. A current goal of NPIC is to selectively expand the institutional base of the PCDB to include even more hospitals actively engaged in the treatment of Pediatric AIDS. However, even without this expansion, the PCDB should provide valuable insights regarding a population which has previously been characterized by a relative dirth of information.

FOOTNOTES

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AIDS, BLACKS, AND HISPANICS: WHAT IS THE CONNECTION?

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(Not available for publication)

IDENTIFYING RISK FACTORS FOR HIV INFECTION IN WOMEN VISITING PUBLICLY-SUBSIDIZED FAMILY PLANNING CLINICS IN NEW YORK STATE

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The New York State Department of Health (NYSDOH) surveyed clients in New York State publicly-subsidized family planning (FP) programs to assess risk for HIV infection. There were four specific objectives:

- o to estimate the distribution of HIV risk factors for women who visit FP clinics;
- o to estimate the total number of women visiting FP clinics in 1988 who were at risk for HIV infection;
- o to examine HIV risk factors by selected demographic characteristics; and
- o to compare HIV risk factors by pregnancy status.

In 1988, the NYSDOH FP network consisted of 67 publicly-subsidized projects with oversight over approximately 200 clinics. Thirty-nine clinic sites were located in NYC and served approximately 30 percent of FP clients. One hundred and sixty-six clinics were located throughout the rest of the state and served about 70 percent of FP clients. With the exception of the county of Putnam, there was at least one FP clinic site in every county. Overall, FP projects provided family planning services to approximately 293,000 women with approximately 580,000 clinic visits.

In February, 1988, HIV risk assessment survey forms were provided to FP projects with instructions to begin implementation at all clinic sites. The survey was to be administered by the staff to all unduplicated clients through June 30, 1988. A few projects continued the survey through July, 1988. Client participation was voluntary and confidential. No responses were to be retained in the client's medical chart.

Three of the 67 FP projects were excluded from participation in the survey: one is an infertility program, one had no clients at the time of the survey, and one is an Indian reservation with different reporting requirements. Of the remaining 64 FP projects, nine projects (14%) either did not respond or used incorrect project identifiers (1). These projects accounted for 10 percent of the population of women served annually. Two of the non-participating projects were located in the Albany Region, three in the Buffalo Region, two in New York City, one in the New Rochelle Region, and one in the Rochester Region. Assessment of representativeness and annual estimates of the number of women at risk are based on the 55 participating projects that served approximately 249,000 women. In the sample survey, 62.5 percent of women are white, non-Hispanic; 22.7 percent are black, non-Hispanic; 11.7 percent are Hispanic; and 3.1 percent are of other racial/ethnic origins or had missing data. By comparison, among women served annually, 64 percent are white, non-Hispanic; 20.7 percent are black, non-Hispanic; 11.7 percent are Hispanic; and 3.6 percent are of other race/ethnic origins. [Table 1 here]

The questionnaire included the site identifier, date of administration, age, gender, race/ethnicity, county of client's origin, and HIV risk factors. Risk factors included history of ever being an IV drug user, being a blood transfusion recipient, having lived in a high-risk country,(2) having a coagulation disorder, being a sex partner of a bisexual, being a sex partner of an IV drug user, being a sex partner of a hemophiliac, being a sex partner of a person with AIDS, ARC or HIV infection, being a sex partner of a person with unknown sex history, and having three or more sex partners in any six-month period since 1978.

Table 2 shows the percent of the population reporting each HIV risk factor. The overall proportion of clients at risk was based on the number of clients checking at least one of the above items. Each survey item was completed by more than 98 percent of respondents except for "lived in a high-risk country," which had a response rate of 89 percent. A few staff from one large agency in NYC considered this item discriminatory and would not complete it. [Table 2 here]

As shown, the most frequently reported HIV risk factor was "being a sex partner of a person with an unknown sex history", with almost one in five women reporting this risk factor. This was followed by reporting three or more multiple sex partners: 7.5 percent of women reported having three sex partners in any six-month period since 1978 and 5.4 percent of women reported four or more sex partners.

The next most frequently reported risk factors were being a "sex partner of an IV drug user" (2.1%), a "blood transfusion recipient" (1.7%), a "sex partner of a bisexual" (1.4%), having "lived in a high-risk country" (1.1%), having been "ever an IV drug user" (.6%), a "sex partner of a person with AIDS, ARC or HIV infection" (.1%), a "sex partner of a hemophiliac" (.1%), having "lived in a high risk country" and having a "coagulation disorder" (.1%). Table 3 provides yearly estimates of the number of women at risk for HIV infection for each individual HIV risk factor. These estimates assume the survey is representative of women served annually and that women know and admit to their HIV risk behaviors. In 1988, we estimate that approximately 62,000 at risk women were seen in FP clinics: most of these women were at risk because of not knowing the sex history of their sex partners. Approximately 32,000 women had multiple sex partners (three or more sex partners in any six-month period), 5,200 women were at risk from having sex with an IV drug user, and 1,500 were past or current IV drug users. [Table 3 here]

Data on the distribution of individual HIV-associated risk factors by race/ethnic status is presented in Table 4. A higher proportion of white women reported IV drug use, being a sex partner of an IVDU, a bisexual, and/or a person with an unknown sex history, and having multiple sex partners than did black or Hispanic women. A higher proportion of black or Hispanic women reported being a sex partner of a person with AIDS, ARC of HIV infection, blood transfusion recipient, or having lived in a high-risk country. [Table 4 here]

Since the majority of women with AIDS are black or Hispanic women, we expected a higher proportion of black and Hispanic women than white, non-Hispanic women to report an HIV risk factor. The unexpected finding may be explained by the following: (1) black and Hispanic women visiting FP agencies may not be representative of the population of women with HIV infection or AIDS, (2) since NYC is the epicenter of AIDS in New York State, infected women may be utilizing other health care/support systems already in place or none at all, (3) some staff were resistant to gathering information on IV drug use, sexual activity and country of origin. This resistance stemmed from concern about patient privacy and confidentiality issues along with concern that teenagers would shy away from very needed family planning if questions were too personal or too intrusive.

Among women with no reported HIV risk factors, 6.5 percent reported being pregnant and 13.8 percent reported planning a pregnancy in the near future. Among women who reported at least one HIV risk factor, 9.1 percent reported being pregnant and 13.2 percent reported planning a pregnancy in the near future.

Table 5 provides data on pregnancy status and pregnancy plans by individual HIV risk factor. Among women who reported ever being an IV drug user, 13.7 percent reported being pregnant and 19.6 percent reported planning a pregnancy in the near future. Of women who reported being a sex partner of an IVDU, 10.3 percent reported being pregnant and 15 percent reported planning a pregnancy in the near future. The high proportion of IV drug users reporting a pregnancy may reflect differences in utilization patterns for IV drug using women (i.e., the primary reason for IV drug using women to seek family planning services may be for pregnancy testing rather than for obtaining methods of contraception). Close to 20 percent of women from a high-risk country reported being pregnant and 32 percent reported planning a pregnancy in the near future. [Table 5 here]

Highlights:

o Approximately 25 percent (12,105) of the sample surveyed reported at least one HIV risk factor. In 1988, we estimate that one in four women visiting FP projects had at least one HIV risk factor. The majority of these women were at risk due to lack of knowledge regarding the sex history of their sex partners. If we exclude this risk factor, 15.8 percent of women seen were at risk for HIV infection.

o More than 1 in 5 women who reported at least one HIV risk factor reported being pregnant or planning a pregnancy in the near future.

o Nearly one in three ever IV drug users reported being pregnant or planning a pregnancy in the near future. Approximately one in four women who reported being a sex partner of an IVDU reported being pregnant or planning a pregnancy in the near future.

o White women were more likely than minority women to report ever being an IV drug user and being a sex partner of an IV drug user.

In conclusion, because FP projects serve a large number of women at risk for HIV infection, they are in a unique position to play an important role in helping to prevent the transmission of the HIV virus to women, to assist in efforts to prevent transmission of the HIV virus from women to their unborn children, and to refer HIV infected women to providers of health care services for monitoring and treatment.

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(1) A total of 681 surveys had unidentifiable project coes. The nine non-participating projects served 29,605 women annually.

(2) Countries include Haiti and central African countries of Zaire, Zambia, Burundi, Cameroon, Congo, Gabau, Equatorial Africa, Guinea, Kenya, Rwanda, Tanzania or Uganda.

TABLE 1 DISTRIBUTION OF WOMEN IN HIV RISK FACTOR SURVEY AND IN FP 12-MONTH DATA SYSTEM (REFERENCE POPULATION) BY RACE/ETHNICITY FOR NYS AND IN EACH REGION, NEW YORK STATE, 1988

	HIV RISK FACTOR SURVEY		REFERENCE POP. FP ANNUAL CLIENTS	
	(N= 48560)		(N=249,023)(1)	
NEW YORK STATE	(N)	(%)	(N)	(%)
White, Non-Hisp.	30371	62.5	144868	64.0
Black, Non-Hisp.	11002	22.7	46803	20.7
Hispanic	5703	11.7	26547	11.7
Other/missing	1484	3.1	8036	3.6
TOTAL	48560	100.0	226254	100.0
ALBANY				
White, Non-Hisp.	7561	91.2	30020	92.5
Black, Non-Hisp.	459	5.5	1536	4.7
Hispanic	172	2.1	432	1.3
Other/Missing	98	1.2	471	1.5
TOTAL	8290	100.0	32469	100.0
BUFFALO				
White, Non-Hisp.	4600	76.0	18559	79.4
Black, Non-Hisp.	1253	20.7	3718	15.9
Hispanic	172	2.8	518	2.2
Other/missing	32	.5	581	2.5
TOTAL	6057	100.0	23375	100.0
ROCHESTER				
White, Non-Hisp.	2803	93.2	12591	87.2
Black, Non-Hisp.	133	4.4	863	5.9
Hispanic	47	1.6	157	1.1
Other/Missing	24	.8	835	5.8
TOTAL	3007	100.0	14446	100.0
SYRACUSE				
White, Non-Hisp.	7027	90.5	35925	91.9
Black, Non-Hisp.	484	6.2	1921	5.0
Hispanic	156	2.0	292	0.7
Other/missing	100	1.3	947	2.4
TOTAL	7767	100.0	39085	100.0
NEW ROCHELLE				
White, Non-Hisp.	7503	65.0	45000	66.4
Black, Non-Hisp.	2475	21.4	13723	20.2
Hispanic	1391	12.0	7298	10.8
Other/missing	183	1.6	1779	2.6
TOTAL	11552	100.0	67800	100.0
NEW YORK CITY				
White, Non-Hisp.	591	5.3	2764	5.6
Black, Non-Hisp.	5977	53.3	25042	51.0
Hispanic	3599	32.1	17850	36.4
Other/missing	1039	9.3	3423	7.0
TOTAL	11206	100.0	49079*	100.0

(1) No racial/ethnic data available from one large agency in NYC.

TABLE 2 DISTRIBUTION OF HIV RISK FACTORS AMONG WOMEN VISITING FP PROJECTS, NEW YORK STATE, 1988 (N=48,560)

HIV RISK FACTOR(1)	# AT RISK	# RESPONSES	% AT RISK
SEX PARTNER OF...			
IV DRUG USER	1014	48318	2.1
BISEXUAL	689	48221	1.4
HEMOPHILIAC	52	48312	0.1
PERSON W/AIDS, ARC OR HIV	64	48252	0.1
EVER AN IV DRUG USER	309	48348	0.6
COAGULATION DISORDER	50	48386	0.1
LIVED IN HIGH-RISK CTRY(2)	489	43421	1.1
BLOOD TRANS.RECIPIENT	829	48391	1.7
SEX PARTNER OF PERSON W/UNKNOWN SEX HISTORY	10104	48178	21.0
AT LEAST ONE OF ABOVE	12105	48560	24.9
MULTIPLE SEX PARTNERS(3)			
THREE	3608	48032	7.5
FOUR OR MORE	2570	48032	5.4

(1) HIV risk factors are not mutually exclusive.

(2) Countries include Haiti and central African countries of Zaire, Zambia, Burundi, Cameroon, Congo, Gabau, Equatorial Africa, Guinea, Kenya, Rwanda, Tanzania or Uganda.

(3) In any six-month period since 1978.

TABLE 3 1988 ANNUAL ESTIMATES(1) OF THE NUMBER OF WOMEN AT RISK FOR HIV INFECTION VISITING FP PROJECTS IN THE NEW YORK STATE, 1988

HIV RISK FACTORS(2)	% OF SURVEY POP. AT RISK	ESTIMATE OF YEARLY POP. AT RISK
SEX PARTNER OF...		
IV DRUG USER	2.10	5229
BISEXUAL	1.43	3561
HEMOPHILIAC	0.11	274
PERSON W/AIDS, ARC OR HIV	0.13	324
EVER AN IV DRUG USER	0.64	1494
COAGULATION DISORDER	0.10	249
LIVED IN HIGH-RISK CTRY	1.13	2813
BLOOD TRANS. RECIPIENT(3)	1.71	4258
SEX PARTNER OF PERSON W/UNKNOWN SEX HISTORY	20.97	52220
AT LEAST ONE OF THE ABOVE	24.90	62007
MULTIPLE SEX PARTNERS: (4)		
THREE	7.51	18701
FOUR OR MORE	5.35	13323

(1) Includes 55 participating projects.

(2) Individual HIV risk factors are not mutually exclusive.

(3) Between 1978 and March 1985.(4) During any 6-month period.

TABLE 4 DISTRIBUTION OF HIV RISK FACTORS BY RACE/ETHNICITY NEW YORK STATE, 1988

HIV RISK FACTOR(1)	WHITE		BLACK OR HISPANIC	
SEX PARTNER OF...	(N)	(%)	(N)	(%)
IV DRUG USER**	708/30223	2.34	289/16632	1.74
BISEXUAL**	529/30371	1.74	162/16705	0.97
HEMOPHILIAC	38/30228	0.13	11/16623	0.07
PERSON W/AIDS, ARC OR HIV**	20/30216	0.07	41/16575	0.25
EVER AN IV DRUG USER	208/30238	0.69	93/16649	0.56
COAGULATION DISORDER	24/30279	0.08	22/16648	0.13
LIVED IN HIGH-RISK CTRY	108/29979	0.36	368/12827	2.87
BLOOD TRANS. RECIPIENT	467/30262	1.54	337/16667	2.02
SEX PARTNER OF PERSON W/UNKNOWN SEX HISTORY	6728/30157	22.30	3250/16563	19.60
MULTIPLE SEX PARTNERS(2)				
THREE	2482/30068	8.25	1078/16510	6.53
FOUR OR MORE	1750/30068	5.82	788/16510	4.77

(1) HIV Risk factors are not mutually exclusive.
** Statistically significant at the .001 level.

TABLE 5 PREGNANCY STATUS BY HIV RISK FACTORS(1), NEW YORK STATE, 1988

HIV RISK STATUS	NUMBER PREGNANT	NUMBER AT RISK	PERCENT PREGNANT
SEX PARTNER OF...			
IV DRUG USER	99	959	10.3**
BISEXUAL	42	661	6.4
HEMOPHILIAC	4	47	8.5
PERSON W/AIDS, ARC OR HIV	3	57	5.3
EVER AN IV DRUG USER	37	269	13.7**
COAGULATION DISORDER	7	44	15.9**
LIVED IN HIGH-RISK CTRY	87	439	19.8**
BLOOD TRANS.RECIPIENT	70	775	9.0**
SEX PARTNER OF PERSON W/UNKNOWN SEX HISTORY	882	9675	9.1**
MULTIPLE SEX PARTNERS(2)			
THREE	230	3391	6.8
FOUR OR MORE	214	2391	8.9**
AT LEAST ONE RISK	1212	13569	8.9**
NO REPORTED RISK	2083	(32252)*	6.5

*No reported risk. ** Statistically significant at .05 level.
(1) HIV risk factors are not mutually exclusive.
(2) In any six-month period since 1978.

HIV INFECTION AMONG HOMELESS MEN IN A NEW YORK CITY SHELTER

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(Not available for publication)

Session Z

Injuries

PHCRS

AN EVALUATION OF EXTERNAL CAUSE OF INJURY CODES USING HOSPITAL RECORDS FROM THE INDIAN HEALTH SERVICE, 1985

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(Not available for publication)

TRAUMATIC HEAD AND SPINAL CORD INJURY:
A STUDY OF PATIENT SERVICES AND POLICY IN IOWA

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Introduction

Every year more than 80,000 people in the U.S. suffer a permanently disabling injury of the brain or spinal cord. With the exception of inner city studies, in which acts of violence led to a significant percentage of the brain injuries reported, motor vehicle crashes account for the majority of such injuries and involve predominantly young persons. Motorcycle accidents account for 15 percent of all motor vehicle deaths. The second leading cause of brain injury in most studies is falls in a more elderly population.[1]

While most acute illnesses are resolved with short-term hospital stays or outpatient medical services, traumatic head and spinal cord injuries more often require extensive inpatient hospitalization and multiplicity of therapeutic and extended care-services. The direct costs of these services are extremely high and a significant number of patients with this trauma rely upon the Iowa Medicaid program for service reimbursement. Many patients experience severe disabilities, imposing further indirect societal costs due to removal from the work force and lost wages. High social costs are also paid by individuals and families associated with this trauma. Dramatic changes in life occur, often at a young age, and high levels of dependency may be incurred for the remainder of a patient's life.

The authors review herein the readily available sources of data in an attempt to present a comprehensive picture of the problem of head injury in Iowa.

Methods

Traumatic head and spinal injured patients are defined as persons admitted to a hospital with any of the following ICD-9 codes.

Table 1. ICD-9 Codes

Traumatic Head Injury	800-804, 850-854, 907.0
Traumatic Cervical Injury	806.0, 806.1, 952.0
Other Traumatic Cord Injury	344, 907.2-907.5, 907.9 952.1-952.4, 952.8, 952.9

Patient records were obtained from the Central Head Injury Registry operated by the Department of Human Services. These records were derived from patient discharge summary abstracts covering the years 1983 through 1986 of Iowa hospitals participating in the Health Services Data System (HSDS) operated by Servi-Share of Iowa. Approximately 65 percent of all discharges in Iowa for the above period are summarized on the Servi-Share data tape. The central Head Injury Registry data were limited to head injury admissions.

The Iowa Foundation for Medical Care's database of Medicaid and Medicare claims paid during the year 1986 was reviewed to obtain comparative estimates of the costs of hospitalization for cases of head and spinal cord injury. Data from the Iowa Department of Transportation are reported for temporal trends in motor vehicle fatalities and motorcycle fatalities.

Results

The rate of brain injury accidents in Iowa is shown for age groupings in Table 2. The highest incidence of injury for Iowans as a percent of persons among each age category occurs in the age group of those from 15 to 19. These findings are consistent with those of other U.S. studies.[2]

Table 2. Age-Specific Rates of Head Injury Hospitalizations
1984 - 1986 Hospital Admissions Per 100,000 By Age

	Age of Patient						
Year	0-4	5-14	15-19	20-34	35-64	65+	Total
1984	43.7	193.0	244.7	211.1	96.4	188.7	159.1
1985	61.1	158.9	269.0	161.8	79.5	143.4	133.1
1986	81.3	139.1	241.0	132.3	72.8	124.2	117.3

Table 3. Medicaid & Medicare Hospital Costs for Injuries (1986)

Injury	No. of Cases	Length of Stay Sum	Sum of Charges	Avg Length Stay	Charge Per Day	Charge Per Case
Traumatic Head	735	6,122	$3,595,80	8.3	$587	$4,892
Traumatic Cervical	23	620	$519,647	27.0	$838	$22,593
Other Traumatic	1,355	16,372	$7,709,687	12.1	$471	$5,690
TOTAL	2,374	25,173	$12,992.764	10.6	$516	$5,473

Data on cost per hospitalization for Medicaid and Medicare patients are given in Table 3 based upon hospital claims paid during the year 1986. Thirty-one percent of the injury cases included hospitalization for traumatic head injury, 57 percent of the cases concerned hospitalization for other traumatic injury, and only one percent of the cases represented hospitalization for traumatic cervical injury. Approximately $13 million was spent by Medicaid and Medicare for inpatient hospital care of trauma patients. The average hospital charge for each case was $5,473. Patients with cervical injury experienced longer lengths of stay, 27 days, and a correspondingly higher cost per case of $22,500 dollars.

The principal source of payment is shown in Table 4. Accordingly, the major burden of payment for hospital services rests with private insurance carriers who enroll more than 55 percent of these patients.

Table 4. Principal Source of Payment for Head Injury Hospitalization in Iowa in 1986.

Private Insurance	55%
Medicare	19%
Medicaid	10%
Self-pay	10%
State/County	6%

(Based upon 2,288 admissions to Iowa hospitals in 1986 from the Health Services Data Systems data, representing approximately 65% of the total admissions to Iowa Hospitals.)

Trends in Motor Vehicle Deaths

An average of 41 Iowans of age 0 to 15 years died each year of motor vehicle injuries during the period shown in Table 5. The rate of motor vehicle deaths, however, declined dramatically during the years 1982 through 1985.

Table 5. Rate of Motor Vehicle Accidents and Deaths per 1,000 population in Iowa (1977 to 1986)

Year	Accidents per 1,000 pop	Deaths per 1,000 pop
1970	547.0	5.68
71	525.3	4.99
72	536.7	5.11
73	546.2	4.60
74	528.2	3.97
75	531.1	3.78*
76	531.4	4.26
77	461.3	3.36
78	468.6	3.34
79	458.7	3.45
80	425.0	3.42
81	364.8	3.27
82	338.3	2.64
83	310.4	2.59
84	293.4	1.96
85	307.3	2.28**
86	301.2	2.15***

* 55 speed limit
** child restraint, 21 yr. drinking age
*** seat belt law

It is our conclusion that increased public awareness of child restraint effectiveness, and the passage of corresponding legislation, have strongly affected the death rates among children as evidenced by Table 6.

Table 6. Persons 15 years & younger involved in motor vehicle accidents in Iowa

	Number Killed by Age				Fatal Accident
Year	Under 4	5-9	10-14	15	Rate
1980	14	18	19	12	2.0
1981	18	14	13	11	2.8
1982	9	9	20	8	3.1
1983	5	6	18	5	1.7
1984	9	11	12	5	1.4
1985	4	7	11	4	0.8
1986	8	6	5	9	1.1

Motorcycle Helmets

Between 1967 and 1976, 40 states enacted laws requiring the use of motorcycle helmets. A comparison of eight states that adopted that law with eight contiguous states that did not revealed a decline in motorcycle fatalities of 30 percent as a result of the helmet law.[3] Twenty-seven states repealed their helmet laws after 1976, and motorcycle fatality rates promptly rose to rates nearly equal to those prior to enactment. The effect of the helmet law on motorcycle fatalities in Iowa is evident from Table 7. Despite being so short-lived, the helmet law had a dramatic effect on lowering fatalities. A helmet law in Iowa could be expected to reduce serious head injury as well as crash fatalities.

The impression of the Iowa head Injury Association is that there are many more instances of head injury occurring in Iowa than are diagnosed clinically in hospitalized patients. If one could accurately pinpoint the number of concussive and subconcussive injuries that occur in sporting and other injuries the number of "head injuries" might be in the many thousands per year.

Table 7. Effects of Helmet Law Legislation
(Iowa Department of Transportation Data)

Number of Motorcycle Fatalities in Iowa

MONTH	BEFORE LAW (9/74-6/75)	DURING LAW (9/75-6/76)	AFTER REPEAL (9/76-6/77)
September	12	2	8
October	1	5	5
November	3	2	1
December	-	-	1
January	-	-	-
February	1	-	-
March	-	4	1
April	2	2	8
May	7	8	13
June	19	11	9
TOTAL	45	34	47
Fatality Rate (per 10,000 registrations)	3.4	2.2	3.14

The helmet law went into effect September 1, 1975 but was repealed July 1, 1976. The data strongly suggest that head injuries decreased while the helmet law was in effect, but increased after the law was repealed.

The burden to society from brain and spinal cord injury is becoming more substantial as a result of increased survival with residual disability. More than 75,000 Americans each year sustain brain injuries that result in long-term disability, including 2,000 who remain in permanent vegetative states. In addition, over 6,000 Americans are rendered quadriplegic or paraplegic due to injuries. Improvements in emergency medical services and trauma care have resulted in increased survival of persons with nervous system as well as musculoskeletal, visceral and burn injuries.[4] The expected need for rehabilitative services is therefore increasing. Many survivors need functional rehabilitation of cognition, sensation, mobility and motor control after injury. Appropriate acute care, rehabilitative services and after care can help improve quality of life and functional status, and diminish preventable disabilities.[5]

Neurologic injury is extremely costly and warrants extensive restorative and rehabilitative care, in addition to appropriate acute and sub-acute trauma care. Nationwide, there are fifteen regional spinal cord centers. Fewer than ten percent of the 5,000 to 10,000 persons with new spinal cord injuries receive specialized treatment at such centers. Attempts at patient tracking, with adequate follow-up and support services, have proven efficacious and cost-effective in model settings. The national Spinal Cord Injury Center Program documented home placement in 85 percent of their hospitalizations and a reduction in re-hospitalization for complications as a result of instituting a system for patient follow-up and referral.[6] Rehabilitation not only improves self reliance, and deinstitutionalization for up to 75 percent of patients, but also (ten-fold estimated), dramatically reduces in the cost of lifetime care as compared with custodial care.[7] Failure in adequate rehabilitation results in preventable complications (i.e. increased dependency, contractures, pressure sores and infections) at a cost of further injury to the victim and health care dollars to society. Rehabilitation and public health experts estimate that expenditures in rehabilitation will save subsequent government expenditures for health care and custodial care.

Conclusions

Previous studies have documented motor vehicle and motorcycle injuries as the predominant causes of head injury fatalities. There are opportunities for the prevention of traumatic injury, primarily by means of reducing traffic accidents. Speed limits, safety belt laws, drunk driving laws, and voluntary prevention programs have been among the many attempts historically used to affect a reduction in traumatic injury of this kind. The Iowa Legislature should reinstate laws requiring the use of motorcycle helmets, and adopt new legislation requiring the use of moped helmets. A strong association has been drawn between the use of helmets, and reduced injury and deaths. Given the young average age of motorcycle and moped riders, we believe that laws have a stronger influence on the use of helmets than do individual judgments. Traumatic injuries or deaths among persons of younger ages also incur high social costs above and beyond any financial losses. The Iowa Legislature should adopt stricter drunk driving laws, given the strong association between use of alcohol and drugs and motor vehicle accidents resulting with traumatic injury.

This study was hampered by a lack of uniform data available for chronic care of traumatic head- and spinal-injured patients. Services provided after hospitalization, including vocational rehabilitation, physician outpatient services, long-term care and other after-care services do not have uniform definitions and records available for adequately describing this scenario in more specific terms.

Similarly, the study is limited to hospitalizations and hence misses both fatalities resultant from head and spinal cord injuries and injuries which have not resulted in hospitalization. Current Iowa legislation (H.F. #2484) for the Head Injury Central Registry should be supported with increased funding. Traumatic spinal cord injury should be explicitly recognized by the registry, and data gathered accordingly. Data from all service sectors, including after care, are needed to track individuals and help in the planning and allocation of funds and services. With adequate funding a proposed state-wide registry for persons with traumatic brain and spinal cord injury will provide invaluable information necessary to determine true incidence of head injuries and prognoses vis-a-vis functional and neurologic sequelae, as well as survival. Without such a data base, services will be allocated on the basis of poorly recognized needs and will be palliative instead of preventive. While such a registry will help to determine the adequacy of local services to those with neurologic injury, it will also allow for the evaluation and assessment of current policies and proposed interventions in preventing devastating neurologic injuries.

Increased funding is desirable for public education programs which encourage the proper use of seat belts and helmets, and generally, safe conduct. The effectiveness of these programs should be carefully evaluated. Past benefits to the scores of Iowans and their families would suggest that such a commitment would result in an investment in Iowa's future and not simply expenditure of state revenues.

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A UNIQUE APPROACH TO SURVEILLANCE OF SEVERE AND CATASTROPHIC INJURIES: AN AGRICULTURAL CASE STUDY

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It is no secret that information pertaining to agricultural trauma is difficult or impossible to find when it is needed. The outcome associated with this situation is predictable: appropriate strategies for health promotion and injury prevention and control within agricultural enterprises cannot be developed since information which could identify where intervention ought to be focused as well as the nature of such intervention does not exist.

Several agencies and organizations have attempted to fill the surveillance gap. These agencies include the National Safety Council (N.S.C.), the Department of Labor, the Centers for Disease Control (CDC), the Agricultural Extension offices of several states, and a few land grant universities, equipment manufacturers, and county public health departments. The majority of this effort produces, at best, an approximation of the injury situation, usually consisting of estimates of the phenomena.

For example, according to N.S.C. estimates, there were 49 deaths/100,000 farm workers in agriculture in 1985(1) compared with a rate of approximately 11 deaths/100,000 workers for all occupations. This ranked agriculture as one of the most hazardous occupations in 1985, comparable with mining (50/100,000) and above construction (37/100,000). Since these data do not include persons under 15 years of age, actual farm work-related death rates are much higher.

Agriculture-related morbidity statistics are especially difficult to access. Two common, but limited, sources of data are the Occupational Safety and Health Administration (O.S.H.A.) and Workers' Compensation records. While O.S.H.A. requires reporting of injuries that occur on the job, the jurisdiction of this agency encompasses only those businesses employing 10 or more individuals, and excludes inspection of family enterprises for compliance with standards. Since many farmers are self-employed and rarely hire more than 10 non-family laborers, the vast majority of farms in the United States (U.S.) are excluded from relevant reporting and regulations. Estimates from a study in Wisconsin indicated that not more than 30 to 50 percent of the farms in that state hired non-family laborers.(2) Findings from a survey in Minnesota, in 1978, resulted in an estimate of less than one non-family employee per Minnesota farm; less than two percent reported more than 10 non-family laborers.(3) Thus, the magnitude of morbidity, in particular, among rural farming communities cannot be documented at the present time.

In addition to the multiple data sources routinely utilized by the N.S.C., a national survey involving a random sample of farms and ranches in several representative states has been orchestrated for several years by this organization.(4) In cooperation with state and local agricultural extension agencies, local volunteer interviewers contacted farms every three months to obtain data relevant to injuries that may have occurred during that time. Data generated through this surveillance program were limited by the methodology; however, they remain a primary source of national data. Based on results from a Minnesota survey,(3) using a methodology approximating that of the N.S.C., it was reported that an injury was experienced on one in every 4.6 farms in 1978; a farm-related injury occurred on one of every seven farms.

The National Electronic Injury Surveillance System (NEISS) has also been used to establish a baseline from which one might design injury control strategies.(43) It too is limited since case identification is dependent upon involvement of hospital-based trauma centers and emergency rooms, many of which are located in urban areas. Numerous events escape detection and data pertaining to source and mechanism of injury may be incomplete.

Attempting to Characterize Agricultural Trauma

In general, the literature reveals a paucity of research on agricultural injuries. Particularly noteworthy is the lack of well controlled and conducted epidemiological studies of specific etiological risk factors for agricultural injuries. The literature can be loosely divided into three areas: case descriptions of agricultural injuries relating to a particular type of injury; reviews of agricultural injuries and the hazards of farming; and descriptive surveys of agricultural injuries.

Case descriptions and review of a series of clinical cases include a study which examined the severity and frequencies of agricultural injuries utilizing standardized reporting techniques from twenty-two states.(5) Injuries resulting from a specific source have, also, been reported: augers,(6-8) cornpickers,(9-11) hay balers,(12,13) tractors/power take-off units,(2,14-17) animal handling,(18) anhydrous ammonia,(19-21) and auto-highway.(5,22) Other papers have reviewed agricultural injuries specific to certain anatomic sites such as: ophthalmic,(20,23) respiratory,(19,21,24,25) dermatologic,(26) and musculoskeletal.(27) The majority of these papers attempted to define epidemiological parameters of the injuries or discuss aspects of prevention. However, because of methodological limitations, identification of important specific etiologic factors was not possible.

The literature also contains reviews of agricultural injuries and the reported hazards in farming; but, these reviews are descriptive in nature and do not allow for the determination of specific risk factors. Through these reviews, various types of injuries in agricultural workers have been described.(16,22,28-32) Although preventive measures are often suggested, they are not supported by epidemiological data.

Surveys of agricultural injuries have been reported from efforts in Minnesota, Wisconsin, New York, Alberta, Saskatchewan, Great Britain, and Sweden.(3,33-39,54) Several of the studies obtained their cases from patients attending clinics or hospitals; two sampled the farming population of a defined area and others obtained their information from police accident reports, compensation claims and rehabilitation centers. One study examined death certificates and reports from the state medical examiner's office.(40) Frequencies, types and distributions of injuries by person, time and place were detailed. However, the methodologies prevented testing of hypotheses for possible etiological significance.

In several studies, there was a primary focus on human behavior without consideration of environmental variables. One report concluded that operator carelessness was the usual cause of injury;(9) 58 percent of the injured farmers associated their personal carelessness with the injurious outcomes. In another study of grain auger injuries,(6) the investigators reported that 67 percent of the injuries occurred to the age groups between 16 and 25 and 46 and 75 years. Based on personal interviews and questionnaire data they concluded that inexperience in the younger group and careless and slowed reactions in the older group were contributory.

In a rural Wisconsin county case-control study,(44) reported in 1961, no major differences in degree of exposure to machines or animals, amount of safety education, health status of the farmer, and type of farm were found between case farms and control farms. Although previous injuries were reported on 47 percent of the case farms, this documentation was in evidence for only 23 percent of the control farms. The main conclusions were that the farmer is primarily responsible for the injury occurrence and that prevention measures should be focused on changing the work patterns and habits of the farmer.

Robertson(15) emphasizes that the focus on human behavior as a cause of injuries is not appropriate in terms of prevention. The significance of an injury is the extent and outcome of the damage done, not whether human behavior is at "fault." Injuries are predictable and the result of non-random events; therefore, efforts for prevention need to incorporate public health principles, not the traditional focus on human behavior.

The purpose of this study was to investigate the types and severities of farm-related trauma reported through a specific surveillance system and to identify variables associated with this trauma. While Department of Labor-required reporting of work-related injuries continues to be limited to farms employing 10 or more non-family employees, this investigation facilitated identification of severe and catastrophic farm-related trauma from all types of farms throughout the state of Minnesota.

Surveillance Methods and Materials

Following approval to conduct an archival study, by the Committee on the Use of Human Subjects in Research, University of Minnesota, this investigation was initiated to identify all farm-related trauma in the state of Minnesota between September 1, 1981 and August 31, 1983. Farm-related trauma was defined as an injury occurring to individuals on any farm in Minnesota or on any public road involving farm machinery. Data for this study were generated through a surveillance system facilitated by the Minnesota Newspaper Association Clipping Service. This service was responsible for forwarding all clippings related to agricultural trauma that were published throughout the state of Minnesota in every daily and weekly newspaper. Upon receipt of these clippings, data were abstracted to a coded form. Variables abstracted included age, gender, severity, including fatal or non-fatal outcome, type of injury, body part involved, mechanism of the injury, equipment or source of the injury, date and time of injury, contributing factors, time to medical care, whether injuries were multiple or non-multiple, whether one or more than one person was injured in the incident, and the county in which the injury occurred. Fatal events were further verified through death certificates registered by the Minnesota State Department of Health.

Limitations of this surveillance system include the fact that only the more severe and catastrophic events may reach the attention of the press. Also, data relevant to the variables addressed by this study may not be identified for each injury event. In addition, identification of published farm-related trauma events may be further limited by the expertise of the individuals involved with this assignment.

Death certificates have been used for a long time for injury surveillance. They are, however, limited as a data source. Frequently, the occupation may be misleading, particularly in the case of multiple occupations (farmer-carpenter, machinist-farmer), or the source of injury, including farm-relatedness of the event, is not identified. In particular, this may be evidenced when an individual succumbs later to complications of the injury and/or other sequelae develop following lengthy hospitalization.

Results

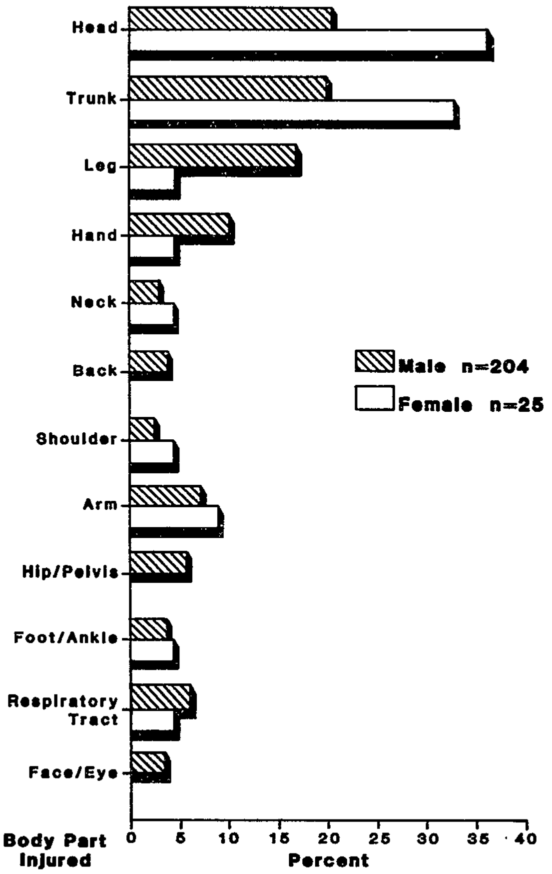
Through separate analysis of the variables for each of the study years it was determined there was no more than a five percent difference in the findings between the years. Thus, with few exceptions, data are presented in aggregate for the two-year period of study.

Between September 1, 1981 and August 31, 1983, a total of 304 agricultural trauma events were identified. According to gender, 90 percent were male; 10 percent were female. Of these cases, 49 percent were fatal and 51 percent non-fatal; 48 percent of males and 58 percent of females died. Ages of those injured ranged from one to 92 years. While the mean age for males was 30 years (S.D.=26), it was 16 years for females (S.D.=21). Multiple injuries were involved in 43 percent of all events. Furthermore, in nine percent of the events, more than one person was involved.

Parts of Body Injured

Analyzed by part of body, the head (22 percent) was associated most frequently with agricultural trauma events. The chest and abdomen, identified as part of the trunk in Figure 1, were involved in 21 percent of the events. Head, chest, and chest/abdomen injuries together accounted for the majority (77 percent) of fatal injuries; 61 percent of the non-fatal injuries involved extremities. The leg was involved in 15 percent of the injuries, making it the most commonly injured extremity; hands-fingers were involved in 10 percent of the events while the arm accounted for seven percent of the injuries. Respiratory injuries accounted for six percent of identified injury events. Differences between males and females in the most common body parts involved are illustrated. Of all events associated with females 36 percent involved head injuries and 32 percent were chest/abdomen injuries.

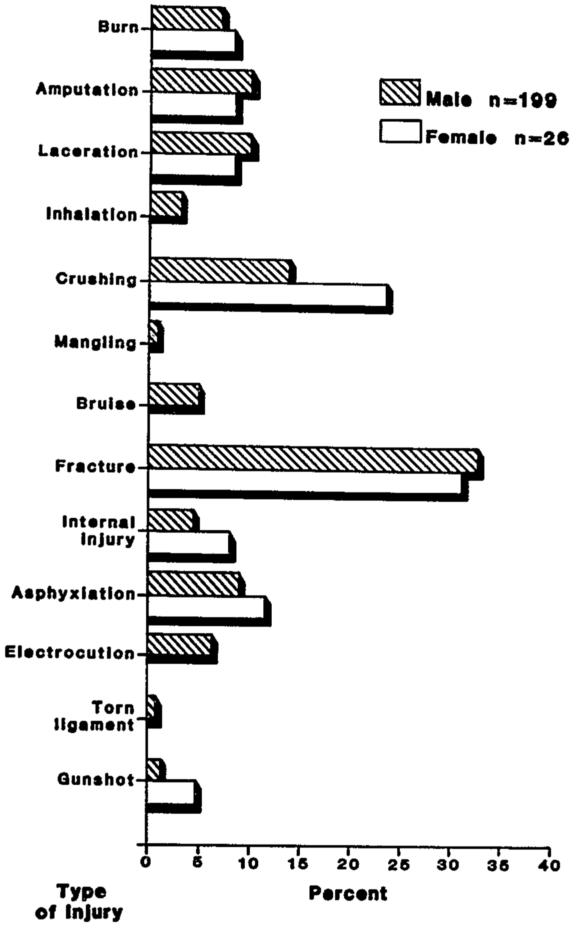
Figure 1
Severe and Fatal Farm-Related Injuries
by Part of Body Injured and Gender,
September 1981 - August 1983



Type of Injury

Figure 2 indicates fractures were the most common type of injury, accounting for 32 percent of the total; 37 percent of fracture injuries were fatal and accounted for 23 percent of all fatal injuries. Crushing injuries were associated with 15 percent of all events; 94 percent of crushing injuries were fatal, accounting for 27 percent of all fatal injuries. Amputations, lacerations, and asphyxiations, each, accounted for nine percent of the total. Differences in the type of injury, by gender, are also noted, in large part associated with the mechanism of injury.

Figure 2
Severe and Fatal Farm-Related Injuries
by Type of Injury and Gender,
September 1981 - August 1983



Age Distribution

Figure 3 indicates that of the cases for which the variable of age was reported, 54 percent of the females and seven percent of the males were found to be under 10 years of age. Of total injuries to males, 15 percent occurred in the 20 to 24 year age cohort. Additionally, 11 percent of the total cases identified were 70

Figure 3
Severe and Fatal Farm-Related Injuries
by Age Cohort and Gender,
September 1981 - August 1983

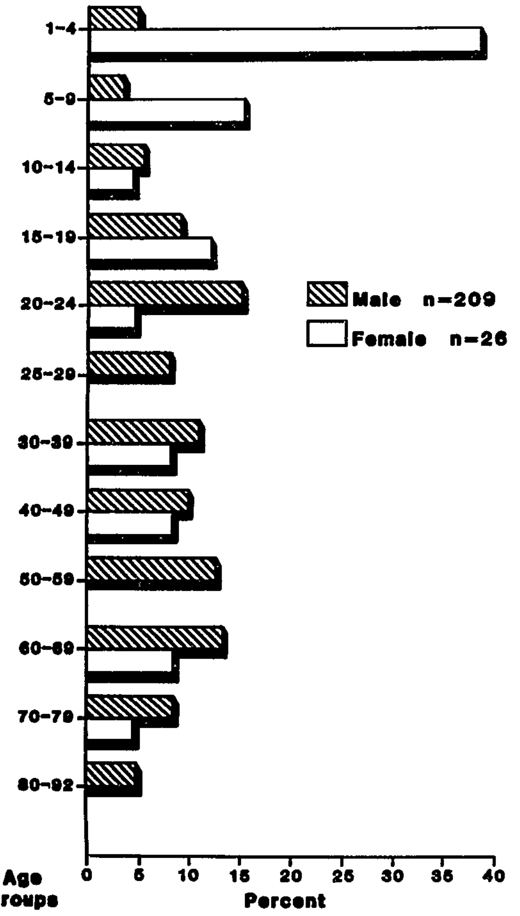
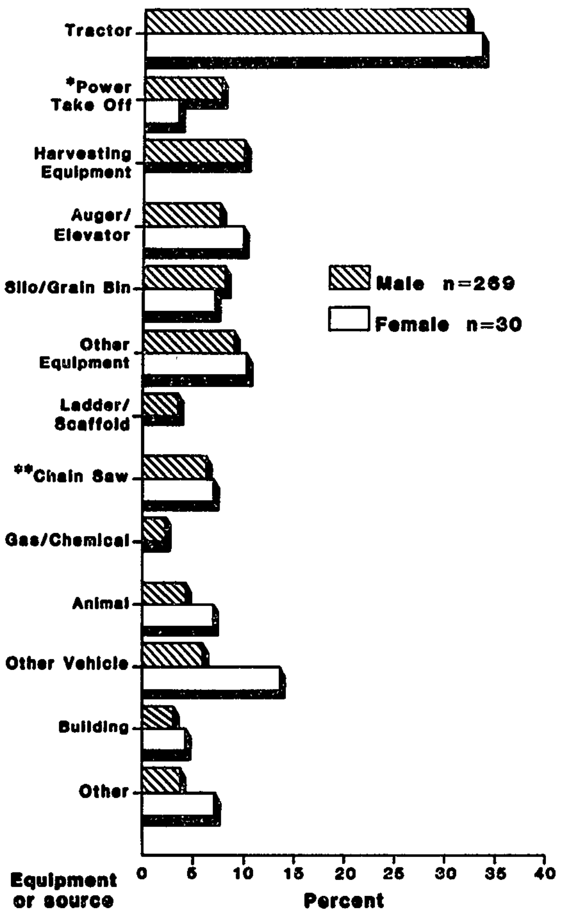


Figure 4
Severe and Fatal Farm-Related Injuries
by Equipment (Source) and Gender,
September 1981 - August 1983



*Power Source for Power take off was the farm tractor
**Wood cutting-related injuries

years of age or older while 23 percent were under the age of 18 years. Of particular interest is the finding that eight percent of all cases were in the one to four year age cohort. In addition, analysis revealed extremely high percentages of fatal cases in age groups 1-4 (90 percent), 5-9 (70 percent), 50-59 and 60-69 (75 percent, each), 70-79 (88 percent), and ≥ 80 (100 percent).

Source of Injury

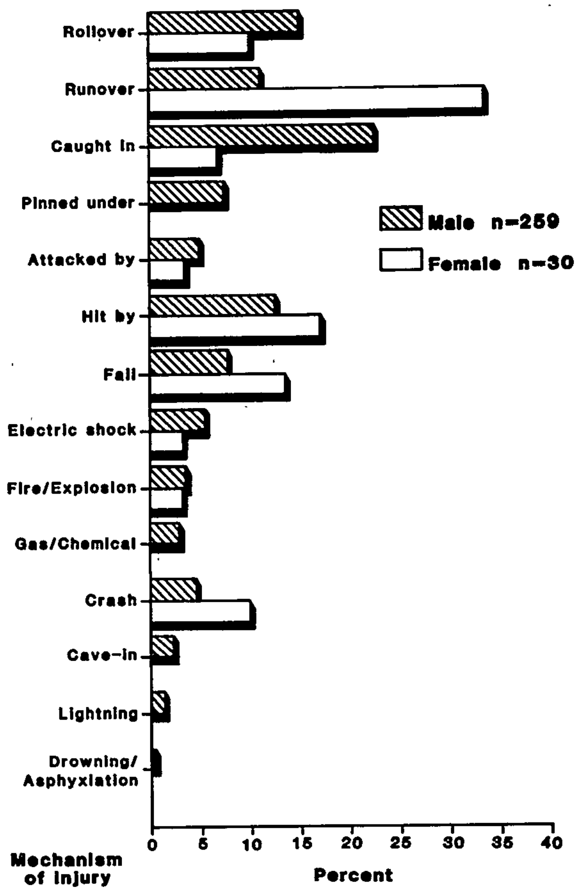
As shown in Figure 4, tractors, not including the P.T.O., were the leading source of injury, accounting for 32 percent of all injuries. In addition, 35 percent of all fatal events and 29 percent of non-fatal events were tractor-related. Harvesting equipment accounted for nine percent of all events. In addition, augers and elevators, and silos and grain bins, each, accounted for eight percent of total injuries while power take-offs (P.T.O.s) were the cause of injury in seven percent of the events. Other sources were also identified including harvesting equipment, ladders, haylofts, scaffolding, gas, and chemicals which were associated only with injuries among males. All other sources were associated with both sexes.

Tractors were associated with injuries in every age group and were an especially frequent source of injury among the 15 to 19 year old youths (68 percent). With the exception of one event, harvesting equipment was associated with individuals 20 years of age and older. Injuries associated with animals occurred primarily in the 40 to 69 year age cohorts. Buildings, including the home, were associated with 18 percent of the injuries in the 70 to 79 year age cohort and 38 percent of those in the 80 to 92 age cohort.

Mechanisms of Injury

As Figure 5 indicates the most common mechanism of injury, "getting caught in machinery," accounted for 21 percent of injury events and 10 percent of all fatal injuries. Thirty-one percent of non-fatal injuries were also associated with this mechanism. "Rollovers" (15 percent) and "being run over" or "falling off and being run over" (13 percent) were also associated with a large percentage of the injuries. However, "rollovers," "being run

Figure 5
Severe and Fatal Farm-Related Injuries
by Mechanism of Injury and Gender,
September 1981 - August 1983



over," and "falling off and being run over" accounted for 35 percent of the fatal injuries. According to gender, there was an observed difference between males and females in the five leading mechanisms of injury. The major differences were in events associated with the mechanism of "being run over" (females, 33 percent; males, 11 percent) and the mechanism of "being caught in" (females, seven percent; males, 22 percent).

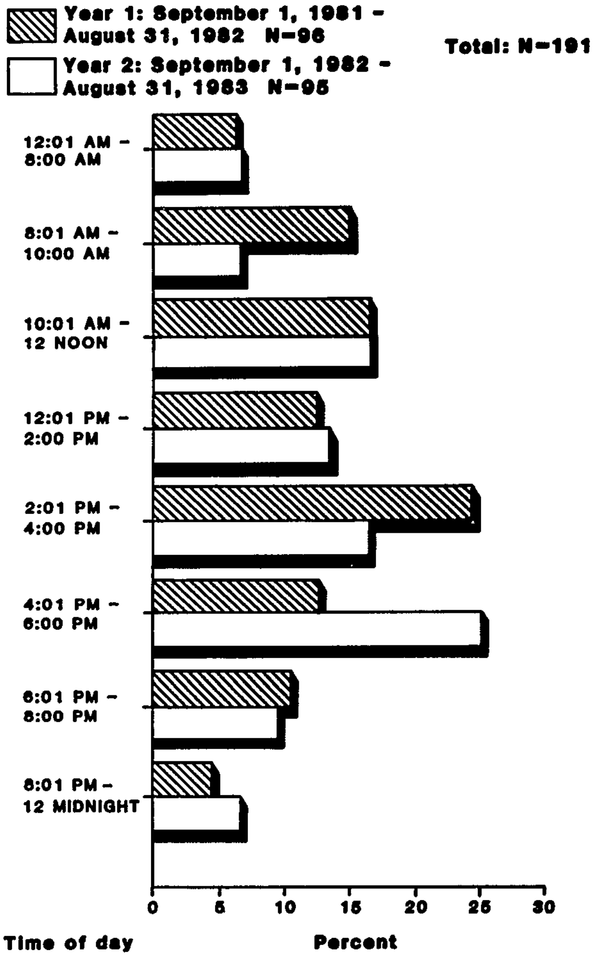
Nearly every age group was injured by being caught in machinery, and by rollovers. Among those within the age cohort one to four years, 73 percent were injured by being run over; 50 percent of five to nine year olds were run over. Electric shock injuries were most frequently identified in the 20 to 24 and 25 to 29 year cohort, accounting for approximately 20 percent of the injuries in each of these age groups.

Month and Time of Injury

Data relevant to the month of injury reveal the greatest frequency of injuries during the months between June and October. Fifty-five percent of the fatal injuries and 60 percent of the non-fatal injuries occurred during these months.

Although data were not available for all injury events, Figure 6 shows a similar pattern between the two years of study, according to time of day when the injuries occurred. In particular, a peaking is demonstrated in the afternoon hours for both years of study.

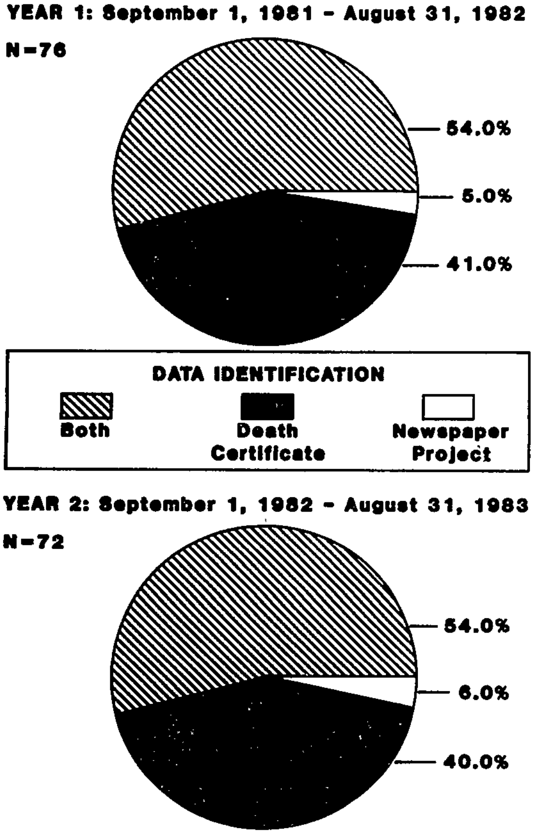
Figure 6
Severe and Fatal Farm-Related Injuries
by Time of Day and Study Year



Concordance of Farm-Related Mortality Data Between the Newspaper Surveillance Project and Death Certificates

As shown in Figure 7, a total of 76 fatal cases were identified in the first year of study; 72 were identified in the second year. The degree of concordance in these events between the newspaper clipping surveillance project and death certificate data is portrayed in this figure. In the first year of study 54 percent of the cases were documented by both sources while 41 percent were documented only through death certificates. However, five percent of the cases were identified only by the newspaper clipping surveillance project. Similar findings were also encountered in the second year of study.

Figure 7
Concordance of Farm-Related Mortality Data
Between the Newspaper Surveillance Project
and Death Certificate Data



Implications for Injury Surveillance

Through this investigation the use of a newspaper clipping service to facilitate surveillance of farm-related trauma was found to be of some value in detecting fatal events. While only five to six percent of the fatalities were identified through this surveillance system that had not been identified through death certificate data, the clipping service surveillance system provided more detail regarding the variables associated with the injury, including contributory factors and the source and mechanism of injury. However, 40 percent of the fatal injuries identified by death certificate data were not identified through the clipping service surveillance system. Therefore, using the clipping service surveillance system in conjunction with death certificate data would provide more comprehensive information about farm-related fatalities.

More important, use of clipping service surveillance systems to detect non-fatal serious and catastrophic injuries is feasible since these data are not readily available through other systems. Furthermore, the data are based on reported current events and, although subject to potential error, the process does not rely on personal interview and the memory of injury events months after the fact, as in the case of other surveillance efforts.(1) Based on an earlier study (53) that utilized newspaper clippings in concert with physician reports, it is expected that only a small percentage of all farm-related trauma will be detected. Therefore, while this approach may be used to provide better information at the present time it is essential to develop more comprehensive surveillance systems for farm-related trauma, indeed for all types of injury events. Through such endeavors, strategies for the prevention and control of severe and catastrophic injuries, in particular, can be developed.

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PRODUCT-REATED INJURY AND DEATH DATA - RIDE-ON MOWER EXAMPLE

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1. INTRODUCTION

This paper discusses some of the Consumer Product Safety Commission's unique types of data, which are needed to assess intervention strategies. It also discusses the process used to collect and analyze these data. Examples are drawn from a recent analysis of hazards associated with ride-on mowers (i.e. riding mowers, lawn tractors, garden tractors). This discussion also characterizes the attributes of specificity, reliability, and measurability needed from these data to support the conclusions. Injury and death data will be examined separately.

A great deal of data was collected when investigating ride-on mower accidents: product data, sequence of events, demographic traits of the injured population, the environment in which the mower was used and behavioral data. The results of the data analysis are published in a separate report. For the purpose of this paper, it will suffice to focus on the product and sequence of events data to illustrate how intervention targets are identified and assessed and how data sources are integrated.

2. DATA SOURCES.

Where and how are data that are needed to identify intervention targets obtained?

As with the previous speakers, the ride-on mower data originate from hospital records, death certificates, and newspaper clippings. But those documents are **only starting points**. They are used not just for data abstracting, but also for establishing the mechanism to obtain information **not** available from those documents - the Commission's data requirements go **beyond** the information available on those documents.

Injury data are collected through the National Electronic Injury Surveillance System (NEISS), managed by the Commission. It is a structured hierarchical tri-level system. The first level starts with one source: the emergency room record. The second level is the telephone interview. The third level is an on-site investigation. Follow-up for the second and third level is with the injured person identified in the emergency room record or with the parent or guardian if the injured person is a child.

At the emergency room level, available data are abstracted from information recorded on the emergency room form. At the telephone level, the respondent reacts to verbal cues from a questionnaire. At the on-site level, a trained investigator examines the site of the accident, reconstructs the accident, takes photographs or videotapes, notes other information which the respondent did not volunteer during the telephone interview because he/she may not have thought they were relevant to the accident.

Death data are collected through two levels. But each level has multiple sources.

The first level originates with death certificates, supplemented by newspaper clippings. When both sources are present, typically more details are available. And of course, one or more of these sources can alert the Commission to a case of interest.

The second level consists of obtaining more detailed information on the accidents identified at the first level. This is being done through multiple sources: police investigations, medical examiner reports, telephone or on-site follow-up with the deceased's family.

3. DATA SPECIFICITY.

3.1. Product Specificity.

The target scope for intervention is identified in terms of products. These products define a more or less homogeneous category where hazards can be addressed similarly. They also define a manufacturing group through which intervention may be effected.

With the ride-on mower hazard analysis, the product specificity needed is not mower, not power mower, but riding power mower (to be differentiated from the walk-behind power mower); it is not tractor, but lawn tractor or garden tractor (to be differentiated from farm tractor).

Mention of a product on a record is one criterion by which a case is captured in the Commission's injury or death data collection systems.

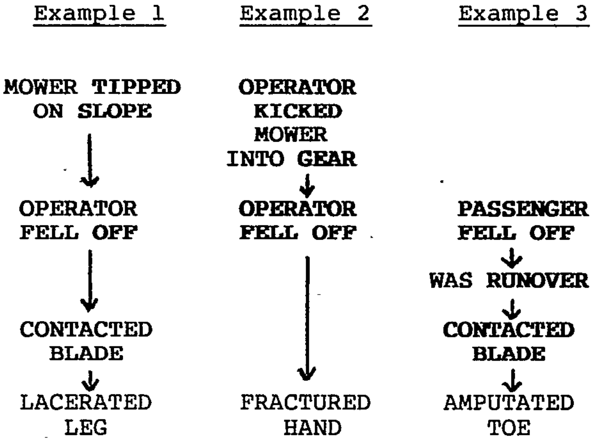
With the NEISS injury data, the product specificity can be characterized at each level as follows. At the first level or the emergency room level, the product specificity is not always available from the record. The general categories of mower or power mower rather than the more specific ride-on mower category appear in the majority of the emergency room records. Therefore, a telephone follow-up is necessary to determine which case in this general category involves a ride-on mower. Once the ride-on mower specificity is consistently determined for all mower cases captured through the emergency room, the on-site investigation provides additional information on the product configuration, that is to say, product design and layout, controls, safety features, any user's modifications to the product. It also provides photographs or videotapes.

With the death data, product specificity varies depending on the source of information. Ride-on mower cases are captured from death certificates in specific E-code categories. The product mentioned on the certificate is sometimes riding mower, sometimes lawn or garden tractor but more often tractor, without reference as to whether it is a farm tractor or a consumer type. Newsclips tend to be more specific. At the second or follow-up level, the majority of the tractor cases are screened out as farm tractors, based on what medical examiners, or police reports, or survivors indicate. But photographs, and product configuration are not consistently available.

3.2. Sequence of Events Specificity.

It is important that the sequence be as detailed as possible to ensure that the events at which intervention is likely to be targeted are included.

Stated below are three examples of sequence of events:



Intervention can be at any point(s) in a sequence. Obviously, at the ending point of a sequence - when the injury has taken place - the only intervention is treatment, the injury can no longer be prevented.

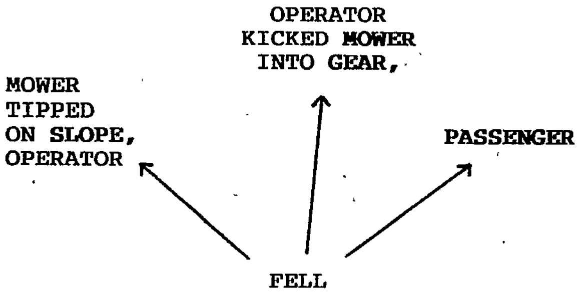
One of the things that can be learned from looking at these three examples is that in establishing a sequence of events, it is important to distinguish between the **immediate event** (before the injury) and the **initiating event**, which often is the intervention target. This distinction is important because what is often listed on health records is the immediate event leading to the injury (rather than the chain of events preceding the immediate event) since concern is more with the treatment than the prevention of the injury. However, to assess intervention strategies, it is necessary to go beyond that information to identify the initiating events.

This is not to say that immediate event and initiating event cannot be one and the same. For certain hazards, they are the same. One example is the "thrown object" hazard classification where a rock or a small debris is hurled out from under the mower deck or discharge chute and hit a bystander in the mowing area. Another example is the "blade contact" hazard classification where the operator was injured while clearing a clogged discharge chute and placing the hand too close to the rotating blade.

However, for hazards involving a vehicle in motion with complex interaction between user's behavior, product configuration and environment characteristics, the immediate event and the initiating event tend **not** to be the same. The same event (or hazard classification) may be the initiating event in one sequence, but the immediate event before the injury in another sequence. In yet another sequence, it may be an intermediate event between the initiating and the immediate events. Hazards are not single events but a sequence of hazards.

With available health records or registration records, there are two ways information about the initiating event can be lost: 1) different initiating events can be lumped into the same immediate event and only one strategy is considered when many are required; and 2) the same initiating event can be dispersed into different immediate events and different strategies are considered when only one is required. Either way, the data do not support effectively the assessment of intervention strategies.

The first phenomenon, the **lumping** phenomenon can be illustrated by going back to the three examples given earlier. They involve **three** different sequences of events, and **one** event common to all three: FALL, which can be denoted as the immediate event.



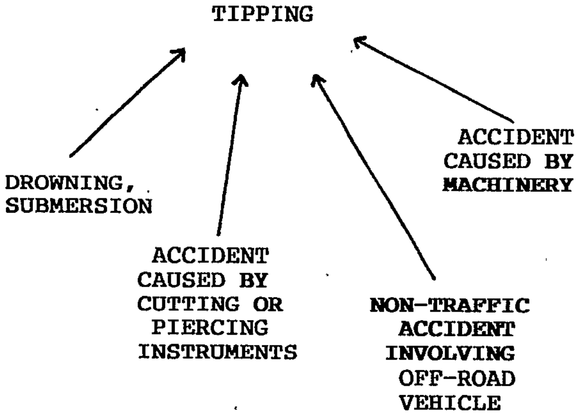
Different intervention strategies might be required depending on whether:

. the operator fell off during a tipping incident - intervention may be directed towards improving the stability of the mower on slope, or

. the victim fell off when he kicked the mower into gear while dismounting and the mower suddenly lurched forward - intervention may be directed towards improving the control layout or mechanical performance as it relates to user's behavioral characteristics, or

. a young passenger who was given a ride on the mower fell off - intervention may be directed towards raising parents' awareness of this hazard.

The second phenomenon, the **dispersion** phenomenon can be illustrated by classifying ride-on mower hazards using the E-codes assigned to the Death Certificates.



The above diagram shows that one case was coded as "drowning or submersion" and the other case as "accident caused by cutting or piercing instruments". With more detailed information, these two different accidents were found to result from the same initiating event, tipping. In one case, the tipping occurred on a slope near a pond. In the other case, the tipping ended up with both mower and operator falling down the slope and then the mower landing on top of the operator. In both cases, the listed E-codes refer to the immediate event before the injury, i.e. the immediate cause of the injury.

Other E-codes assigned to death certificates involving mower tipping describe general hazard categories such as "non-traffic accident involving off-road vehicle," or "accident caused by machinery."

Thus, E-codes are found in the above examples to designate the immediate events leading to death or general hazard information, both of which are not particularly effective to identify intervention targets for a product.

In conjunction with this discussion on sequence of events specificity, the data collection possibilities can be characterized as follows.

With the NEISS injury data, the emergency room record sometimes lists the initiating event, but more often it lists the immediate event before the injury, for example, "fell and fractured leg." Therefore, the telephone interview is necessary to capture in a consistent fashion the sequence of events, for example, "mower tipped, operator fell and fractured leg," as well as some sequence context. The on-site investigation gives both the sequence of events and the sequence context, including details about the interaction between the product, the person, and the environment. For example: "riding mower was mowing uphill when rear wheels slipped; riding mower travelled backwards down the hill; 53 year old operator applied combined brake/clutch pedal and attempted to put the mower in reverse but the chain slipped off the gear unit, rendering the brakes useless; mower picked up speed, heading towards car at bottom of hill; the operator turned the steering wheel which caused the unit to skid sideways and backwards, and to tip; operator fell."

Mortality data sometimes yield an event, or a sequence and often yield the immediate event preceding the death or a general category of health hazard. Information obtained at the follow-up level vary with the source. The interaction between the product and the person is often lacking because this is the type of information that can only be provided by the operator.

4. MEASURABILITY AND RELIABILITY.

Before examining some analytical output, a few comments about the data measurability and reliability may be appropriate. With data specificity, it is possible to effectively identify intervention targets. With data measurability and reliability, it is possible to assess the effectiveness of various intervention strategies.

The measurability of the injury data revolves around the fact that the NEISS starts off with a national probability sample at the emergency room level. As a result, the data collection process can be structured in such a way that the characteristic of the statistical sample gets passed on to the next two levels.

The reliability of the injury data rests on a balancing act between **data specificity per case and data measurability for a number of cases.** For the purposes of the ride-on mower hazard analysis, this balancing act can be best achieved at the telephone level. This does not mean that only information collected at this level is used. It means that given the data collecting mechanism employed and the coverage of hazard patterns desired, it is the best place to have a good mix of data specificity and sample size, and it is the best place to merge the most reliable information from all three levels.

With mortality data, data integration is obtained by fusing different sources. It is a matter of eliminating duplicates and resolving conflicting information.

5. ANALYTICAL OUTPUT.

The two pie charts on the next page give a distribution of hazards for injury data and death data, based on classification of available initiating events.

The two pie charts show that:

1) A multitude of hazards must be considered when assessing intervention strategies with ride-on mower accidents. This is different from another product in the same general category: walk-behind mowers.

2) The charts also show that death data are not as detailed as injury data. The three shaded portions for both injury and death data show that hazards that were differentiated in the injury data had to be lumped together in the death data, for lack of consistent specificity.

3) The charts also suggest that it is necessary to look at both injury and death data when assessing intervention strategies. Death data are not as detailed as injury data, but they give a feel for the severity of some of the hazards:

- Some hazards that appear in the injury pie chart do not show up in the death pie chart: blade contact, contact with other power driven parts, contact with hot surface, and thrown object.

- The charts also show that some hazards assume a greater portion of the death pie chart than of the injury pie chart, such as tipping/sliding or walls/banks related hazards and runover/backover.

It should be noted that in those hazards that appear in the injury pie chart but not in the death pie chart, the immediate and the initiating event happen to be the same. In contrast, those hazards that assume a greater portion of the death pie chart than the injury pie chart are related to a vehicle in motion, and often the initiating event is not the same as the immediate event before the injury. This could imply that the more severe injuries tend to be associated not with single hazards but sequence of hazards involving complex interaction between the product, the person and the environment.

6. CONCLUSIONS.

In conclusion, to identify product hazards, we can start with available health or registration records, but we need to go beyond them. We need to structure them, and we need to use them to establish the mechanism to obtain more detailed information that are specific, measurable and reliable. Both injury data and death data must be considered in that process. Death data are not as detailed as injury data but they identify hazard patterns where injuries tend to be more severe. And we need the injury data (which has considerable information input from the injured person) to understand better how accidents happen and to help fill gaps of that understanding in the death data.

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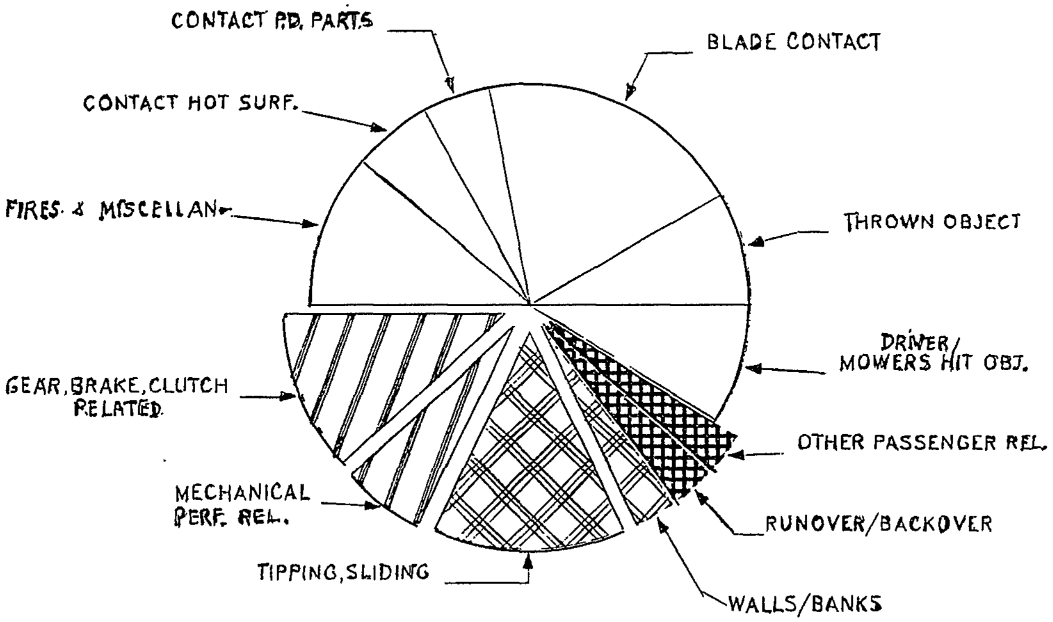
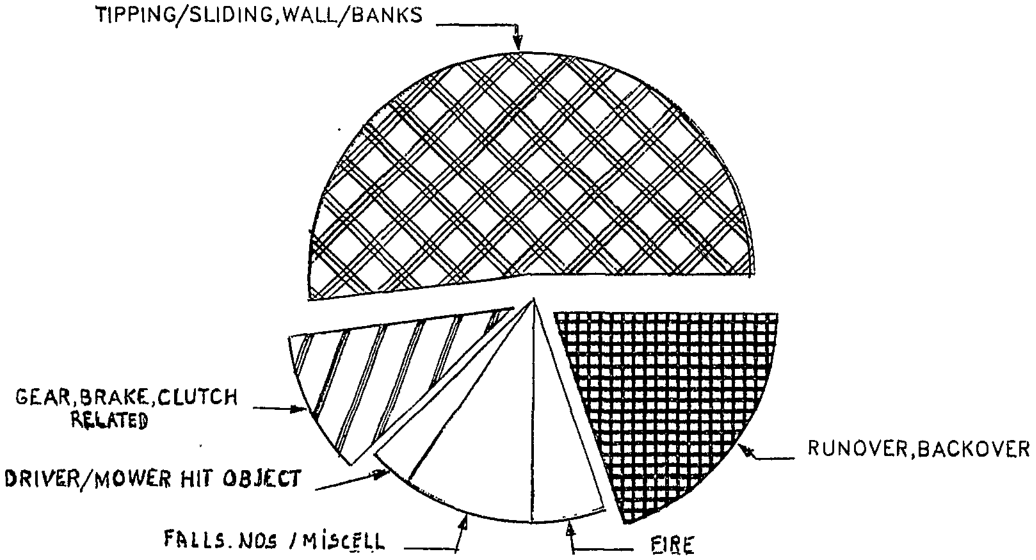
Van Ty Smith, Eliane. 1988. Ride-on Mower Hazard Analysis. U.S. Consumer Product Safety Commission, Directorate for Epidemiology, Division of Hazard Analysis.

INJURIES AND DEATHS ASSOCIATED WITH RIDE-ON MOWERS
YEARS 1983-1986

INJURIES



DEATHS



Session AA

Maternal and Infant Health

PHCRS

AN ASSESSMENT OF THE APGAR SCORE SYSTEM IN PRENATAL CARE EVALUATION BY A LOCAL HEALTH DEPARTMENT

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I. INTRODUCTION.

Reduction of the infant mortality rate (IMR) to 9.0 per thousand live births per year is one of the nations 1990 health objectives[1].

Programs to reduce infant mortality (IMR[2]) are carried out in many US jurisdictions under many different local conditions, including several in Kansas City, Missouri. All these programs have the central mission of reducing the incidence and prevalence of poor pregnancy outcomes such as low birth weight and infant mortality. Public health activities to improve pregnancy outcomes in Kansas City more than doubled in patient load and dollars spent during the interval from City FY[3] 83-84 to FY 87-88. In addition to the $165,456 budgeted to the Kansas City Health Department Prenatal Program in FY 87-88, the WIC[4] budget for FY 84-85 had grown to $3.569M. The 1985 KCMO IMR of 12.4 increased to 16.1 in 1986, and was 14.9 in 1987. Therefore, the Kansas City Health Department needed some evaluation of these, as well as other publicly-funded maternal and child health programs operating in Kansas City.

An infant health status indicator seemed necessary for such an evaluation. In order to be most useful, a pregnancy outcome measure should be universally available (*i.e.*, available for nearly all persons), reliable, objective, and based on standard units and meaning. The only possible candidates for outcome measures satisfying these criteria are: infant mortality, birth weight, and Apgar score.

Some characteristics of IMR which are desirable for an outcome measure are that it is objective, available for virtually all infants, and has a very clear meaning as a health status indicator. However, it has two serious weaknesses for use by local areas such as Kansas City. First, infant mortality is actually quite rare[5], which means that small changes in the IMR require several years of data for reliable detection within populations the size of Kansas City. This makes it difficult to have reliable comparisons from year to year. Second, there is a broad range of factors impacting on the health status of the mother and fetus during pregnancy which are not reflected by the IMR and therefore do not result in infant death.

Birth weight has been employed in many studies regarding prenatal care, primarily because it is reliable and nearly complete data is available for it. However, birth weight also has some serious weaknesses for evaluating such things as prenatal care in public health operations. Birth weight is greatly influenced by several factors of which only some relate to the prenatal care during pregnancy. These include the genetic constitution of the infant and parents, gestation length, mother's overall health status, metabolic or infectious diseases, and many other factors. The data available on the birth certificate for adjusting for these factors are the mother's pre-pregnancy weight and date of last normal menses. Thus important determinants of birth weight are unavailable for use in public maternal and child health program evaluation.

Because of the weaknesses of mortality and birth weight as measures of efficacy, use of the Apgar score can be given serious consideration. The Apgar score is widely recorded in the confidential portion of the birth certificate in the U.S.[6] and other countries as an indicator of the status of the newborn. The confidential section of the birth certificate was developed for medical, statistical and research purposes, and is not in general available for any other purposes, not even to the family or the newborn at any time.

DATA BASE

This study analyzed data from the birth certificates of children born in Kansas City Missouri or to Kansas City Missouri residents for the years 1979-1984. For these years a total of approximately 75,000 births were recorded, including approximately 25,000 births to non-residents. We restricted this study to residents with births occurring in "larger" hospitals (at least 300 total births for the whole period) and births to mothers whose race was reported to be white or Black. This resulted in 13 hospitals (including one "hospital" which delivered all births outside Missouri) with a total of 44,352 births. The variables studied were the following: Apgar score, birth weight, mother's race, mother's age, mother's educational attainment, reported gestational period, mother's reported smoking behavior, method of delivery (Caesarian/non-Caesarian), reported complications of pregnancy, and reported complications of labor and delivery.

METHODS & RESULTS

This study began with the question of using the Apgar score together with birth weight to help evaluate prenatal care programs in Kansas City, Missouri. In our initial investigations we found, for the four most selected attending physicians, the following correlations (n's) between Apgar scores and birth weights : 0.148 (1377), -0.048 (471), 0.342 (415), and 0.109 (380)[7]. One possible explanation for these low correlations is that whereas birth weights are objectively determined, Apgar scores are less clearly defined and more judgementally, or subjectively, determined; and thus subject to greater variation due to the training and experience of the judge. One of the five components which make up the total Apgar score -- heart rate -- is objectively defined; the other four components -- respiratory effort, muscle tone, reflex irritability and color -- are evaluator judgments. If these judgments differ among evaluators then differences in the scoring system might be revealed by hospital of birth. Hospital of birth (place) was used as an organizing perspective in statistical analyses of the variation in Apgar scores from birth certificates.

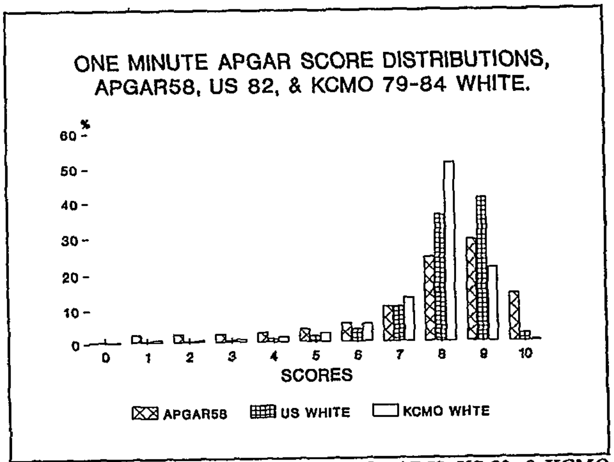

Figure A. Apgar Score Distributions, APGAR58, US 82, & KCMO 79-84.

The Apgar score distributions for all US births (1983) are substantially different from the Kansas City, Missouri (1979-84) score distributions, and both these score distributions differ markedly from the Virginia Apgar *et al.* (1958) score distributions (Figure A). Yet the distributions of birth weights for Kansas City and the US as a whole are virtually identical (Figure B).

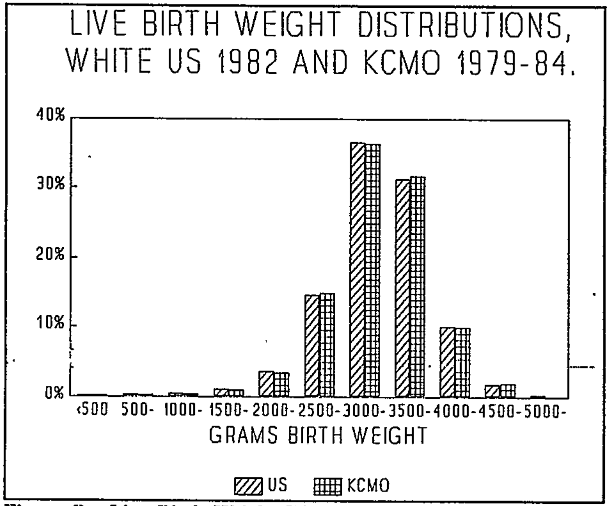

Figure B. Live Birth Weight Distributions, White US 1982 and KCMO 1979-84.

There are only slight differences in Apgar scores by mother's race (Figure C). This contrasts with much larger differences in birth weights by mother's race -- *e.g.*, Black infants have nearly double the low birth weight rate of whites. Within Kansas City, Missouri the distribution of Apgar scores is markedly different by hospital of birth (Figure C). We sought a plausible explanation (in the statistical sense) for these differences using the birth certificate data.

The mean Apgar scores plotted against birth weight for the groups with large enough numbers appear random around their place means (Figure D).

Similarly, Apgar score means plotted against weeks gestation reveals little relationship between the two (Figure E).

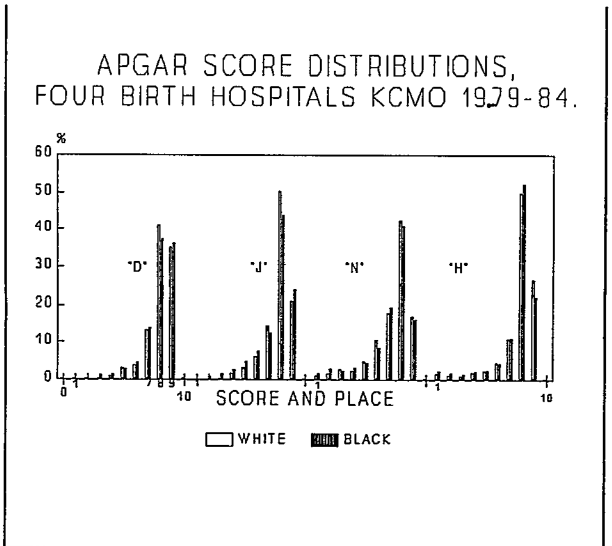

Figure C. Apgar Score Distributions by Race for Four Places.

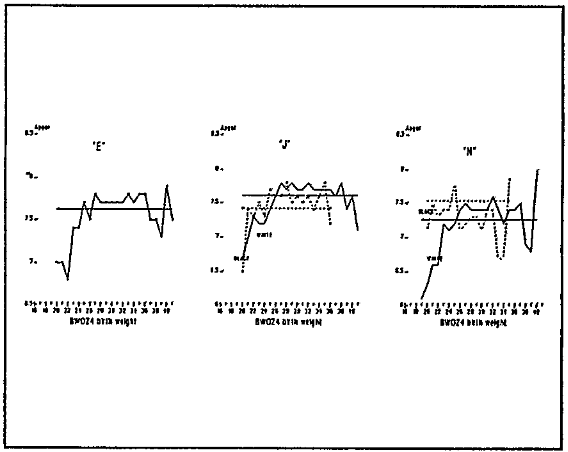

Figure D. Plots of Mean Apgar Scores by Birth Weight (BWOZ4) by Race for Selected Places of Birth.

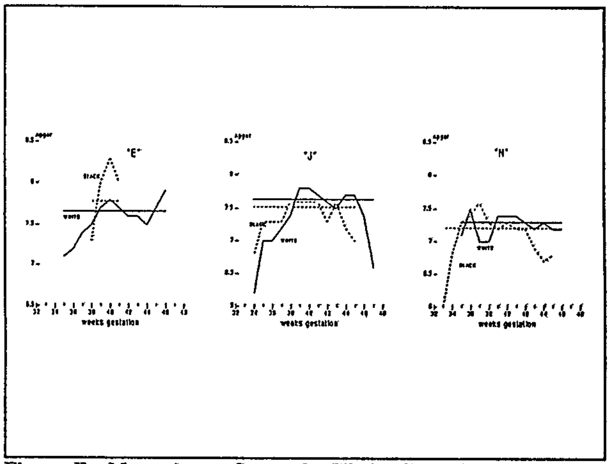

Figure E. Mean Apgar Scores by Weeks Gestation by Race for Selected Hospitals.

To assess the combined effects of birth weight and gestation length on Apgar score, we regressed score on birth weight, gestation length, and gestation length squared separately for each race and place of birth with sufficient numbers of births with having gestation lengths between 25 and 50 weeks inclusive. Fifteen of the 23 multiple correlations were significantly different from zero with the forward stepwise algorithm, but, with one exception, the R^2s were less than 0.08. We also tested equality of the additive constant terms from the regression as these would measure the differences in mean Apgar scores after having accounted for differences in birth weights and gestation lengths by place. There were some shifts in ranking compared to place mean score rankings, but the grouping is very similar and there are still significant differences by place. We interpret this as indicating only a negligible relationship between score and these variables.

We compared the relationship of mother's education to Apgar score with the education/birth weight relationship. We used six education categories (1-8 years, 9-11, 12, 13-15, 16, >16) within race and place, and found 58 increases, 25 decreased, and 4 ties in birth weight differences associated with increases in education. The probability of 29 or fewer minuses in 83 equiprobable trials is 0.004. Following the same procedures with Apgar scores, we found 43 increases, 31 decreases and 5 ties in Apgar score means associated with increases in education. The probability of 31 or fewer minuses in 74 equiprobable trials is 0.25, not strong evidence of any influences other than chance involved.

We probed for a relationship between scores and complications of pregnancy, complications of labor or delivery, Caesarian delivery, race, and age of mother by various regression techniques using place means. We found only a modest relationship between birth weight and Apgar score ($r^2 = 0.082$). Substituting SCORE6 (score ≤ 6) for score to overcome possible problems due to non-linearity resulted in no improvement. Also, the percentage of SCORE6 among only the low birth weight infants ranged from 24% for place D to 53% for place M, again suggesting no consistent relationship across place between low scores and low birth weight.

The mean birth weights of infants whose mothers smoked during pregnancy is less than the others in each place, but no consistent association of Apgar scores with smoking is seen (Figure F).

Our overall conclusion is that variations is the Apgar score distributions by hospital of birth in Kansas City are not explicable by any of the variables considered in this study.

This study was limited in scope to Kansas City, Missouri resident birth certificate data for 1979-84. The numbers involved in this study are adequate to support our conclusions about the use of the Apgar score within Kansas City, and we expect these conclusions to hold generally (on the basis of the other, although limited, published work as well as this work). We can not, of course, extend our conclusions with much certainty beyond this without further study. Secondly, we wonder whether hospital is the correct unit of analysis for a study of this kind. We found differences by hospital of birth, but with no further differences explainable by statistical analysis. This result was disappointing, in terms of understanding a useful application of this variation. Perhaps a study using groupings of the data by physicians or otherwise would reveal such utilitarian differences and provide some insight into the Apgar scoring system. Thirdly, the observed score distributions were so different from those usually encountered in statistical studies that the standard statistical methods were not completely valid here. Other researchers might use very different methodologies and possibly arrive at different conclusions. We think different conclusions are unlikely but certainly possible. Finally, we note that all the data used came from birth certificates, with clear limitations in terms of possible variables, and some weaknesses as well in the quality of the data. We did not attempt to estimate the magnitudes of these errors. Some variables are undoubtedly better than others in this regard -- such as birth weight compared to gestational length, for example. The fact that we analyzed a large data set helps some here, but there is still need for further work.

FOOTNOTES & REFERENCES

1. 1990 OBJECTIVES FOR THE NATION, Promoting Health/Preventing Disease: US Government Printing Office, Washington, D.C., 1980.
2. Infant deaths per 1,000 live births.
3. May 1 through April 30.
4. Women, Infant, and Children nutrition program funded from the Department of Agriculture.
5. There are about 115 infant deaths per year in Kansas City. This is approximately 1.5% of live births.
6. Except for California, Delaware, Oklahoma, and Texas.
7. Numbers in parentheses are the number of cases. Attending physicians, as indicated on the birth certificate, were selected on the basis of rank order of numbers of deliveries.

Apgar, V., D. Holedale, L. Jones, *et al.* 1958. Evaluation of the Newborn Infant - Second Report JAMA 1958; 168:1985-8.

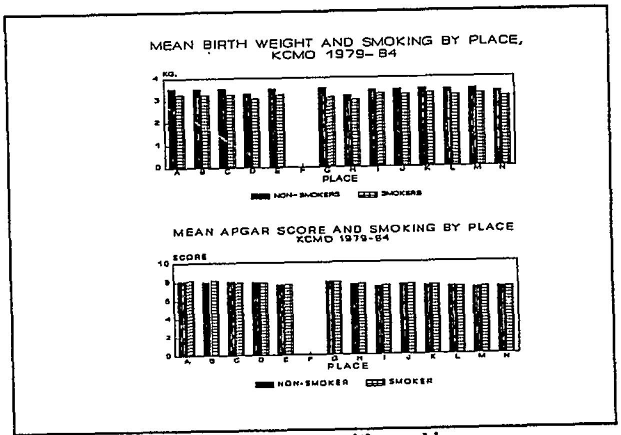

Figure F. Birth weight and Apgar with smoking.

HISPANIC PREGNANCY OUTCOMES: METHODOLOGICAL CONSIDERATIONS AND RESULTS

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Introduction

It is common practice in public health to take into consideration race when assessing health status. The importance of this stems from the fact that, in general, minorities have worse health status characteristics than Whites. Race-specific health statistics usually take the form of either two categories, White and Non-White, or three categories, White, Black and Other.

Hispanics are a minority group for which there is little health status reporting. Public health professionals recognize the need for Hispanic-specific data but are currently unable to do much about it due to the lack of an Hispanic identifier on many of the forms on which statistical data is collected.

However, there is an important data source which does contain Hispanic data which, until recently, has not been utilized to its fullest in assessing the health status of Hispanics. Since 1979, all Illinois birth and death certificates have contained a data item referred to as "origin or descent" in which the persons origin can be indicated. For Hispanics, the entry in this field gets coded to one of five categories: Mexican, Puerto Rican, Cuban, Central or South American, and other Hispanic. By grouping together individuals with one of the five Hispanic codes, Hispanic birth and death statistics can be produced.

This approach has only limited usefulness for mortality statistics due to the lack of adequate population denominators and hence the inability to calculate valid mortality rates. However, it is possible to calculate valid natality and infant mortality statistics from this data.

Since a substantial proportion of Illinois births are to Hispanics (9.9 percent in 1987), the Illinois Department of Public Health recalculated its natality and infant mortality statistics from 1980 to 1987 by ethnicity rather than just race. In the process, several methodological results were obtained which need to be taken into consideration when reporting on Hispanic pregnancy outcomes.

Data Sources and Methods

Illinois live birth, death and linked birth/death files for the years 1980 to 1987 (1986 for linked birth/death) were processed. It was not possible to obtain Hispanic data on fetal deaths as the origin or descent field is not present on these forms. All data reported here is based on individuals residing in Illinois at the time of birth.

The "origin or descent" field was the primary means for determining if a person was of Hispanic origin. Basing identification on Hispanic surname instead of or in addition to the origin field was investigated, however this is the less common practice and so was not done for the data presented here.

Unless otherwise indicated, only the mother's entry in the origin field was used. There is no commonly accepted algorithm for assigning origin to an infant based on both the mother's and father's origin.

Although it is possible to report on five different Hispanic groups, only Mexicans and Puerto Ricans are separated out in this report because the other categories are too general (Central and South American and Other Hispanic) or because there are too few births in Illinois to produce valid statistics (Cubans).

The "Place of Birth" field of the mother was also used in determining if a woman was to be classified as Mexican or Puerto Rican. (See the results section for an explanation of this).

Based upon entries on the origin, place of birth, and race fields, five mutually exclusive ethnic groups were formed: Asian, Black, Mexican, Puerto Rican, and White. The order of assignment was (1) Mexican: a woman born in Mexico or whose origin is indicated as Mexican; (2) Puerto Rican: if not assigned as Mexican, a woman born in Puerto Rico or whose origin is indicated as Puerto Rican; (3) Other Hispanic: if not previously assigned, a woman whose origin is coded as Cuban, Central or South American, or Other Hispanic; (4) if not previously assigned, the three race groups of Asian, Black and White were formed based on the entry for mother's race.

Results

Inclusion of Place of Birth

In the course of analyzing the hospital of birth for Hispanics (results not reported here), we discovered that several hospitals, including one tertiary level hospital, never recorded the specific Hispanic nationality, but instead just recorded "Hispanic". This was discovered by examining the field on the birth certificate "Mother's place of birth" and noting that, for example, the place of birth might be indicated as Mexican but the origin field was coded as "Other Hispanic". After consultation with members from the Hispanic community, we decided to include in our Mexican and Puerto Rican categories not just individuals who indicated that they were of Mexican or Puerto Rican descent, but also those individuals who indicated that they were born in Mexico or Puerto Rico. This had the effect of increasing the number of Mexican births by 8.3 percent and Puerto Rican births by 5.8 percent.

Necessity of Using the Linked Birth/Death File

Race-specific infant mortality rates are traditionally calculated by (1) taking the death tape and determining the number of deaths to children under one year of age who are of a particular race, (2) taking the live birth tape and determining the number of live births that were of the same race (determined usually by an algorithm which takes into consideration both mother's and father's race) and (3) multiplying by 1000. There is a chance that invalid rates will be obtained if there is significant discrepancy between what race the mother and father call themselves and the race that is assigned to the dead infant on the death certificate. In general, this has not been found to be a problem when reporting on Black and White infant mortality rates.

Hispanic infant mortality rates are not calculated from the race field but rather from the "origin or descent" field. The method used for calculating race-specific infant mortality rates can also be used to calculate origin-specific rates by just substituting the value in the origin field with the race field. Although in theory this should work, in fact invalid Hispanic infant mortality rates are obtained. Using 1985 data, we found that the Hispanic infant mortality rate when calculated using separate birth and death files was 5.8 per thousand. This is much lower than the rate for any other racial or ethnic group in Illinois and is unrealistic.

An alternate method to use for calculating infant mortality rates is to use the linked birth/death file rather than the death file as the basis for determining the number of deaths. By using this file, the field indicating origin on the birth certificate, rather than the death certificate, can be used. For our purposes, this meant using mother's origin or descent and assigning both the birth and death this value, while ignoring the entry on the death certificate. When calculated using the live birth file and the linked birth/death file, the infant mortality rate for 1986 was 10.2 per thousand. Investigation determined that the large difference in infant mortality rates between the two methods is the result of the above mentioned discrepancy between what the mother indicates as her origin and what origin is indicated on the death certificate for the infant. In approximately 40% of the infant deaths to mothers who indicated there origin was Hispanic, the infant's origin was recorded as "American" rather than one of the Hispanic origins.

Sub-division of Hispanics by Nationality

Although there is inadequate reporting of health statistics for Hispanics, what reporting there is usually has lumped together the various Hispanic nationalities into the general category of "Hispanic". This can be useful for some purposes, such as trying to estimate the number of people who only speak Spanish. However, it can be misleading when reporting on health status.

The two major Hispanic groups in Illinois are those of Mexican and Puerto Rican descent. For Hispanic live births in 1987, 68 percent of the mothers were of Mexican descent, 18 percent of Puerto Rican descent, and the rest of the other Hispanic nationalities. Although they speak a common language, the Mexican and Puerto Rican groups generally live in distinct neighborhoods and have differing socioeconomic and cultural characteristics. They also have very different birth statistics, as can be seen from Table I. As an example, the low birthweight percentages are 5.5 and 8.3 for women of Mexican and Puerto Rican descent, respectively. These results indicate that whenever possible, Hispanic statistics should be reported by nationality.

White Race versus White Ethnic Categories

An important "side-effect" of separating Hispanics from the usual racial categories is a more accurate assessment of the health status of non-Hispanic Whites. Traditional race classification has greatly distorted many of the birth statistics of this group as it has included the majority of the Hispanics. Table II contrasts the birth statistics of Whites with and without Hispanics included (data is for births in 1987 to residents of Chicago). As an illustration of the distortion, it can be seen that the percentage of women delivering in 1987 without a high school education is 39.9 percent for the White with Hispanic category and 19.3 percent of the White, non-Hispanic category.

The Effect of Place of Birth of Mother

Statistics were generated to determine what effect place of birth of mother had on Mexican and Puerto Rican birth outcomes for women residing in the city of Chicago (Table III). Large differences were found between Mexican women born in Mexico and Mexican women born in the United States for all birth statistics. Particularly striking are the excess teen births, single births, low and very low birthweight births, and infant deaths to Mexican women born in the U.S. There are 50 percent more infant deaths among Mexican women born in the U.S. This is in stark contrast to the more favorable prenatal care and educational status of these women. The Puerto Rican differences are less striking, with the exception of neonatal and infant mortality rates where, in contrast to Mexican women, there is an excess of neonatal deaths to women born in Puerto Rico compared to their mainland U.S. counterparts (14.3 versus 10.1).

Trend Analysis

The results from three such trend analyses are shown in the three figures. The top figure shows that the percent of live births to women who have a single marital status is increasing for all ethnic groups. The middle figure shows sharp declines for all ethnic groups except Blacks in the percent of women who are not beginning prenatal care in the first trimester of pregnancy. There appears to be a leveling off of these percentages for Puerto Rican women. The bottom figure shows that infant mortality rates have dropped for all ethnic groups except perhaps Mexicans, where there is some indication of a recent increase in rates. Puerto Rican rates may have remained constant if the rate for 1986 is considered a fluke. Asian, Black and White rates seem to have all levelled off in recent years.

Conclusions

The data presented here serves to emphasize the importance of doing routine health status reporting by ethnicity rather than race. As can be seen most clearly from Table I, great differences can be seen in the pregnancy outcomes of Hispanics in general, and Mexican and Puerto Rican women in particular, when compared to Asian, Black, and White women.

This investigation also showed that obtaining valid statistics for Hispanic women is not as straightforward as might be initially expected. Factors to take into consideration include separating Hispanics by nationality, supplementing the origin field with mother's place of birth, the use of linked birth/death

TABLE I
NATALITY RATES AND PERCENTS BY ETHNICITY

	ALL GROUPS	ASIAN	BLACK	MEXICAN	PUERTO RICAN	WHITE	ALL HISP
LIVE BIRTHS	180441	4158	40025	12335	3193	117772	18049
% OF BIRTHS	100.0%	2.3%	22.2%	6.8%	1.8%	65.3%	10.0%
MULT. BIRTHS	2.4%	1.5%	2.7%	1.5%	2.1%	2.4%	1.7%
MATERNAL AGE							
<= 14	0.3%	0.0%	1.1%	0.2%	0.5%	0.1%	0.2%
15-17	4.8%	0.6%	11.7%	4.5%	9.0%	2.5%	5.2%
18-19	7.3%	1.8%	13.5%	8.3%	13.6%	5.1%	9.1%
20-24	26.2%	15.5%	33.0%	32.2%	35.1%	23.4%	32.3%
25-29	32.6%	34.1%	23.2%	29.3%	26.0%	36.3%	28.9%
30-34	21.0%	33.6%	12.5%	17.3%	11.2%	24.1%	16.6%
35-39	6.7%	12.2%	4.3%	6.8%	3.9%	7.4%	6.3%
>= 40	1.0%	2.1%	0.6%	1.4%	0.8%	1.0%	1.3%
MARITAL STATUS							
Married	71.9%	95.0%	26.3%	74.9%	46.6%	87.0%	69.1%
Single	28.1%	5.0%	73.7%	25.1%	53.4%	13.0%	30.9%
NUMBER PREV. BTHS.							
0	32.0%	38.4%	29.0%	28.4%	30.5%	33.2%	29.1%
1	30.1%	32.2%	26.1%	25.7%	28.9%	32.0%	26.8%
2	19.5%	17.1%	19.8%	20.0%	19.5%	19.4%	19.8%
3	9.8%	7.2%	11.9%	12.0%	11.0%	8.9%	11.8%
4 or more	8.6%	5.1%	13.1%	13.9%	10.1%	6.5%	12.6%
EDUCATION							
0 - 8th	5.0%	5.5%	2.5%	44.5%	11.3%	1.3%	34.4%
9th - 11th	16.9%	5.4%	32.1%	22.7%	37.5%	10.9%	25.2%
HS Grad.	37.8%	20.8%	38.3%	21.6%	31.5%	40.2%	24.6%
13th-15th	21.7%	18.3%	20.9%	8.5%	14.9%	23.7%	11.3%
Coll. Grad	18.7%	50.1%	6.2%	2.7%	4.8%	23.9%	4.5%
PRENATAL CARE							
1st Trim.	78.4%	79.6%	64.1%	69.2%	74.8%	84.4%	70.4%
2nd Trim.	16.7%	16.0%	26.5%	23.1%	19.0%	12.5%	22.2%
3rd Trim.	3.3%	4.0%	5.4%	5.5%	4.4%	2.3%	5.2%
No Care	1.6%	0.4%	4.0%	2.3%	1.9%	0.8%	2.1%
ADEQUACY OF CARE							
Inadequate	5.8%	4.7%	13.2%	9.9%	8.9%	2.8%	9.4%
Intermed.	25.9%	26.7%	39.7%	37.8%	32.0%	19.6%	36.2%
Adequate	68.3%	68.6%	47.0%	52.3%	59.1%	77.7%	54.5%
BIRTHWEIGHT							
499 or less	0.2%	0.1%	0.5%	0.2%	0.2%	0.1%	0.1%
500 - 1499	1.2%	0.8%	2.5%	1.0%	1.3%	0.8%	1.1%
1500 - 2499	6.0%	5.7%	11.0%	4.3%	6.8%	4.5%	4.9%
2500 and up	92.6%	93.4%	86.0%	94.6%	91.7%	94.6%	93.9%
MORTALITY RATES							
Neo. Dth	7.9	5.0	14.1	7.4	8.6	6.0	7.6
Post-neo	3.8	2.2	8.0	2.9	3.9	2.6	3.0
Infant Dth	11.6	7.2	21.9	10.3	12.6	8.6	10.6
Adj. Neo.	7.2	6.6	7.3	8.4	7.1	7.6	8.0
Adj. Post-ND	4.0	2.4	6.7	3.6	4.0	3.0	3.4
Adj. Infant	10.9	8.9	13.7	11.6	10.9	10.4	11.2

YEAR: 1987 for percents, combined 1985 and 1986 for mortality rates.
"ALL GROUPS" represents births to all residents of Illinois.
"ALL HISP" column includes women whose origin is coded as Mexican, Puerto Rican, Cuban, Central or South American, or Other Hispanic.
"ADEQUACY OF CARE" refers to the "Kessner" index.
Mortality rates are per 1000 live births.
"Adj." refers to birthweight adjusted mortality rates.
Adjusted rates are adjusted to the 1980 Illinois birthweight distribution using the direct adjustment method.

TABLE II
WHITE RACE versus WHITE ETHNICITY
CHICAGO, 1987

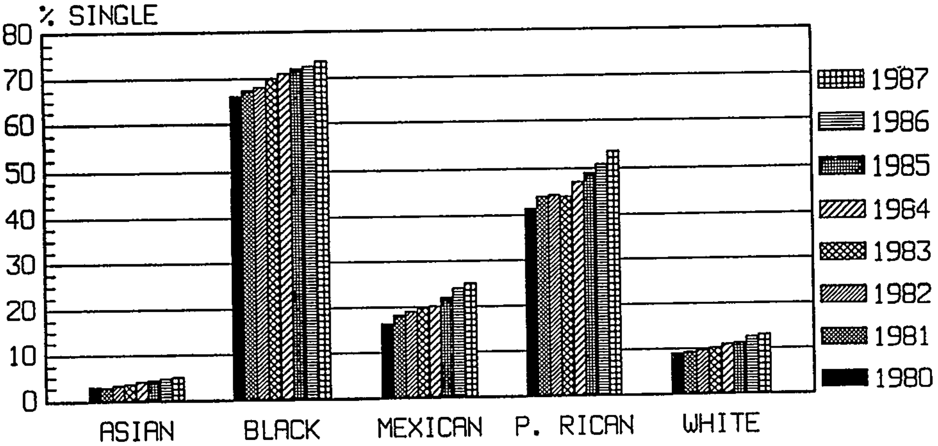
	RACE FIELD ONLY	RACE AND ORIGIN FIELDS			
	WHITE	WHITE	MEXICAN	PUERTO RICAN	ALL HISPANICS
Live births	26096	13954	8193	2774	12440
Teens	11.3%	8.0%	12.7%	24.3%	15.1%
Not Married	25.8%	18.2%	27.3%	56.7%	35.1%
Not HS Grad	39.9%	19.3%	70.6%	51.3%	63.0%
Inadeq Care	22.7%	18.2%	28.7%	24.3%	28.0%
% of Chicago Teen Births	28.8%	10.9%	10.2%	6.6%	18.4%
% of Chicago Births that Receive Inadeq Care	36.9%	15.9%	14.7%	4.2%	21.6%

TABLE III
EFFECT OF PLACE OF BIRTH OF MOTHER ON MEXICAN AND PUERTO RICAN BIRTH STATISTICS
CHICAGO, 1985-1987

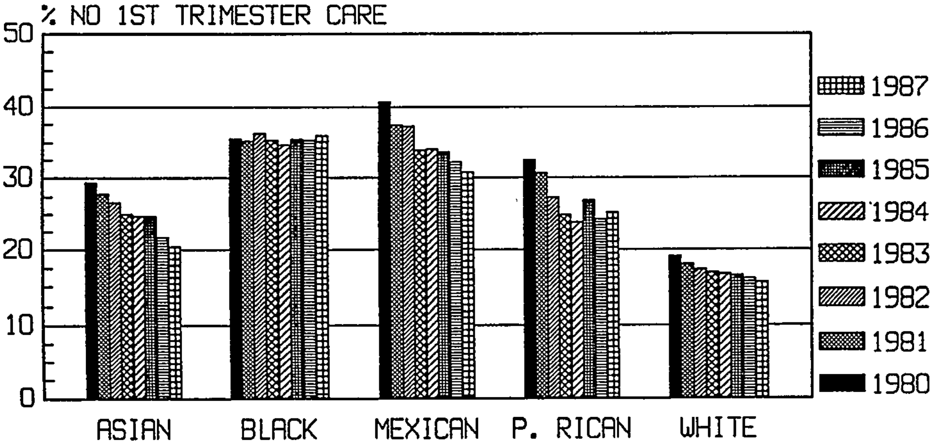
	MEXICAN ORIGIN		PUERTO RICAN ORIGIN	
	Born in Mexico	U.S.	Born in Puerto Rico	Mainland U.S.
% Teens	11.5	21.2	15.9	30.1
% Not Married	22.8	39.9	50.7	57.6
% Low Care	7.9	5.9	6.4	6.2
% Not HS Grad.	79.8	45.0	52.4	52.0
% 3 or more births by age 19	6.4	8.2	13.9	10.6
% VLBW	1.1	1.3	1.7	1.4
% LBW	5.2	6.8	8.6	8.6
Neo. mort. rate	6.4	9.0	10.7	6.3
Post-neo rate	2.9	4.9	3.6	3.8
Infant mort. rate	9.3	13.9	14.3	10.1

(NOTE: Mortality rates based on combined 1985 and 1986 data.)

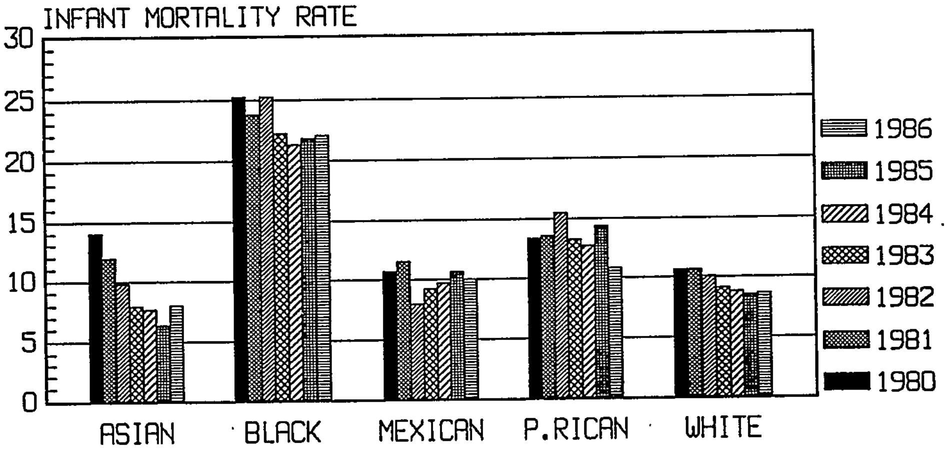
PERCENT OF LIVE BIRTHS TO WOMEN WHO ARE SINGLE BY ETHNICITY ILLINOIS ... 1980-1987



PERCENT OF LIVE BIRTHS TO WOMEN NOT GETTING CARE IN 1ST TRIM. BY ETHNICITY ILLINOIS ... 1980-1987



INFANT MORTALITY RATE (per 1000 live births) BY ETHNICITY ILLINOIS ... 1980-1986



MATERNAL MARITAL STATUS AND INFANT HEALTH

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Marital status has been gaining prominence as a demographic risk factor for infant health outcomes in the U.S. The number and proportion of births out of wedlock have increased more than fivefold since 1950. In 1987, 24% of all births were to unmarried women (17% of white births and 62% of black births) (1). As of 1980, the percentage of low birthweight for unmarried mothers was double that for married women (11.6% vs. 5.8%) (2). As demonstrated by national studies and an analysis of North Carolina vital statistics for the period 1968-85 (3), the heightened risk of single mothers for poor birth outcomes has not diminished as nonmarital fertility has become more common. However, the importance of marital status varies by race, age and other factors. Differentials by marital status in low birthweight and infant mortality are considerably greater for whites than blacks, and little effect for marital status is seen among mothers under age 20 (4-6). This variation is not surprising since marriage is only protective by virtue of the economic and social supports it can provide.

Briefly, today, I want to make three points about marital status as a risk factor:

1. Both research and policy have been hindered by a deviance model of out-of-wedlock childbearing, which is both biased and outdated but remains the dominant paradigm in our society.
2. Marital status is an imprecise variable which confronts the researcher with many measurement problems.
3. The explanatory value of marital status is very limited. However, variations in effect may provide clues to the needs and strengths of single mothers that could guide future research and planning.

1.) Single motherhood violates both maternity and marriage norms, two key areas in which gender-based expectations have shaped women's lives. The dominant family ethic has traditionally assigned women to their "proper place" in the home as wives, doing essential household labor and reproducing and socializing new generations of workers (7). Even as women have moved steadily into the labor force, this family ethic has maintained its ideological force. Long before Moynihan's (8) naming of so-called "illegitimacy" as the heart of a "tangle of pathology" obstructing black progress, single mothers were labeled as deviant and pathological in social science literature (9-11). Recent research on fertility and childbearing reflects the restriction of social "legitimacy" to marital births. Researchers have tended to exclude single mothers or to concentrate on them as a problematic group targeted for pregnancy prevention.

For example, fertility data in the U.S. census are obtained from women's responses to a question about the number of children they have ever borne. The 1980 census was the first to systematically enumerate children born to never-married women; prior to 1980, this question was largely restricted to ever-married women. Thus an undetermined number of births to single women have been excluded from trend data on fertility derived from the census.

Two major data sources on contraceptive utilization, fertility decision-making and reproductive outcomes are the National Fertility Survey (NFS) and the National Survey of Family Growth (NSFG). Both the 1970 and 1975 National Fertility Surveys limited samples to ever-married women. Cycles I and II of the NSFG were based on national probability samples of ever-married women and those never-married mothers who had at least one biological child living with them at the time of the survey. The World Fertility Survey (WFS), a model for comparative studies, used similar guidelines. Thus survey samples have frequently eliminated never-married women who had chosen to give children up for adoption or whose children were living in other households -- with relatives, fictive kin or foster families. Cycle III of the NSFG, conducted in 1982, sampled all women aged 15-44, eliminating the marital bias of the earlier cycles. Rindfuss and Parnell (12) categorically state that this was the first fertility survey which did not exclude potential mothers due to unmarried status.

The bias tends to be reversed in research on adolescent pregnancy. Married teens are not visible in most studies. The (often unstated) assumption is that **out-of-wedlock** teen pregnancies are the real problem. Information on marital status is frequently missing and only a careful reading between the lines reveals that married teens are not included in many studies of school-age pregnancy. The implication is that married teenage mothers are not at risk, despite evidence to the contrary. The literature demonstrates the instability of teen marriage and the heightened risk of married teen mothers for school dropout and repeated teen childbearing (13, 14). Family planning needs of married teenage girls, however, are rarely addressed.

Stigma attached to out-of-wedlock childbearing limits the scope of data gathering due to ethical and legal as well as conceptual problems. The 1980 National Natality Survey (NNS) questionnaire soliciting data on behavior during pregnancy was only mailed to married women. These questionnaires contained a standard consent form for obtaining medical records. Registrars in approximately half the states objected to sending questionnaires to unmarried mothers, fearing legal repercussions stemming from charges of invasion of privacy. Because of these concerns about confidentiality in the NNS, unmarried mothers had no opportunity to report on such survey items as smoking and drinking patterns during pregnancy. Medical record data as well as survey data were incomplete for out-of-wedlock births because the response rates from hospitals and physicians were lower when consent forms were lacking (15).

One can argue that stratification of data by marital status may contribute to the stigmatization of single mothers. Eleven states currently omit information about mother's marital status from the birth record. Women's privacy is thus respected and children avoid the handicap of starting out in life identified as "illegitimate." However, when this information is missing on even the confidential section of the birth certificate, estimation procedures are still performed for federal statistical purposes. Marital status data are still reported but perhaps less accurately than they would be otherwise. Whether or not the usefulness of data categorized by marital status outweighs the potential harm remains unclear.

2.) Definitional problems create inconsistencies and hinder comparative analyses. In some states "legitimacy" is determined by whether the mother has ever been married, in others by whether she is married at the time of the birth. Depending on where she gives birth, a mother may be asked whether her child is "legitimate," whether she is married to the father of the child or simply whether she is married. States tend to apply inclusive definitions; children are often considered "legitimate" if the mother is married at the time of conception or at any time during the pregnancy. In one state, Hawaii, a birth is coded as if the parents were married if the father acknowledges the baby before it leaves the hospital.

Jones et al. (16) argue that the vital registration system promotes a narrow legal definition of "illegitimacy" that is inappropriate for policy purposes. A broader social definition of "out-of-wedlock" births would include all women who are not in intact marriages at the time they give birth. Using the marital and reproductive histories of women in the June 1980 Current Population Survey, Jones et al. classified each birth according to both social and legal definitions. They found that the prevalence of "out-of-wedlock" increased considerably when they applied the social definition, especially among older, white, middle-classs women. According to their estimates, one million births occurring between 1968 and 1977 would be reclassified "out-of-wedlock" using this schema. They suggest that the revised definition would describe the socioeconomic situation of mother and infant with greater accuracy, and that policy-oriented research should not rely exclusively on birth certificate coding of out-of-wedlock births.

"Illegitimacy" is a value-laden issue, historically restricting the legal rights of women and children. Thus it is not surprising that respondent bias has been detected in the false reporting of marital status as "married" or "separated," rather than single (17). The resulting distortion of research findings is difficult to estimate. Differential bias may stem from disproportionate involvement of social welfare agencies with poor and minority families. Eligibility requirements for AFDC have encouraged reporting of unmarried status, reducing motivation and ability of participants to disguise out-of-wedlock births even if they chose to do so. Middle-class and white out-of-wedlock births might be underreported due to economic and status differences and the rigidity of cultural standards of marriage and inheritance. The work of Jones et al. suggests that the legal definition of "legitimacy" may itself function to conceal nonmarital births to more socially and economically privileged women.

Other definitional problems exist. For example, the "unmarried" category includes women living in stable unions with their children's fathers or other partners. The circumstances of women in consensual unions may closely resemble legally sanctioned marriage. In addition, common-law marriage requirements vary by state and over time. Offspring of common-law marriages are probably recorded inconsistently as marital or nonmarital births within and between states. Effects of marital status on birth outcomes may be underestimated when women in "informal" or common-law marriages are grouped with single women. Lesbian mothers are another group legally defined by their relationships to men. Lesbians are generally considered single regardless of the stability of their primary relationships or the economic and social supports they receive from partners.

3.) Effects of marital status are neither uniform nor inevitable. To understand the complexity of the situation of single mothers, we must go beyond simply using marital status as a proxy for social class. A few examples stand out as indications of underlying dynamics that may be obscured by moralistic and racist assumptions about unmarried mothers (3).

The assumption that all unmarried women are "high risk" is questionable, though unmarried status seems to be an accurate marker for late entry into care. The worst prenatal care patterns are found among white unmarried women, perhaps due to stigmatization and lack of social support as well as economic factors.

Unmarried status as a risk factor for infant death seems to be most prominent in the postneonatal period, suggesting the importance of environmental conditions and the need for interventions beyond maternity care.

Unmarried motherhood is usually accompanied by a dearth of economic resources, but need not imply a lack of psychosocial supports. Social support appears to moderate the effect of stress during pregnancy (18). Some data indicate that teens tend to have healthier babies if they are not married, which is not surprising considering the instability and impoverishment of many teen marriages. Most single teen mothers remain in relatives' homes, receiving help with child care and other necessities.

Stack (19) and others have described extended kin networks transcending household boundaries as a survival mechanism for black single mothers. Reeb's (20) study of 140 black pregnant women at a university hospital center in Cleveland highlights the distinction between being single and being isolated. He found that the size of a woman's perceived family (the people she felt closest to), rather than the size of her immediate household, was related to family functioning and psychosocial adjustment. Family functioning, in turn, was the only one of numerous demographic, biomedical and psychosocial variables to make a significant contribution to both low birthweight and complications of labor. Positive birth outcomes were associated with large networks of perceived family support, not with being married.

This is not to suggest that social support can substitute for material resources or access to care. Marital status is a strong predictor of insurance status; unmarried women are 2-3 times as likely to be uninsured as married women. Medicaid, the coverage which has traditionally been targeted to single mothers on AFDC, has increased access to care but has not reduced disparities in infant health outcomes by marital status.

In conclusion, as long as women and children are discriminated against on the basis of family structure, data revealing the needs of single mothers must be improved and should be interpreted in the context of gender, race, class and culture.

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DIFFERENCES IN BIRTHWEIGHTS, PRENATAL CARE AND SELECTED RISK FACTORS: MEDICAID VS. NON-MEDICAID - THE TEXAS EXPERIENCE

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It is well recognized that low birthweight increases the risk of infant mortality and morbidity and also increases the cost of medical care (1-3). Nationally, about seven percent of infants born are of low birthweight (< 5.5 lbs). Low birthweight infants represent two-thirds of neonatal deaths and 60% of all infant deaths (4). The major factors known to be responsible for high incidences of low birthweight are the quantity and quality of prenatal care, multiple births, socio-economic status, age and marital status of the mother (5).

The Medicaid program is a federal/state medical assistance program, administered by states to provide medical assistance to low income families and to low income aged, blind and disabled people. On an average, Medicaid provides coverage to at least half of the residents living in poverty in the United States. While states like California and New York serve more than 90 per cent of their poverty populations, Texas until recently, had very restrictive Medicaid eligibility criteria. Coverage extended only to eligible persons below 25% of the federal poverty level (6). However, as a result of the Omnibus Budget Reconciliation Act of 1986 and the increasing burden of uncompensated care faced by hospitals in Texas, the Medicaid program came under tremendous pressure to expand its Medicaid eligibility criteria (7). The present study attempted to investigate the differences and similarities in birth outcome between Medicaid and non-Medicaid populations to provide a base line for future evaluations of Medicaid program changes and expansions.

METHODOLOGY

The basic design of the study involved integrating information on infant Medicaid eligibility status with birth records (Figure 1). Two computer files were linked to produce this information. Data on the Medicaid population were obtained from the Texas Department of Human Services (TDHS). This information included eligibility status and identifying characteristics such as infant's name, birthdate, sex and case name. The data on birth characteristics were obtained through the birth records maintained by the Bureau of Vital Statistics, Texas Department of Health (TDH). The birth file, based on recorded birth certificates, included information on births such as infant's name, date of birth, sex, birthweight, frequency of prenatal visits, month prenatal visit initiated, length of pregnancy, mother's name, age and marital status, and father's occupation.

The scope of the study was limited to births occurring in January 1986. The June 1987 TDHS Medicaid eligibility file, which had over 1.9 million records, was used to identify Medicaid eligible infants born in January 1986. The number of Medicaid eligible infants for January 1986 was 5,382. Similarly, births for January 1986 were identified from the 1986 birth file containing over 300,000 birth records. Births in Texas in January 1986 totaled 25,732, of which 25,538 contained sufficient information for inclusion in the study.

The initial match between the two data files was based on a key composed of a 15 character string. This string contained the first six characters of the infant's last name, the first six characters of the infant's first name, the day of birth (2 characters) and the infant's sex. During the first pass, 71% of the Medicaid records matched with birth records. A subsequent match was conducted on the remaining Medicaid and birth records to accommodate different naming conventions used in the two data files. A final matching rate of 86.6% was obtained through this two-step process. For analysis purposes, the 4,659 matched birth records were classified as Medicaid and the 20,879 non-matched birth records were classified as non-Medicaid .

The main statistical tool used for analysis was the Chi-square test. The differences in the birth outcome for the two population groups were determined after controlling for one or more of the following variables: race, prenatal visits, trimester prenatal care was initiated, gestational age, mother's age, and mother's marital status.

The interpretation of the results of this study is subject to three major constraints. First, even though a baby was eligible for benefits under the Medicaid program upon birth, the mother may or may not have been eligible for the program prior to delivery. Second, information relating to prenatal care and marital status is based on birth record data which are the products of the mother's recall. In the present study, these areas are treated by using the phrase "mothers reported ...". The accuracy of the findings of this study depends on the quality of the responses in these specific areas. Third, with Medicaid coverage extending to persons below 25% of the federal poverty level in Texas during the time period under study, the non-Medicaid group included the remaining poverty population as well as the population above the poverty level. Thus, Medicaid group represents the poorest of the poor, whereas the non-Medicaid group comprises mixed income groups. In this regard, the two groups do not represent distinct socio-economic classes.

RESULTS

Approximately one out of every six births in the study group was eligible for coverage under the Medicaid program. The differences in the birthweights, level of prenatal care, and selected risk factors for Medicaid and non-Medicaid births are summarized in Table 1. In terms of ethnic composition, mothers of Medicaid infants were predominantly Hispanic and Black, whereas mothers of non-Medicaid infants were predominantly Anglo. Forty-three percent of mothers of Medicaid infants were Hispanic, 31% were Black and 26% were Anglo. Over 60% of non-Medicaid mothers were Anglo, 30% were Hispanic, and 10% were Black. Thus, there were three times more Black mothers in the Medicaid group than in the non-Medicaid group (Figure 2). Black mothers represented 13% of the total mothers for January 1986.

The mothers of Medicaid infants were younger than the mothers of non-Medicaid infants (Figure 3). Thirty-one percent of Medicaid infants were born to teenage mothers, whereas only 13% of the mothers of non-Medicaid infants were teenagers. In other words, one out of every three Medicaid infants was born to a teenage mother; one out of every eight non-Medicaid infants was born to a teenage mother.

The primary finding of the study was that the mothers of Medicaid infants have a much higher proportion of low birthweight infants than mothers of non-Medicaid infants (Figure 4). Approximately 9.2% of the Medicaid infants weighed less than 5.5 pounds compared with 5.6% for non-Medicaid infants and 6.2% for all infants ($P < .001$). The U.S. Surgeon General's goal for the nation states that no more than 5% of the infants born should weigh less than 5.5 pounds by 1990. Texas ranks 17th among the states with a low birthweight incidence that is higher than the national goal (8).

The Surgeon General's goal also states that by 1990, no racial or ethnic group should experience a low infant birthweight rate exceeding 9% of live births (9). Within race subgroups, Black mothers showed the highest incidence of low birthweight infants in both Medicaid (12.4%) and non-Medicaid (9.7%) populations (Figure 5). The proportion of low birthweight Black infants for the Medicaid population was as high as the national average of 12% for this race group. Although the proportion of Hispanic low birthweight infants was higher for the Medicaid population (7.4%) as compared to the non-Medicaid population (5.1%), the proportions for both Medicaid and non-Medicaid Hispanic populations were well below the Surgeon General's goal of 9%. The Anglo Medicaid low birthweight rate at 8.5% was not significantly lower than the national goal.

Studies have documented that Black women have a higher proportion of teenage births, out-of-wedlock births and a higher incidence of multiple births (10,11). These births are more likely to be unintended and associated with low birthweight. The analysis of marital status for ethnic subgroups revealed that more than half of Black mothers reported being unmarried. Nine percent of Anglo mothers and 19% of Hispanic mothers reported being unmarried. The proportion of unmarried mothers was higher for all race groups in the Medicaid population than in the non-Medicaid population. It was as high as 79% for Black medicaid mothers (Figure 6). Black mothers are also more likely to receive prenatal care later in pregnancy. It is suspected that even if better prenatal care and education were made available, Black mothers may still produce low birthweight infants. Biologically, It is possible that Black mothers have a tendency to produce low birthweight infants. This gives a different meaning to low birthweight for Blacks than for other race groups, requiring attention for further research (12).

Numerous studies have documented that teenage mothers generally have fewer economic, social and emotional resources to draw on than women who delay pregnancy until their twenties and thirties (13-14). Table 2 demonstrates that teenage mothers did not show statistically significant differences ($p < .05$) in the birthweights for Medicaid and non-Medicaid groups for Anglo, Hispanic or Black women. In the 20-34 years age group, Anglo women showed significant differences in birthweights between the Medicaid and non-Medicaid populations. This may be due to socio-economic factors indicating that non-Medicaid Anglo women are more likely to exhibit higher economic stability, higher education level, and/or two parent families than Medicaid Anglo women. The difference in birthweight between the Medicaid and Non-Medicaid groups for Black women was significant only for the 30-34 year age group. The non-Medicaid "older" Black women may show higher socio-economic and educational stability than Medicaid Black women in the same age group.

Inadequate prenatal care is considered one of the major risk factors influencing birth outcome. A comparison of prenatal care in terms of number of visits for the two groups under study revealed that mothers of Medicaid infants reported making fewer visits than mothers of non-Medicaid infants (Figure 7). On an average, mothers of Medicaid infants reported making eight prenatal visits as compared with ten visits for mothers of non-Medicaid infants. Over one-half of mothers of Medicaid infants reported making fewer than eight prenatal visits in comparison to only one-third of non-Medicaid mothers.

Although the incidence of low birthweight was higher for the Medicaid infants than the non-Medicaid infants for all categories of visits, the difference in incidence of low birthweight between the two populations was statistically significant for the categories of 9-11 prenatal visits and 12 or more visits ($p < .01$) (Figure 8). Thus, prenatal visits alone did not adequately explain the differences in the percentage of low birthweight infants between the two groups. Other factors, such as income, education, and nutrition may also contribute to the differences in the incidence of low birthweight infants between the Medicaid and non-Medicaid populations.

The trimester prenatal care was initiated was also assessed as a measurement of adequacy of care. Less than half of the mothers of

Medicaid infants reported initiating prenatal care in the first trimester of pregnancy as compared with 71% in the case of mothers of non-Medicaid infants (Figure 9). The proportion of mothers of Medicaid infants starting prenatal care in the third trimester was twice as high (13.4%) as the proportion for mothers of non-Medicaid infants (6.3%). Of the 23,641 mothers who reported this information, alarmingly, 1,108 mothers or 4.7% reported receiving "no care". The percentage of mothers of Medicaid infants reporting "no care" (7.6%) was twice as high as for mothers of non-Medicaid infants (3.7%).

The Kessner Index, one of the most refined measures of prenatal care, was also used as an indicator of the quantitative adequacy of prenatal care (15). Prenatal care was categorized as adequate, inadequate or intermediate based on the number of prenatal visits and the trimester care began in relation to the length of gestation (Table 3). Based on this "prenatal care index", a higher percentage of mothers of Medicaid infants (70%) reported experiencing intermediate or inadequate care than mothers of non-Medicaid infants (41%) (Figure 10).

CONCLUSIONS

This bench mark study was an effort to investigate the differences and similarities in the birth outcome between the Medicaid and non-Medicaid populations. It was undertaken at a time when Medicaid coverage in Texas was limited to persons below 25% of the federal poverty level. The results, therefore, are not surprising.

To summarize, the percent of low birthweight infants was 9.2% for the Medicaid population compared to 5.6% for the non-Medicaid population ($p < 0.001$). Across ethnic groups, Black mothers showed the highest incidence of low birthweight infants. Mothers of Medicaid infants were younger than mothers of non-Medicaid infants. Mothers of Medicaid infants were predominantly Hispanic; mothers of non-Medicaid infants were predominantly Anglo. Mothers of Medicaid infants reported making fewer prenatal visits and initiating prenatal care later in pregnancy than mothers of non-medicaid infants. Prenatal care alone did not adequately explain the differences in the percentage of low birthweight infants between the two groups. Other factors such as income, education and nutrition may also account for the differences in the incidence of low birthweight infants between the Medicaid and non-Medicaid populations.

The Medicaid program in Texas has since extended its coverage in terms of the number of eligibles and the scope of its services. Currently, the program covers all pregnant women with income up to 100% of the federal poverty level. As of September 1, 1989, this coverage is further expanded to pregnant women with incomes up to 130% of the federal poverty level. The differences in birth outcome between comparable Medicaid and non-Medicaid population groups should be studied again in the near future, to evaluate the impact of these Medicaid eligibility changes.

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Table 1

Birthweights, Prenatal Visits And Selected Risk Factors
By Texas Medicaid Status - January 1986

	% of Total non-Medicaid	% of Total Medicaid	All Births
Under 5.5 Lbs. 2500 grams)	5.6	9.2	6.2
Race of Mother			
Anglo	60.2	26.2	54.5
Black	9.7	30.8	13.2
Hispanic	30.1	43.0	32.3
Age of Mother			
Under 18	5.1	12.9	6.4
18-20	12.8	27.8	15.3
21-24	26.0	28.0	26.4
25-29	32.1	19.3	29.9
30-34	17.7	8.0	16.1
35-39	5.6	3.4	5.2
40+	0.7	0.6	0.7
Unmarried Mothers			
Anglo	6.9	36.5	9.3
Black	36.7	79.1	53.3
hispanic	13.7	36.7	18.9
Occupational Status of Father			
Skilled	58.9	19.0	52.2
Unskilled	29.3	31.2	29.7
Father not Reported on Birth Certificate	11.8	49.7	18.2
Prenatal Visits			
0	4.0	8.2	4.7
1-2	3.2	7.2	3.9
3-5	7.8	16.7	9.3
6-8	16.2	22.0	17.1
9-11	25.6	23.9	25.3
12+	43.3	22.0	39.7
Prenatal Care Initiated			
1st Trimester	70.6	43.5	66.1
2nd Trimester	19.4	35.5	22.1
3rd Trimester	6.3	13.4	7.5
No Care	3.7	7.6	4.3
Prenatal Care Index (Based on Kessner Index)			
Adequate Care	58.4	29.9	53.7
Intermediate Care	29.2	43.7	31.6
Inadequate Care	12.3	26.4	14.7

Figure 2

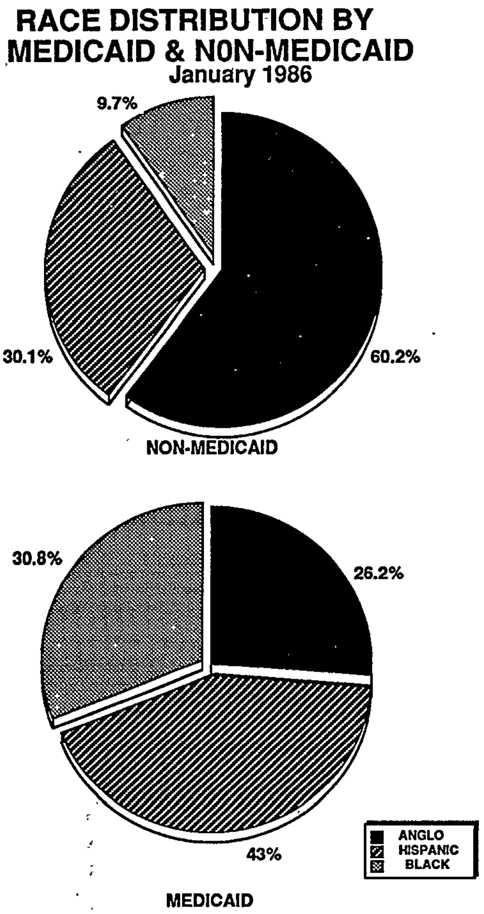


Figure 1

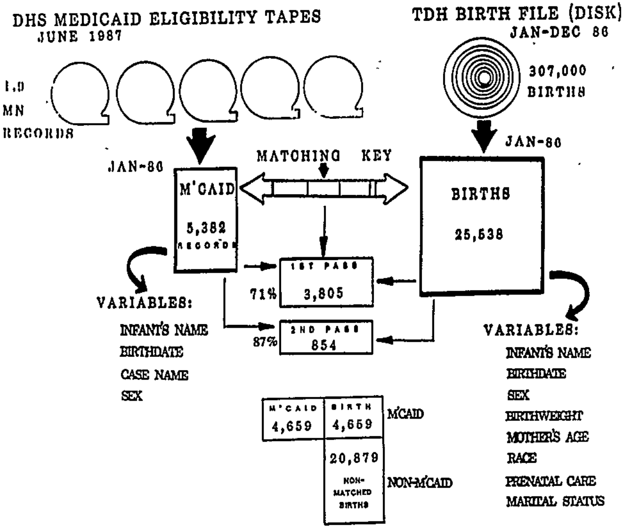


Figure 3

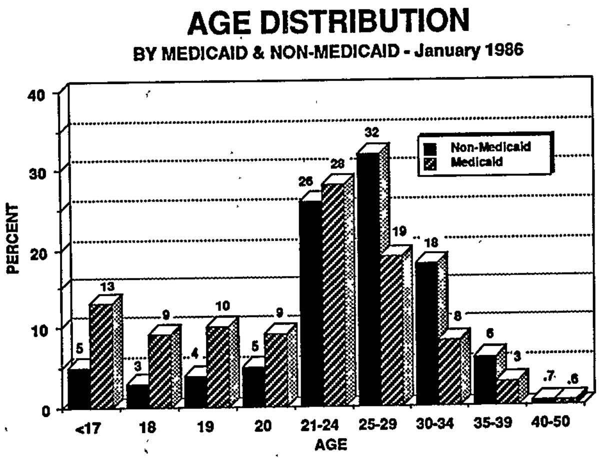


Figure 4

PERCENT LOW BIRTHWEIGHT

BY MEDICAID & NON-MEDICAID - January 1986

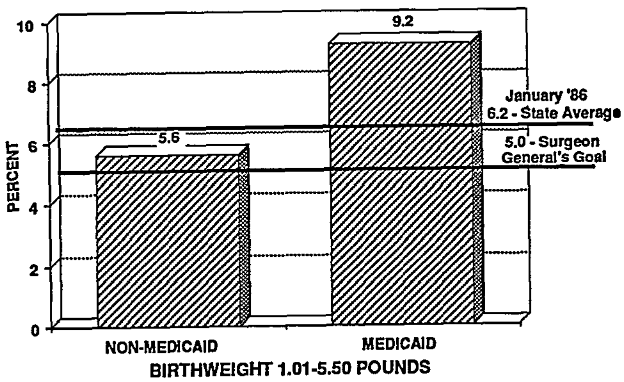


Figure 5

PERCENT LOW BIRTHWEIGHT BY RACE

BY MEDICAID & NON-MEDICAID - January 1986

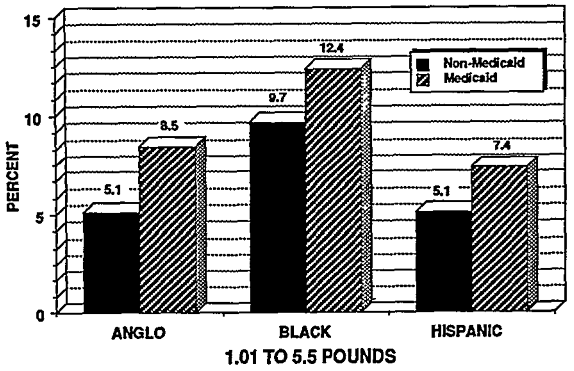


Figure 6

MARITAL STATUS OF MOTHER - BY RACE

By medicaid and Non-Medicaid - January 1986

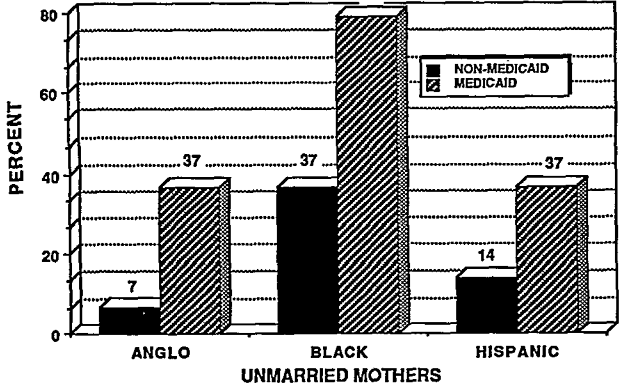


Table 2

SIGNIFICANT DIFFERENCES IN BIRTHWEIGHTS BY MEDICAID AND NON-MEDICAID CONTROLLED FOR AGE AND RACE SUBGROUPS (p < .05)

	ANGLO	BLACK	HISPANIC
UNDER 15			
AGE 15-16			
AGE 17			
AGE 18			
AGE 19			
AGE 20	YES		
AGE 21-24	YES		YES
AGE 25-29	YES		
AGE 30-34	YES	YES	
AGE 35-39			YES

Figure 7

PERCENT OF POPULATION BY PRENATAL VISITS

By Medicaid & Non-Medicaid - January 1986

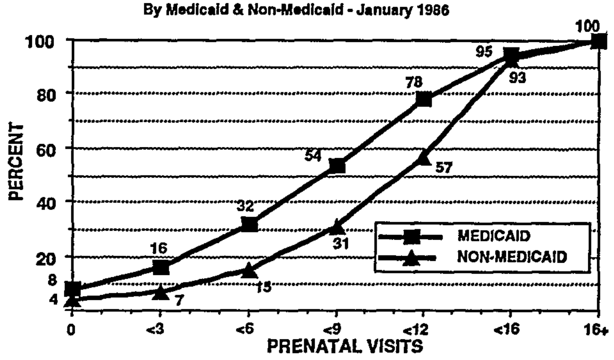
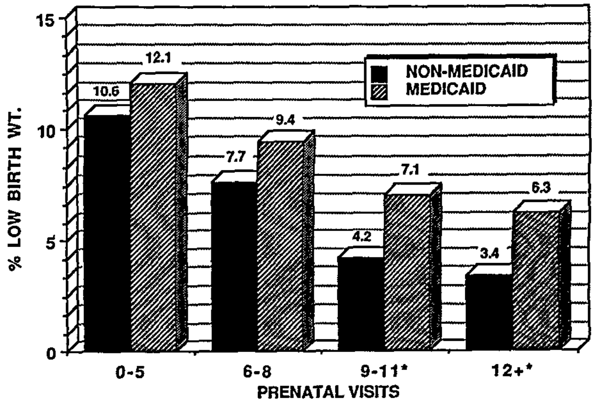


Figure 8

BIRTH <5.5 LBS BY VISITS

BY MEDICAID & NON-MEDICAID - January 1986



*Statistically significant at 1% level.

Figure 9

PRENATAL CARE INITIATED

BY MEDICAID & NON-MEDICAID - January 1986

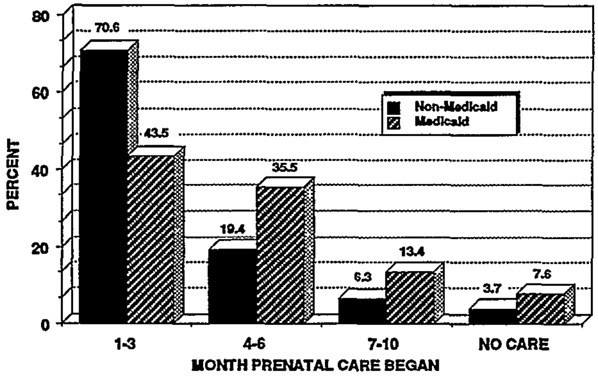


Table 3

Criteria for Adequacy-of-Care Index Levels*

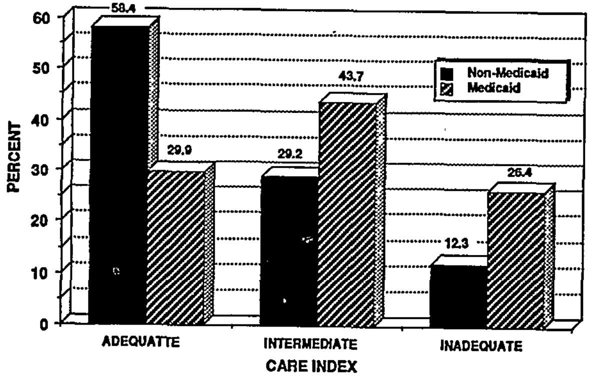
Adequacy of Care	Trimester of First Prenatal Visit	Gestation (Weeks)	Number of Prenatal Visits
Adequate	First (1-3 months)and	17-21	and 3 or more
		22-25	and 4 or more
		26-29	and 5 or more
		30-31	and 6 or more
		32-33	and 7 or more
		34-35	and 8 or more
		36-48	and 9 or more
Inadequate	Third (7-9 months) or	17-21	and 0
		22-29	and 1 or less
		30-31	and 2 or less
		32-33	and 3 or less
		34-48	and 4 or less
Intermediate	All other combinations		

* Adapted from Kessner DH, Singer J, Kalk CE, Schlesinger ER. "Infant Death: An Analysis by Maternal Risk and Health Care." Contrasts in Health Status. Vol. 1. Washington, D. C. Institute of Medicine. National Academy of Sciences, 1973.

Figure 10

PRENATAL CARE INDEX*

BY MEDICAID & NON-MEDICAID - January 1986



*Adapted from Kessner Index

Session BB

Children and Youth

PHCRS

UNITED STATES VIRGIN ISLANDS 1988 SURVEY: A USEFUL TOOL FOR NEEDS ASSESSMENT AND COMMUNITY DIAGNOSIS

Cora L.E. Christian and Corinne Halyard, Virgin Islands Department of Health

INTRODUCTION

BACKGROUND/U.S. VIRGIN ISLANDS

The Virgin Islands, part of the Antilles Chain, is located at the eastern end of the Greater and the northern end of the Lesser Antilles. To the west of the United States Virgin Islands is Puerto Rico and immediately to the northeast are the British Virgin Islands.

Of the many islands and cays comprising the United States Virgin Islands, only three are of economic or clinical significance; most of the others are uninhabited. The largest, St. Croix with 84 square miles, is mostly flat and, therefore, the most suitable of the islands for intensive economic development; it has two harbors Christiansted, the larger town on the north and Frederiksted, the more depressed area on the west. Forty miles due north, St. Thomas with 28 square miles has rugged mountains that rise sharply from the sea to heights of up to 1500 feet; St. Thomas has a fine natural harbor at Charlotte Amalie, which also is the seat of government of the United States Virgin Islands. A few miles east of St. Thomas, St. John, covering 20 square miles, offers similar land and seascapes. The preservation of St. John's natural beauty has been assured by the inclusion of more than half of the island in the Virgin Islands National Park.

The Virgin Islands population has grown from approximately 25,000 (1960) to 100,000 (1980). This was due to the closing of Cuba to the American tourist and the shift of the American tourist to the Virgin Islands. Well over 80% of the Virgin Islands population is Black, including Hispanics.

The United States Virgin Islands has a socio-economic structure that closely approximates that of the mainland United States of America with a health delivery system modeled on United States standards.

BACKGROUND/1988 HOUSEHOLD SURVEY

In 1981, with the creation of a Division of Ambulatory Care Services, it was clear that there was a need for a data base to plan services. No baseline data were available, only clinic records. No staff were available to gather these data. However, it was felt that nurses, as they provided care in the various clinics and in the field, had access to the clinic population. Therefore, they would be able to survey the population and create the necessary data base. However, a survey instrument was necessary.

The survey instrument took two-and-one-half years to design. Input was received from every level of provider in every district of the Virgin Islands. The survey instrument went through several revisions. At the completion of the instrument, due to the shortage of nursing personnel, a decision was made to seek assistance for its use through a technical assistance program. We needed to acquire interviewers who were skilled in doing surveys. Due to a series of very fortunate events, surveyors from Columbia University School of Public Health, University of the Virgin Islands nursing students, high school students and Department of Health employees were brought together to form a fifty member team that conducted a survey of the entire population. The time frame was one month.

In addition to securing the survey team, computerization and programming of the instrument were accomplished through a contract with Richard Hawkins of RESUBA Digital, Inc. We coordinated Hawkins' services through our local computer services.

Issues such as public relations, preparation of staff, security and housing were addressed in order to make sure that the community was prepared for the investigators; that the summer students were properly trained in interviewing techniques and blood pressure measurement; and that the interviewers felt secure as they conducted the interview. Most of the interviews were conducted in the evenings and on weekends. These times were picked to increase success of contact.

METHODS

SUBJECTS

The 1980 Census estimated the United States Virgin Islands population as 96,699; 49% males and 51% females with the age distribution almost identical to the findings of the population surveyed in the 1988 Health Survey. The racial make-up of the population is approximately 73.3 percent black, 14.8 percent white, 10.3 percent Hispanic and 1.2 percent other. Five hundred and eleven (511) households were surveyed and 1526 people were interviewed. One thousand five hundred-Six (1506) interviews were used for analysis due to missing values on the others. The survey used enumeration districts. Subsamples were taken for subpopulations in such a manner as to provide an estimated reliability of survey results for the territory based on the sample error expected when generalized samples of the population are within ± 5 percent at a 95 percent level of confidence. To be more precise, the findings expressed as percentages are within five percentage points of what the entire Virgin Islands population thinks on a given subject. This complex probability sample with a multistage area design ensured that every household, except those living in institutions in the territory, had an equal chance of selection in the sample, irrespective of social class, ethnic, national origin, political, religion, level of education or any other characteristics that define a group in a territory. Therefore, we would be assured that the expressions of the respondents are truly representative of the people of the Virgin Islands.

Official Enumeration Districts (ED's) maps of the Virgin Islands were used as the sample frame. Forty (40) enumeration districts were identified, 20 in St. Croix, 18 in St. Thomas and two (2) in St. John. Twelve (12) households from each enumeration district were selected by choosing every third household on the list. If an address lot was vacant, the next address appearing on the list was selected until an actual household was identified. In cases where there was an apartment or similar complex at a single address, then every household at that address was interviewed. Eventually, this yielded a total of 511 households.

DATA COLLECTION

The purpose of the needs assessment was basically to identify the true health needs of the Virgin Islands population. The goals of the project were:

1. Identification of problems to assist planning and provision of appropriate health care services.
2. Gathering of preliminary data on fertility and contraceptive use focuing on the adolescent population.
3. Provision of trained and skilled staff to implement the survey.
4. Increased awareness by the public of availability of services.
5. Promotion of preventive and health promotion public health services.
6. Promotion of interest in public health services among nursing college and high school students.
7. Creation of a protocol for future health surveys.

We will present results on only two items from the survey-Family Planning ages 10-14 and 15-19 and Hypertension ages 0-18. These age groupings are consistent with national groupings used by the family planning program's guidelines for the Bureau of Common Reporting Requirements (BCRR) Report and the Report of the Second Task Force on Blood Pressure Control in Children 1987, respectively.

FAMILY PLANNING

Family Planning received special attention because of the serious problems that we felt existed from our ongoing servicing of residents within the community, one such problem being teenage pregnancy. At that time we had no accurate information on our teenage pregnancy rate. Doing the needs assessment would help us to gather information to plan for the family planning activities.

The Department made the decision to question all individuals from age ten (10). This decision was based on the ages that have experienced menarche, and the perception in the community that very young children were having babies. We asked questions to obtain the needed responses to ascertain sexual activity. Also, there were questions on mortality, morbidity and issues of choices as pertains to sexual activity. For this discussion, only two questions are presented:

...Are you able to receive the kind of family planning services that you would like to have?

...What are the problems with receiving family planning services?

RESULTS

Eighty (80) percent of females ages 10-14 stated they were unable to receive family planning services, and 63.01% of males ages 10-14 had a similar response. By ages 15-19, the responses were now similar at 34.25% for females and 30.77% for males. By ages 20-24, females, only 19% felt they were unable to receive services **(See Figure 1 on the following page)**. Yet, when asked what were the problems, neither appointments, hours, cost, or transportation were significant contributors. **See Figures 2 and 3 on the following page.**

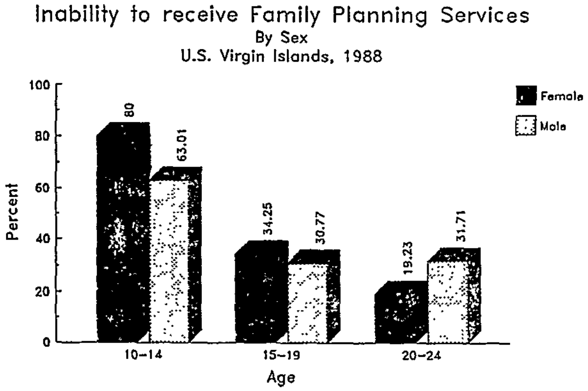


Figure 1

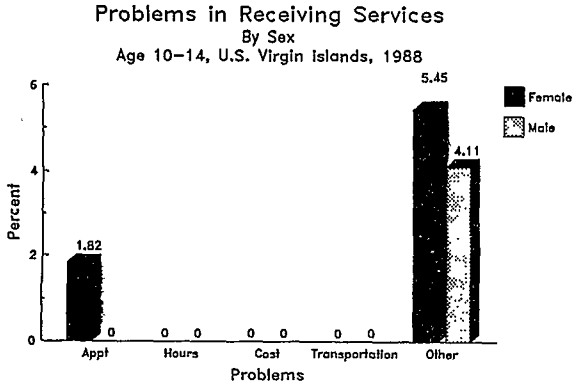


Figure 2

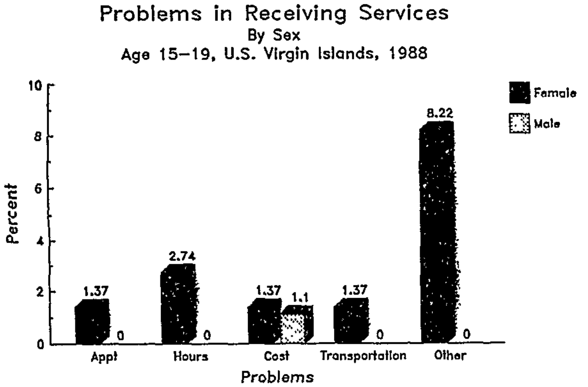


Figure 3

HYPERTENSION

The relationship between hypertension as a risk factor for cardiovascular disease has been clearly shown in adults. However, there is evidence to support the concept that essential hypertension can begin in childhood.

It is estimated that less than 3% of children in the United States have arterial hypertension.[1] This supports the need for early identification of these children so that they may be placed under surveillance. In cases where hypertension cannot be prevented, early appropriate treatment may prevent increasing disability and complications.[2]

The dependent variable is blood pressure, which included age-specific systolic and diastolic blood pressure. Elevated blood pressure for children was determined by guidelines set by the Report of the Second Task Force on Blood Pressure Control in Children-1987.

For this report, elevated blood pressure is described as blood pressure reading greater than the 95th Percentile for each of the respective age groups.

The independent variables are age, island, sex, place of birth or "where born" and obesity. For purposes of this study, children will be described as individuals between the ages of birth to 18. Two terms to be used interchangeably are male and boy or female and girl. The Virgin Islands consists of three islands. St. Croix, the largest, will be evaluated by itself. The smallest island, St. John, will at times be analyzed along with St. Thomas. Place of Birth will be divided into the following categories: St. Croix, St. Thomas and St. John, Puerto Rico, U.S.A, other Caribbean islands, and other countries.

RESULTS

The sample consisted of 231 children of which 50 percent were females. The prevalence of elevated blood pressure was 11.3%. Females (13.79%) had a higher prevalence than males (8.7%). **See Figure 4.**

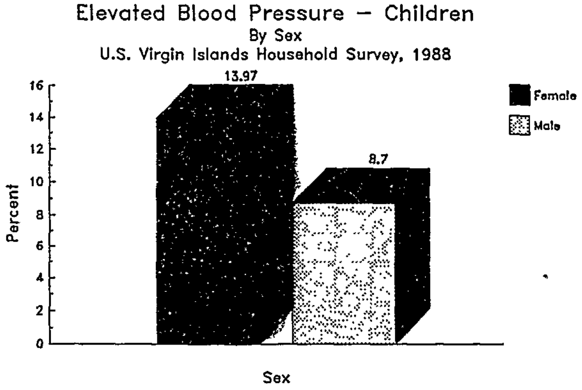


Figure 4

Figure 5 shows the distribution of elevated blood pressure by island. There was a tendency for a higher blood pressure in survey participants on the islands of St. Thomas (16.9) and St. John (16.67) as compared to St. Croix (8.44). When looking at the variable "where born," of those persons in the category "other Caribbean island," results showed 16% versus 14.55% and 8.26%. Other Caribbean island" persons were 1.6 times more likely to have an elevated blood pressure than persons born in the Virgin Islands **(Figure 6)**. Of those persons stating that they were born in the U.S.A, elevated blood pressure was similarily 1.6 times as likely to be higher than those children born in the Virgin Islands.

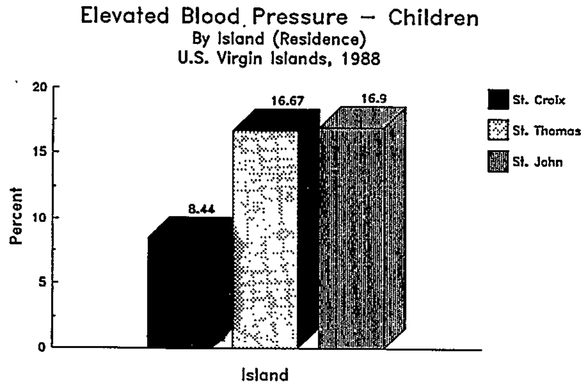

Elevated Blood Pressure – Children
By Island (Residence)
U.S. Virgin Islands, 1988

Figure 5

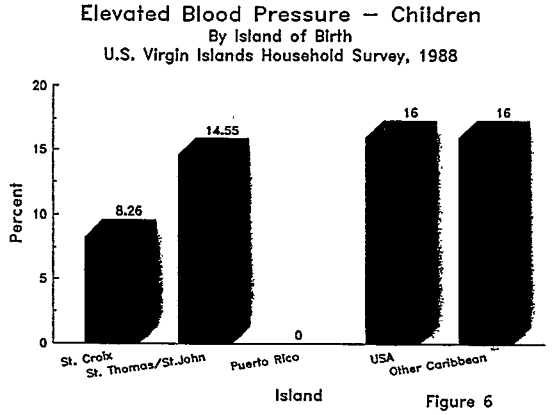

Elevated Blood Pressure – Children
By Island of Birth
U.S. Virgin Islands Household Survey, 1988

Figure 6

When asked about obesity and if they were experiencing any health problems, an individual who had an elevated blood pressure reading was 15% for obese versus 10.9% for nonobese. When asked the question, "Are you concerned about obesity?" individuals who had an elevated reading were 2.6 times as likely to respond yes, 26.67% versus 10.19% **(Figure 7)**.

Anecdotically, the interviewers indicated that those who were concerned about obesity appeared overweight.

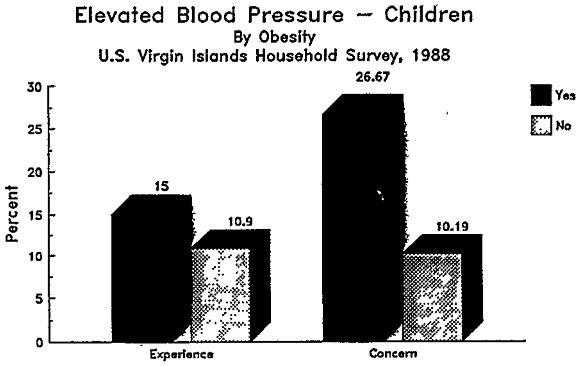

Elevated Blood Pressure – Children
By Obesity
U.S. Virgin Islands Household Survey, 1988

Figure 7

DISCUSSION

The 1988 Survey findings have influenced program development and as a result, several program directors have developed objectives both short term and long term to address the problems identified in the survey.

FAMILY PLANNING

The Health Survey revealed very important data for the Family Planning Program. Most importantly, the data show a need for family life education at the most critical ages of 10-19. Since the majority of young respondents felt there was an inability to receive services, we must find out what family planning services they desire.

Although it was gratifying to see that appointment schedules, clinic hours and transportation were not the reasons why the youth were unable to receive or preferred not to use the services, we must go back and ask specifically. Separate and distinct educational programs will be instituted. The design of these programs are in 1989-1990 goals and objectives.

The Family Planning Program has placed on its agenda:

1. Conduct workshops in 10-15 schools on family life education that educate children ages 10-19. Students will be surveyed by October 1989 to access their problems with the health care system.
2. Educate 75% clergy and community groups on the services available in the Family Planning Program. By October 1991, emphasis will be placed on family life education from kindergarten.
3. Establish a central directory of services, resources, territory experts and projects that will be available to all community and civic groups and schools by May 1990.
4. Offer an intense family life education program to women in child-

bearing years starting at age 10. Since more babies are born than wanted per the results of the survey, the content will include safe sex, contraceptive practices and parenting.

HYPERTENSION

There have been no other studies done on the prevalence of elevated blood pressure in children of the Virgin Islands. These findings provide the opportunity for future research into an area that is poorly understood. It highlights the need for detection, evaluation and referral systems for hypertension in children in the Caribbean. Because blood pressure is hereditary and is a common factor within families, it identifies the population where intervention for children is appropriate. Because of the concentration of a predominantly black population, it is expected that the prevalence will be higher than the U.S. national average.

Children who were in the 6-9 age group were 8 times more likely to have had a measured blood pressure that was elevated. Elijah Saunders, M.D., reported in the Journal of the National Medical Association Volume 81, that black hypertensive are likely to present at a younger age than their white counterparts, a phenomenon that is not well understood. One of the possible reasons for this may be the result of genetic factors while others believe that environmental influences are more important.[3] In our study, we were concerned that the children could have been actively playing outside and called in for a blood pressure reading since the survey was done on weekends and evenings. However, this, could not be confirmed.

The island of St. Thomas as a whole had a higher prevalence of elevated measured blood pressure than St. Croix. One possible reason is that St. Thomas is more cosmopolitan and the racial make-up is somewhat different than St. Croix.

Individuals born in the "other Caribbean islands" also had a blood pressure reading higher than those born in the Virgin Islands. Those born in the U.S.A. also had a higher blood pressure reading than those born in the Virgin Islands. The question could be asked if migration creates undue stress in children which increases their risk of hypertension. An attitudinal study of this problem would assist us in testing this hypothesis.

It has been shown in other studies that obesity is related to hypertension. These children have two risk factors that may benefit from early intervention.

As with many activities in life, the survey raised as many questions as it provided answers. A question of major importance is whether or not family physicians, pediatricians and our Maternal and Child Health clinics are using the unique opportunity during, either episodic illnesses or well child visits, to measure and record blood pressures on all children.

As known from previous studies, height and weight influence blood pressure. Shouldn't our development growth charts not only plot height and weight but also blood pressure? Since the 1977 National Report of the Task Force on Blood Pressure Control in Children, blood pressure elevation has been thought to identify the prehypertensive adults. Early identification and treatment could have tremendous positive impact on reducing our deaths from strokes and other cardiovascular impairments and our morbidity on key organs such as the eyes, heart, brain and kidneys. Dialysis and renal transplant program dollars could be better spent on prevention for a larger number of clients.

Headache is a very common complaint in adolescents. However, severe headaches may be due to elevated blood pressures. Failure to grow and/or gain weight in younger children with diastolic blood pressure 90 mmHg suggests a renal cause. These two examples are symptoms and signs that have so many possible etiologies, but a simple blood pressure measurement could bring to us the right conclusion, if only it were measured.

As a result of this survey, the Program Director of Maternal Child Health and Crippled Children Services is developing objectives to evaluate Hypertension in children:

1. Every clinic protocol with reflect the requirement of blood pressure readings for all clients on an annual basis if normotensive and more frequently per the recommendations of the Second Task Force on Blood Pressure Control in Children.
2. All school physicals done by our numerous sites or districts will include blood pressure measurement. If abnormal, follow-up will be required.
3. All private physicians have received a letter informing them of our findings and recommending blood pressure readings on all children.

The Community Health Services Program of which the Hypertension Program is a subset, has targeted:

1. Extend training in blood pressure measurement to all nurses, aides and other staff seeing patients to assure reliable measurement and recording of blood pressure in children.
2. Further explore the following association with Hypertension, as suggested by the 1988 Household Survey and children 6-9 year olds.

In addition, the quality of services (confidentiality, counseling and qualifications of physicians) must be and are being addressed. A new data base for all clinic encounters has been designed. Assistance from Regional Office, Centers for Disease Control, and other divisions within the Virgin Islands Department of Health has been received to ensure the product will be an efficient, confidential and integrated data base that can provide the needed information for planning and follow-up.

The above are examples of actual objectives that are a direct result of findings of the assessment and community diagnosis. We strongly believe that the best way to know how to develop a meaningful, useful health system is to ask. The 1988 Survey asked the Virgin Islands population many crucial questions. We were gratified with the overwhelming response and support (98.7%)--a necessary step in ensuring a true assessment. Although we take pride in the partnership fostered by this survey with our population; although we now have for the first time prevalence data on our major health problems; although we have moved one step closer to understanding our mission, we realize the challenge is not yet met. This survey, as a tool for assessment and diagnosis, has raised more questions than it has answered; it has made clear our need for increased skills in survey, surveillance and needs assessment; it has pointed out deficiencies in many program areas; and it has opened a new walk way for us to pursue our mission of prevention, health promotion and protection.

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To our gratification, we encountered absolutely no resistance in any of the households we visited. Although these wonderful people may never see this paper, without their generosity of open, honest responses we would be nowhere.

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TARGETING TEEN-AGE PREGNANCY: THE EFFECT OF A STATE MEDIA CAMPAIGN TO PROMOTE BIRTH CONTROL

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BACKGROUND

Teen-age pregnancy and abortion is epidemic in the United States but not because American women engage in sex earlier or more frequently than those in other countries. Rather, as a 1985 study by the Alan Guttmacher Institute points out, "pregnancy rather than sexual activity itself, is...the major problem."[1] Other countries have made a concerted public effort to help sexually active people to avoid unintended pregnancy.

Though the overwhelming majority of Americans believe in and practice family planning, the mass media, still consider the subject of birth control unmentionable. This posture has denied family planning information to those with the most urgent need for it. In New York State, the situation is particularly serious. Adolescent pregnancy and abortion rates are twice those of neighboring Canada.

In 1987, a coalition of family planning providers in New York State succeeded in adding nearly $6 million to that year's state budget. the new funds were intended to expand the network of family planning clinics, and to initiate a five-year media campaign to build a supportive public climate for the prevention of unintended pregnancy. The target audience was sexually active women in their late teens and early 20s, the group responsible for the majority of abortions.[2]

During the first year, and after focus group research, the Family Planning Media Consortium of New York State and its advertising agency, Smith/Greenland, Inc., prepared and tested the initial messages in two media markets, New York City and Buffalo, New York.

The messages were simple, straightforward, and non-contentious. (1) "Birth control, from saying no, to taking the pill, you're too smart not to use it." (2) "Four out of five young women who don't use birth control get pregnant before they want to." (3) Both young men and young women in a caring relationship should be concerned about having children at the right time. (visual message) (4) "Call (local phone number)" or "Look under Birth Control in the Yellow Pages."

In Buffalo, two network-affiliated TV stations and several radio stations ran the ad all summer during prime time. In New York City, only the Spanish version of the TV ad was shown. The other New York City TV stations claimed the ad was "too controversial" and refused to accept it. As an alternative, the media consortium placed posters on the sides of 500 city buses, produced subway carcards, and made heavy radio placements.

EVALUATION METHODS

The Media Consortium contracted with the Health Services Research Program of the School of Medicine and Biomedical Sciences, State University of New York at Buffalo to design and conduct an evaluation of the media effort. The Syracuse area, which was not exposed to the campaign, provided the control group for the test markets of Buffalo and New York City. To assess the effect of the advertising, large scale interview surveys were conducted among samples of young women, 18 to 26, in the test and control cities before and after the media campaign.

A pre-campaign interview questionnaire was designed and pretested for understandability and reliability. The post-campaign survey instrument differed by the addition of several questions to obtain information regarding awareness of the media message.

Before the media campaign, 1100 women were interviewed to establish the knowledge, attitudes, and family planning behavior baselines. The samples were stratified by geographic subareas within the test market regions to enhance participation from among a number of socio-demographic groupings. Interview quotas were established to assure that the composition of each regional sample would be generally proportional to the number of women of the required age group in each of the subareas.

The sampling procedure for all areas was conducted in the following manner. A random sample of households was drawn from the Metropolitan Telephone Directories for each area in the sample. The number of pages in each of the directories was divided by the number of completed interviews needed in that area to determine the skip pattern of pages in each phone book. Randomly selecting the 2nd column of the designated pages starting with the 5th name down, calls were made to each listed residential name until a completed interview was conducted. Only one completed interview was conducted per designated page.

All interviews were conducted during the hours from 2:00 to 9:00 P.M. to allow for the inclusion of women who worked or attended school. Bi-lingual interviewers were available to assure the participation of Spanish speaking respondents. During the pre-campaign survey 500 interviews were obtained from women in the five boroughs of New York and Nassau, Westchester, and Suffolk counties.

In the Buffalo region, 300 interviews were obtained from women in the City of Buffalo, the remainder of the County of Erie, and Niagara and Chautauqua counties.

In the Syracuse area, 300 interviews were conducted among randomly selected women in the City of Syracuse and the remainder of Onondaga County.

The pre-campaign survey in each area was conducted during a six-week period between May 5th and June 15th, 1987. Shortly thereafter, media activity began in the test areas. In mid-October, after four months of exposure to the media messages, the post-campaign survey was initiated and completed six weeks later on

November 30th, 1987.

The sampling procedure was the same as in phase one except that the names were selected from the third column on the directory page rather than the second column.

Since the major television networks in the New York City area declined to carry the ad and the other media efforts were focused on a smaller geographic area, it was necessary to narrow the post-campaign survey interviewing region to Manhattan, Brooklyn, Queens, and the Bronx. Pre-campaign interviews obtained from outside the area included in the follow-up survey are not included in the analyses. The size of the New York City area sample was reduced as a result and the study involved a total of 1885 respondents instead of the intended 2200.

FINDINGS

Table 1 presents the distribution of total respondents in each area by age and race. Since there were no differences between the first and second wave samples in each locality on demographic variables related to changes in knowledge or attitudes, those samples are combined in the interest of brevity.

Table 1. Characteristics of Respondents

	(N)*	N.Y.C (685) %	Buf. (600) %	Syr. (600) %	Total (1885) %
Age:					
18-20	(549)	24.4	34.2	29.5	29.5
21-23	(549)	18.8	32.5	37.5	29.1
24-26	(787)	56.8	33.2	33.0	41.6
Mean Age in Years	(1885)	23.2	21.9	22.3	22.4
Race:					
White	(1520)	70.2	91.5	81.7	80.6
Black	(203)	10.8	7.0	13.8	10.6
Hispanic	(138)	18.1	.8	1.5	7.3
Religion:					
Catholic	(939)	49.2	58.8	41.5	49.8
Protestant	(484)	11.5	29.3	38.2	25.8
Jewish	(228)	28.2	1.2	4.7	12.1
Other **	(203)	8.9	10.3	13.3	10.5
Education:					
H.S. Grad and Less	(855)	49.2	42.2	42.8	45.4
Some Coll. and Grad.	(1026)	50.2	55.7	54.8	54.4

* Some respondents declined to answer and some analyses do not include "other" responses.

**Includes Not Affiliated/None, Christian/Born Again Christian, Greek Orthodox, Mid-Eastern, Muslim, Jehovah Witness, or Atheist.

The New York City sample included a larger proportion of older women, and Hispanic women than did the Buffalo or Syracuse samples. Since the Buffalo sample included respondents from two additional rural counties, the proportion of black respondents is lower than that for the Syracuse area.

The religious and educational comparisons showed that the New York City sample contained a higher proportion of Jewish women and women who never attended college than did the Buffalo or Syracuse samples.

Additional demographic comparisons of the three area samples, not shown, revealed that the New York City sample included a larger percentage of clerical or sales women, married women, women reporting higher incomes, and respondents classifying themselves as politically liberal or moderate. The few exceptions to the comparability of the base line and follow-up samples with each locality were these:

The follow-up sample in Syracuse, contained fewer Catholics, fewer women in cohabitation relationships, and more college students than did the baseline sample. In New York City, the follow-up sample had fewer Catholics, fewer housewives, and higher percentage of women without children than did the baseline sample. The Buffalo samples differed only in the proportions of housewives, unemployed. None of the differences observed between the baseline and follow-up samples contributed meaningfully to the subsequent findings.

Respondents were asked if they had been sexually active during the six months prior to each interview. Overall, 76.5 percent reported that they were sexually active. Only 5.2 percent refused to answer. The proportion of young women reporting sexual activity ranged from 74 percent in New York City to 82 percent in Syracuse.

Respondents were also asked whether they ever had an unplanned pregnancy and if so, how many. Of the 1448 sexually active women between 18 and 26 years of age, 434 or 30% reported 608 unplanned pregnancies. Based on the number of reported children, a minimum estimate is that at least 257 or 42.2% of those unplanned pregnancies were aborted. The estimate is consistent with official reports of New York State induced abortion rates.[3]

Table 2 includes only sexually active women at risk to unplanned pregnancy. Overall, two-thirds of sexually active women reported that they always use a method of birth control. Over 16% never use birth control and a like percentage sometimes did. New York City respondents were slightly less likely to report always using birth control.

Table 2. Use of Birth Control Among Sexually Active Respondents by Location

Frequency of Usage	N.Y.C. (506) %	Buffalo (451) %	Syracuse (491) %	Total (1448) %
Always	62.5	69.6	69.7	67.2
Not Always	24.5	11.5	14.1	16.9
Never	13.0	18.9	16.2	15.9

Table 3 helps defines the sexually active respondents who reported never using birth control. Significant differences were not apparent for either race or religion. Educational level appears to be the significant influence in deciding to use birth control.

Table 3. Use of Birth Control Among Sexually Active Respondents

Characteristic	(N)	Use of Birth Control Always %	 Not Always %	 Never %
Race:				
White	(1168)	66.9	16.9	15.8
Black	(150)	61.6	15.9	22.5
Hispanic	(88)	65.3	15.8	18.2
Education:				
H.S.Grad. and Less	(617)	60.4	18.6	20.9
Some College and Grad	(762)	72.3	14.9	12.8
Religion:				
Catholic	(680)	65.5	18.3	16.2
Protestant	(364)	67.2	11.8	21.0
Jewish	(170)	68.8	21.2	10.0
Other	(110)	63.6	16.7	19.5

Table 4 provides initial evidence of the effect of the media campaign in reaching and capturing the attention of the target population. In the test market of Buffalo, 84% of the follow-up respondents claimed awareness of the televised message which equated "being smart" with using birth control. In the test area of New York City, 69% of the respondents said that they were aware of the message which was prominently displayed in other media. In the control area of Syracuse where the message was not transmitted, 43% of the respondents claimed that they were aware of it.

Table 4. Reported Awareness of Media Message

Location	(N)	Aware of Message %
Buffalo	(300)	84.3
N.Y.C.	(350)	68.9
Syracuse	(300)	43.3

Some fraction of the control as well as the test groups may have confused the message in question with other advertising related to AIDS or contraceptive marketing. An additional fraction of all three groups responding positively were those who tend to respond in the affirmative to almost all awareness questions. However, if one subtracts the percentage of affirmative responses in the control area from the percentages reported in the test areas, the degree of penetration of the media message remains considerable.

Table 5 shows the variation in the awareness of the media message among population subgroups. In New York City, the more affluent and the better educated were much more likely to be aware of the media message than the lesser educated, and the poorer respondents. In Buffalo, because of the frequency and placement of the television and radio spots, there was very high awareness of the media message among all respondents.

Table 5. Reported Awareness of Media Message by Race, Income and Education

Characteristic	N.Y.C. %	Buffalo %	Syracuse %
Race:			
White	79.8	83.6	41.7
Black	31.6	95.0	48.8
Hispanic	41.8	66.7	40.0
Income:			
<15,000	30.6	88.9	54.8
15-25,000	66.2	79.5	44.6
>25,000	86.5	83.3	31.0
Education:			
H.S.Grad and Less	56.9	86.3	29.5
Some Coll. and Grad	79.6	84.1	51.6

The variation in response by education in the control area suggests that those who answered in the affirmative might have been aware of the thought expressed even though they did not see the actual presentation of the message.

One of the media campaign messages was directed at those women who never use birth control or are casual about its use because they do not realize the high probability (80%) of becoming pregnant before they want to. Table 6 provides a comparison of the responses in each locality, before and after the media campaign, relating to the probability of sexually active women becoming pregnant in the absence of a method of birth control.

Table 6. Estimated Probability of Becoming Pregnant Without Birth Control

Probab.	N.Y.C. T_1 (335) %	 T_2 (350) %	Buffalo T_1 (300) %	 T_2 (300) %	Syracuse T_1 (300) %	 T_2 (300) %
80%	25.9	47.1***	52.0	59.0	53.3	56.3
50%	64.2	38.6***	35.7	29.3	39.3	32.0
10%	4.8	9.1	8.0	10.0	5.3	10.3
Don't Know	5.1	5.1	4.4	1.7	2.0	1.3

***p<0.001

Before the media campaign, only 25.9% of the New York City respondents answered the probability question correctly. Sixty-four percent of those in New York City thought the odds were about fifty-fifty. About 47% of the interviewees in Buffalo and Syracuse estimated the probability incorrectly. However, few in each locality thought that there was only a 10% chance of pregnancy without birth control.

After the media campaign, 47.1% of the New York City respondents answered correctly, a highly significant increase of over 20 percentage points. The already high Buffalo and Syracuse correct response rates showed no significant change.

One might assume that the gain in knowledge in New York City would have been even more impressive if there had been higher levels of awareness of the media message among the less educated and the poor. Such would not have been the case. The media campaign cannot take credit for the change that did take place in New York City.

There was no association between awareness of the media message and gain in knowledge of the risk of pregnancy without birth control. Though something happened in New York City during that time period that was consistent with the goal of the promotion, the data cannot attribute the change to the media intervention.

The relationship of the knowledge of the probability of getting pregnant without birth control to birth control behavior is evident in in table 7.

Table 7. Estimated Probability of Pregnancy Without Birth Control By Use of Birth Control

Probability	(N)	Use of Birth Control Always %	 Not Always %	 Never %
80%	(694)	71.8	14.2	14.0
50%	(565)	64.3	18.6	17.1
10%	(107)	53.3	23.3	23.4
Don't Know	(25)	48.0	17.0	35.0

Almost 72% of those who know that the probability is 80% always use birth control as compared to 53% of those who think that the probability is 10% or the 48% of those who admitted they don't know. Conversely only 14% of those who know the correct probability never use birth control compared to over 23% of those who think the probability is 10% and 35% of those who don't know.

Table 8 presents the percent agreement with some of a larger series of statements designed to reveal certain attitudes or beliefs about birth control. As in most attitude surveys, the percentages of affirmative responses were probably increased by those who were likely to agree to any statement that they interpret to be a socially correct attitude, and those who will answer positively, if answering negatively implies a lack of knowledge.

The respondents in Buffalo and Syracuse were in fairly close agreement on all attitudes. The New York City interviewees differed with upstate women in their responses to several of the statements.

The concern about the side effects of birth control or the beliefs that birth control spoils the pleasure of sex or gives men the wrong impression were of particular interest because they seemed to be both influential in determining behavior and vulnerable to

Table 8. Agreement with Selected Attitudes

	N.Y.C. (685) %	Buffalo (600) %	Syracuse (600) %	Total (1885) %
A lot of people get pregnant even when using birth control.				
% Agree	33.6	47.0	43.5	40.6
Whatever method, there's a hassle involved in getting it or making it work.				
% Agree	51.1	43.5	42.0	46.3
Most people would rather take chances with getting pregnant than use birth control.				
% Agree	26.6	45.8	42.0	37.6
A pregnancy at the wrong time in life can really be a disaster.				
% Agree	80.3	90.7	91.2	87.1
Having a child when you didn't plan to isn't that much of a problem.				
% Agree	22.8	15.5	15.8	18.2
Many women risk pregnancy because they're not comfortable talking to men about birth control.				
% Agree	44.7	76.3	75.3	64.5
The risk of side effects from birth control is more serious than accidental pregnancy.				
% Agree	20.4	18.2	11.3	16.8
Doing anything to avoid pregnancy spoils the spontaneity and pleasure of sex.				
% Agree	31.2	12.7	11.7	19.1
Using birth control looks like you plan ahead to have sex and gives men the wrong impression.				
% Agree	29.2	13.4	15.2	19.7

Table 9 shows the relationship between these beliefs and the use of birth control. Only about one of six women who always use birth control agree with these statements, but the proportions of those who agree increase as the use of birth control decreases. Chi squares computed for each attitude show significant associations between use and attitudes. The finding supports the original premise of the media campaign which was intended to address the misconceptions of women who allowed inappropriate attitudes or beliefs to influence their birth control behavior.

Table 9. Percent of Sexually Active Respondents Who Agreed with Selected Statements by Their Reported Use of Birth Control

	Use of Birth Control		
	Always (1029)	Not Always (260)	Never (256)
Statement	%	%	%
"Side Effects of B.C. Worse Than Pregnancy"	14.6	18.5	27.8
"B.C.Spoils Spontaneity and Pleasure of Sex"	15.1	22.7	27.8
"B.C.Gives Men the Wrong Impression"	17.5	21.9	23.7

Table 10 shows the association of race and education with attitudes toward birth control. Chi squares computed for each of the attitudes by either race or education showed significant relationships. A larger proportion of black than white or Hispanic respondents agree with the first two statements. Both blacks and Hispanics are more likely than whites to agree that birth control gives men the wrong impression. A higher percentage of those with less education agreed with each of the negative statements. Since higher proportions of the less educated are found among blacks and Hispanics, education confounds the differences attributed to race with numbers too small in this study to make the distinction.

Table 10. Agreement with Selected Statements by Race and Education

	(N)	"Side Effects Worse Than Pregnancy" % Agree	"Spoils Pleasure of Sex" % Agree	"Gives Wrong Impres." % Agree
Race:				
White	(1520)	15.9	18.5	18.9
Black	(203)	27.7	31.2	29.2
Hispanic	(138)	18.6	21.4	27.9
Education:				
H.S. Grad. or Less	(847)	20.8	23.2	26.6
Some College, and Grad.	(1006)	14.8	17.5	15.3

Table 11 illustrates the effect of the media campaign on the negative attitudes toward birth control.

Before the media campaign, over 25% of the respondents agreed with all three statements. After the media campaign, there was a significant decrease in the percentage agreement with the first two attitudes among those who were aware of the media message. No change occurred among those who were not reached by the campaign message.

Table 11. Changes in Agreement with Selected Statements by Awareness of the Media Message

	Baseline Sample (635)	Follow-up Sample (650)	
		Aware (494)	Unaware (156)
Selected Statements Re: Birth Control	% Agree	% Agree	% Agree
Spoils Spontaneity, Pleasure of Sex	25.7	14.2***	28.8
Gives Men Wrong Impression	25.7	15.0***	26.9
Side Effects Worse Than Pregnancy	26.1	12.3**	14.1**

**p<0.01, ***p<.001

The percentage of agreement with the third statement also decreased significantly, but without regard for awareness of the media message. Apparently, other influences were operating during that test period. One such inducement was the widely published report of a government study of 9000 women that concluded that the early use of birth control pills does not increase the risk of breast cancer in middle age. Reports of the study and discussions of the findings were carried in most local newspapers and in some radio news programs. It was, in effect, a media campaign of a different kind. Its outcome, however, is clearly distinguishable from those of the effort under study.

SUMMARY

The media campaign of a consortium of family planning providers in New York State revealed some relationships between knowledge, attitudes and birth control behaviors that appear amenable to modification through media messages. Substantial numbers of young women remembered the ad campaign and could identify its theme. Recognition was high even after subtracting those who may have been confused by other ads about AIDS and condoms. In the New York City area, there was a significant increase in awareness of the probability of getting pregnant without birth control, a factor which the study indicates is related to birth control behavior. However, the change cannot be attributed to the media campaign. On the other hand, the study found that repeated exposure to well placed media messages could change negative attitudes that rationalize high-risk behavior.

It appears that this relatively economical and non-contentious intervention may be an effective primary preventive measure that would encourage better informed and more rational decision-making. The findings suggest that continuation of the public information campaign could influence young people toward more acceptance of birth control behavior with eventual reductions in the rates of unwanted pregnancy and abortion.

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ESTIMATING MEDICAID ELIGIBILITY FROM THE CPS

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About two years ago, we were asked to estimate the impact of raising New York's Medicaid eligibility level to the functional equivalent of the poverty level for families with children. Using the Current Population Survey (CPS) files for New York State, we created a microsimulation of the eligible population under the existing and the proposed laws. We then applied a participation rate and some actuarially based cost factors to the estimated newly eligible population, to estimate the proposal's federal, state and local costs. These techniques demonstrated the usefulness of the CPS in estimating Medicaid eligibility, and they called attention to certain problems with using the CPS estimated "uninsured" population as a basis for policy analysis. We then applied these techniques to other groups and other proposals, including a study that estimated Medicaid eligibility among poor and near-poor families in eight large states. Today, I want to use the results from our eight-state study to illustrate our approach and to raise some questions regarding the proper focus of policy research on children's health care coverage.

Defining the Uninsured

As many of you know, the CPS is a nationally representative survey of the non-institutional population. Although the original focus was on unemployment, the March CPS (also known as the Annual Demographic File) is the basis for estimates of several social characteristics including the national estimates of poverty. The CPS involves interviews with over 56,000 households in more than 700 sampling areas spread over nearly 2,000 counties and cities, with coverage in every state. Although the reliability of CPS estimates at a state level is somewhat problematic, state of residence is carried on the file and the weighting procedures include state-level population adjustments. Lacking an annual Census, the March CPS provides probably the best available data source for estimates of social and economic characteristics in large states. Among the available data from the March CPS is information on family composition, employment, and health care coverage.

At the national level, the March CPS has been used by many analysts to estimate the population covered by various social programs and by various forms of health insurance. Frequently, these studies examine the self-report of CPS respondents to questions regarding such coverage. But, using the CPS self-reports to estimate health care coverage, especially Medicaid coverage, is problematic for two reasons: on empirical and the other definitional.

The empirical problem is that CPS respondents under-report their Medicaid coverage. Similar under-reporting occurs for other social programs, most notably AFDC. At one point in the discussion of our bill to extend Medicaid, someone introduced a CPS-based estimate of the State's medically uninsured population. Their figure suggested that the problem was larger than our proposal indicated. And, although they were advocating the passage of the bill, their figure suggested that our proposal would cost much more than we estimated.

On the basis of national data, we knew that the CPS respondents fail to report the full extent of their Medicaid enrollment. The CPS-based national Medicaid enrollment figure is somewhat lower than the number of non-institutional claimants reported by HCFA! Although we don't have national unduplicated counts of Medicaid enrollment, we know it must be considerably higher than the number of Medicaid claimants.

In the case of New York, we compared the CPS-based estimate of Medicaid enrollment to an annual unduplicated count of actual, non-institutional enrollees, derived from a longitudinal research file we built from our MMIS system. We found that the State issued Medicaid cards to 400,000 more people than the Medicaid enrollment reported by New York State respondents to the CPS. The difference represents sixteen percent of our Medicaid caseload.

So, there is an empirical problem with using the CPS-based Medicaid enrollment figures in discussions of children's health care coverage. CPS-based estimates of the uninsured population will be biased by the under-reporting of Medicaid enrollment. But, there is also a definitional problem here. When we discuss health care coverage of the poor, what do we want to define as "coverage"?

We think there is a problem in counting as uninsured those who are enrolled in Medicaid but who filed no claim during the year. So, we think the covered population should be defined to include those enrolled in Medicaid. But we also think there is a problem in counting as uninsured those who are eligible for Medicaid but did not enroll. Unlike certain forms of private insurance that have waiting periods of three or six months for benefits, Medicaid enrollment can occur as soon as the bills begin. In that sense, anyone who is eligible for Medicaid is covered, even if they have not yet applied for the card.

Under this approach to defining health insurance coverage, we need to estimate the population that is eligible for Medicaid, not just the population that is actually enrolled. Regardless of one's position on the definitional question, it is the eligible population that needs to be estimated in order to "cost out" various proposals to extend health insurance coverage, and we believe that population can be simulated from the CPS.

Estimation Method

Estimating the population that is eligible for Medicaid coverage is quite difficult for several reasons. First, eligibility rules are complicated and involve information not available from the CPS: for example, data on resources. Second, financial eligibility for Medicaid is based on an accounting period shorter than the annual income data available from the CPS or the decennial Census (usually monthly income). Third, the allowable deductions from gross income also fluctuate over the months, resulting in Medicaid eligibility at different levels of gross income. Finally, the March CPS identifies respondents by their current state of residence, but reports income and receipt of social benefits for the previous calendar year (when they may have lived somewhere else). Despite these problems, the CPS provides one of the very few bases for simulating Medicaid eligibility.

The specific features of our approach reflect the particular problem we have addressed. Our primary interest has been in estimating those persons who are income-eligible for Medicaid. Therefore we have attended to the non-public-assistance income reported on the CPS. The basic question is whether a given family would be eligible for Medicaid on the basis of their non-public-assistance income, given the eligibility criteria in effect for that family. In our eight-state study, we simulated eligibility in 1987, using the 1986 CPS. The 1985 (non-public-assistance) incomes reported on the 1986 CPS were inflated to 1987 levels by applying the recent historical relationship between the Consumer Price Index (CPI) and wages, to the CPI-derived inflation rate for the major cities in each state. For the eight states included in our study, 1985 incomes were thus inflated by about three to seven percent (most commonly by about five percent) to represent current incomes. To convert gross income to the net income that would determine Medicaid eligibility, we took five-sixths of gross income as net income. That number is based on an approximation developed from the deductions of working poor Medicaid eligibles in New York State.

To simulate the Medicaid eligibility of poor and near-poor children, we classified them into four categories:

- children living in single-parent families
- children living in two-parent families with a recently unemployed parent
- children living in other two-parent families
- other children

Parents of such children were similarly classified into single-parent families, two-parent families with recent unemployment, and other two-parent families; and "caretaker relatives" were treated as parents for this analysis.

For each of these four living arrangements, we attempted to determine the net income level at which the children and parents would be eligible for Medicaid, based on direct conversations with eligibility staff in the eight states. In some states, all living arrangements were tested against the same income standard, while in certain states different levels were used for certain groups of children. In addition, we classified children under age two and below the poverty level as Medicaid eligible at that time (under SOBRA) in all states except Pennsylvania and Texas.

We focused on families whose case incomes were under 150 percent of the poverty income guidelines. Our categorization of family income was based on only the non-public-assistance portion of total income and based only on the income of the children and parents. We did not include the income of other family members (for example an uncle or a twenty-five-year-old brother who lives in the household). Thus, our

Consequently, our "case family" income departs a bit from the income used to measure official poverty.

Illustrative Results

We started with the question, "What proportions of poor children and parents at various income levels are eligible for Medicaid in our selected states? In 1987, eligibility among the poor varied considerably across the eight states, ranging from complete coverage in California to only about one-quarter coverage in Texas. For the eight-state aggregate, we found that about four-fifths of the poor children and about three-quarters of their parents were eligible for Medicaid. Including all families up to 150 percent of the poverty level, we find that three-fifths of children and half of their parents were eligible in these states.

A major reason for developing an estimate of the Medicaid-eligible population was to clarify the meaning of estimates of the "uninsured" which are used in discussions of health care coverage. Figures 1 and 2 show the importance of this distinction for poor families. The graphs classify poor children and their parents into five groups:

- the uninsured who are not eligible for Medicaid (No INS: No MA),
- the uninsured who are eligible for Medicaid (No INS: w/ MA),
- Medicaid eligibles who reported some form on insurance coverage on the CPS, including reported Medicaid coverage (INS: w/ MA),
- Medicaid ineligible persons covered by employer-sponsored group health insurance (GH: No MA), and
- Medicaid ineligible persons covered by other forms of insurance (Other: No MA).

For poor children in these eight states, we found that 79 percent were Medicaid eligible, and another nine percent were covered by some other form of insurance. Only twelve percent were both ineligible for Medicaid and not covered by any other form of insurance. Most importantly, the figure shows that of the 36 percent of poor children who were counted among the "uninsured", two-thirds were estimated to be Medicaid eligible. Of course, some of those may not have been eligible because of resource limits within the Medicaid program, but it seems extremely unlikely that resources account for the basic finding. Similarly, of the 30 percent of poor parents who were among the uninsured, three-fifths were estimated to be eligible for Medicaid. A similar picture emerged for those with income up to 150 percent of the poverty level.

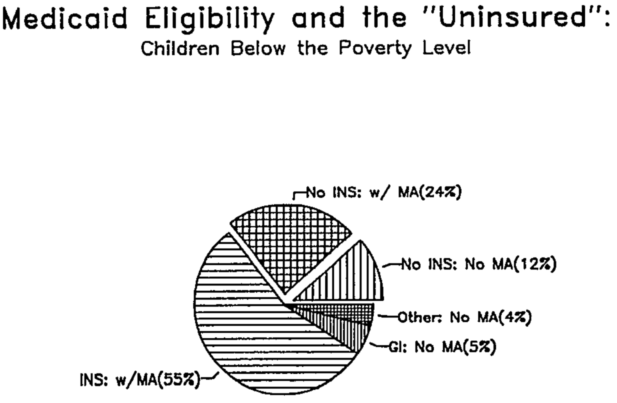
Medicaid Eligibility and the "Uninsured":
Children Below the Poverty Level

Figure 1

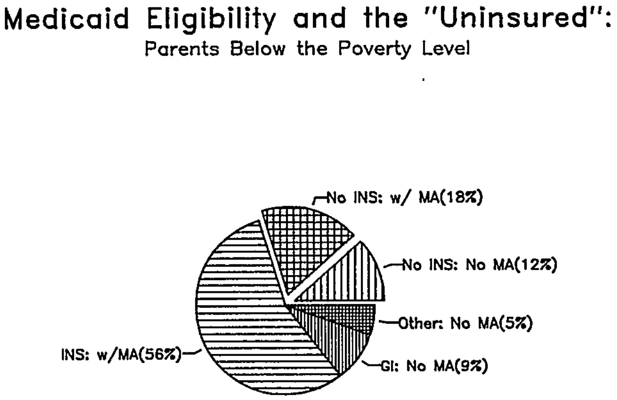
Medicaid Eligibility and the "Uninsured":
Parents Below the Poverty Level

Figure 2

The CPS estimation technique also allows us to focus on the demographic composition of the families who are not currently eligible for Medicaid. For example, Figure 3 shows that two-parent families are disproportionately represented among those who are ineligible for Medicaid and lack other forms of health insurance.

Using the CPS data, we can also examine the extent of employer-sponsored health insurance among poor and near-poor families who are ineligible for Medicaid. Figure 4 shows that about half of those families had insurance that covered the head of the family, and only about two-fifths had insurance that covered the children.

As mentioned at the outset, there are limitations imposed by the CPS data. In the future, a better approach to such microsimulations, at least on the national level, requires the use of the Survey of Income and Program Participation (SIPP). The SIPP provides monthly income data on a nationally representative sample of households, so it allows us to simulate Medicaid eligibility with an accounting period that matches that used in the program. In addition, information about assets is available to help model the "resources: of Medicaid applicants.

We believe the effort required to construct these simulation datasets is offset by the ease with which they can be used. Data sets for some issues can be accommodated on a laptop computer, allowing the simulations to be run in the midst of policy discussions. By investing in these techniques, it is possible to bring defensible estimates to the debate over policy alternatives to improve the health care coverage of children.

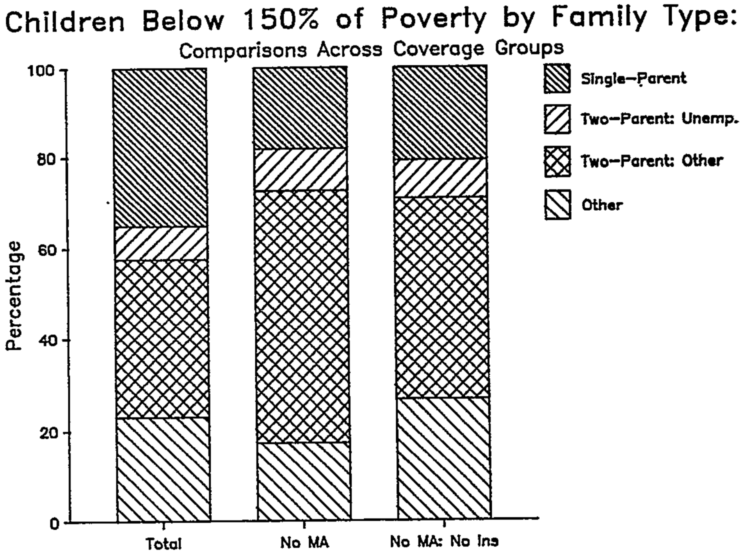

Figure 3

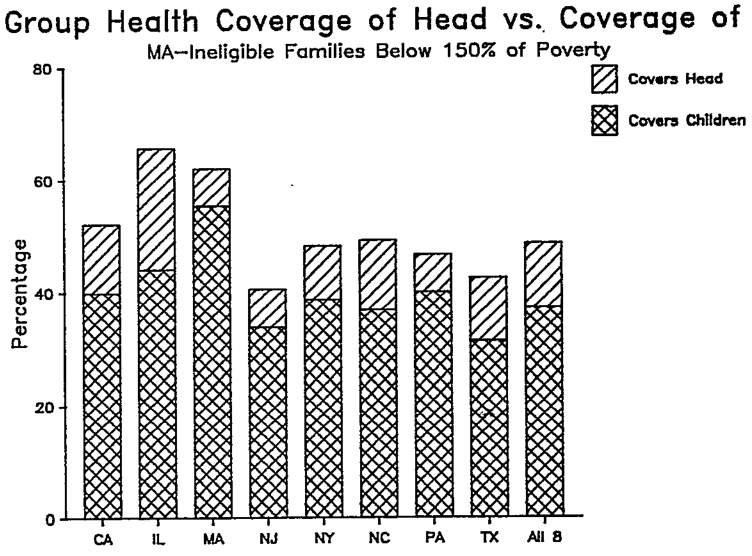

Figure 4

THE 1988 NATIONAL HEALTH INTERVIEW SURVEY ON CHILD HEALTH: NEW OPPORTUNITIES FOR RESEARCH

Gerry E. Hendershot, National Center for Health Statistics

In 1988 the National Center for Health Statistics conducted the National Health Interview Survey on Child Health. This paper describes the survey: its design and content, plans for publications and public use data tapes, opportunities for research, and plans for future data collection.

The National Health Interview Survey (NHIS) has been conducted by the National Center for Health Statistics (NCHS) since 1957 to provide national estimates of statistics on health status and use of medical services. The survey is representative of the civilian, noninstitutionalized population of the United States. The NHIS sample yields information each year on about 47,000 families with about 122,000 family members. The information is collected in face-to-face interviews in the homes of sample families by interviewers employed by the Bureau of the Census.

The NHIS questionnaire has two parts: a basic health and demographic questionnaire that is revised about once a decade, and one or more special topics questionnaires that change each year. The basic questionnaire obtains information for all members of the sample family: adults present at the time of interview respond for themselves, and an adult serves as proxy respondent for children or absent adults. The basic questionnaire covers health conditions; the impact of those conditions; hospitalization and contacts with physicians; and social and economic characteristics.

The basic questionnaire is completed for about 95 percent of the sample families. The data are reported annually in "Current Estimates from the National Health Interview Survey," a publication in Series 10 of Vital and Health Statistics. Public use data tapes containing the data from the basic questionnaire are made available by NCHS through the National Technical Information Service.

The second part of the NHIS questionnaire consists of questions on one or more special topics. Each year NCHS invites other agencies to propose special topics; the proposals are reviewed for feasibility and relevance to public health data needs, and one or more are selected for the NHIS. NCHS collaborates with the proposing agencies in designing and analyzing the special topics surveys. Usually the special topics questionnaires are in the field for one calendar year, but other periods may be used. Usually the special topics surveys select one sample person from each NHIS sample family and require that the sample persons respond for themselves, but other sample designs and respondent rules may be used.

The data collected on a sample person for a special topic can be linked to the data collected on that person in the basic questionnaire or other special topics questionnaires in that data year. The special topics questionnaires in the 1988 NHIS were on AIDS knowledge and attitudes, alcohol dependency, and occupational health (all asked of the same adult sample person); medical device implants (asked of all persons with an implant), and child health.

The 1988 National Health Interview Survey on Child Health was in the field from January 1988 to January 1989. It represents the noninstitutionalized, civilian population aged 0-17 years in the United States. In every NHIS sample family with children in that age range, one child was selected at random for the Child Health sample. Information about the sample child was collected by face-to-face interview in the home. The respondent was the adult member of the family present who knew most about the sample child's health, in most cases the child's mother.

The NHIS on Child Health is a collaborative project of NCHS; the National Center for Child Health and Human Development, National Institutes of Health; and the Office of Maternal and Child Health, Health Resources and Services Administration. Child Trends, a nonprofit research organization, also participated in the project. The major content headings in the Child Health questionnaire were Child Care; Relationships (family) and Mobility (geographic); Birth (e.g., birth weight, prenatal care); Childhood Conditions (e.g., injuries, chronic conditions); Supplemental Condition Page (details on conditions); General Health Status; School (performance, problems); Development, Learning, Behavior; and Health Services (e.g., source of care). Facsimiles of all of the 1988 NHIS questionnaires, including the Child Health questionnaire, will be published in Current Estimates for 1988.

At this writing the processing of the NHIS-CH is not complete, but provisional counts of sample cases in selected categories of interest can be provided. It is important to note that these counts will change with further processing, and that they are unweighted; therefore, they cannot be used to generalize to the national population, but they will be useful to researchers considering analyzing the Child Health data tapes.

The Child Health survey obtained interviews for about 17,100 sample children. The number of sample cases by age was about:

Less than one year	1200
1-2 years	2200
3-5 years	2800
6-8 years	2600
9-11 years	2500
12-14 years	2600
15-17 years	3200

About 10,100 sample children lived with both biological parents, about 5,100 with the biological mother only, about 600 with the biological father only, and about 1400 with neither biological parent; of the latter, about 300 were adopted children.

In the past year, about 6 percent of the sample children had had asthma, about 7 percent had had hay fever, about 8 percent had had eczema or skin allergies, and about 16 percent had had an accident, injury, or poisoning. Also, about 14 percent had ever been "seriously" ill, and about 25 percent had had repeated ear infections during their lifetime.

Plans for publication of findings from the Child Health survey by NCHS and the co-sponsoring agencies include short descriptive reports on child care, injury, developmental problems, passive smoking, and health services, to be presented at the 1989 annual meeting of the American Public Health Association and subsequently published in NCHS's Advance Data series; longer descriptive reports on infectious disease and health correlates of family structure will be published in Vital and Health Statistics, Series 10. Depending on staff availability, other reports of a more analytical nature may be prepared for publication in public health journals.

The analyses planned by NCHS and its co-sponsoring agencies will not begin to exploit the full potential for analysis of this large and rich source of information on the health of our nation's children. To encourage further analyses by the child health research community, NCHS plans an early release of public use data tapes from the NHIS-CH. These tapes will include all the data collected with the Child Health questionnaire and selected items from the basic health and demographic questionnaire. They will be available from the Division of Health Interview Statistics at NCHS at a cost of $200.

Public use data tapes for other special health topics in 1988 also will be available from NCHS, and tapes from the basic health and demographic questionnaire will be available from the National Technical Information Service. Each sample person, family, and household has an identification number which appears on all files, so that data on different files can be merged for analysis.

The National Health Interview Survey on Child Health has a number of features which enhance its utility as a research data base. First, it is the most recent nationally representative survey on child health. Second, it covers a wide range of child health issues and children of all ages. Third, its large size makes it useful for the study of some relatively rare childhood health problems. Fourth, the data from the Child Health survey can be linked to other health data for the sample child collected at the same time with the NHIS basic questionnaire.

Fifth, the Child Health data can be linked to data collected at the same time, using other questionnaires, for other members of the sample child's family; thus, for instance, it is possible to link alcohol consumption data on a sample child's mother (collected with the Alcohol Dependency questionnaire) to child health outcome data collected with the Child Health questionnaire. Finally, the 1988 NHIS on Child Health is identical in design and similar in content to the 1981 NHIS Child Health Supplement, making it possible to analyze trends.

NCHS does not have an extramural research grant or contract program, but both of the collaborating co-sponsor agencies--the National Institute for Child Health and Human Development, and the Office of Maternal and Child Health--do have such programs, and they do make grants and let contracts to support research on topics included in the NHIS-CH.

There are several ways in which the utility of the NHIS-CH could be further enhanced. First, the 1988 respondents or sample children could be reinterviewed to obtain additional information, creating a longitudinal data set. The NHIS has the capability to reinterview sample persons, and has done so in other special topics surveys. Second, the interview data from the NHIS-CH could be matched to vital and administrative records for the same children, such as the National Death Index, creating another kind of longitudinal data set. The NHIS has the capability to make such matches, and has done so in other special topics surveys. Third, the NHIS-CH could be made a cyclical survey, to be fielded, say, every five years, allowing a regular assessment of the health of our nation's children. While there is interest in these enhancements at NCHS and the co-sponsoring agencies and in the health research community, it has not yet been possible to commit the resources necessary to implement them.

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