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The International Symposium was convened from December 7 to 9, 1988, in Bethesda, Maryland, to develop proposals for research in measuring the health and health care of the aging. The Proceedings include papers from the plenary sessions, where measurement issues were identified, and the workshops, where specific proposals for research were outlined. Speakers and participants were distinguished international experts from a dozen different countries and a variety of organizations. They were selected for their expertise in the six topics addressed by the International Symposium: Common chronic diseases, health promotion, vitality, functioning, mortality statistics, and outcomes of nursing home care.

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Contents

Part I. Introduction

Part II. Comparing cardiovascular and cancer statistics

Part III. Health promotion and disease prevention among the aged

Part IV. Functional disability

Part V. International health care research

Part VI. Comparative analysis of health statistics for selected diseases common in older persons in the United States

Part VII. Measuring risk factors and outcomes of institutional long-term care

Part VIII. Assessment of vitality and aging

Part IX. Special activities related to measuring health and health care

Part X. Summary

Symbols

---	Data not available
. . .	Category not applicable
-	Quantity zero
0.0	Quantity more than zero but less than 0.05
Z	Quantity more than zero but less than 500 where numbers are rounded to thousands
*	Figure does not meet standard of reliability or precision
#	Figure suppressed to comply with confidentiality requirements

Part I

Introduction

Chapter 1
Measuring the health and health care of the aging

by Manning Feinleib, M.D., Dr.P.H., Director,
National Center for Health Statistics

As Director of the National Center for Health Statistics (NCHS), I am pleased to welcome you to this International Symposium on Data on Aging. I would like to thank Joan Van Nostrand, Robert Hartford, Sam Notzon, and all the other members of the planning committee for the hard work they have done in organizing the Symposium.

This Symposium marks the beginning of NCHS's International Collaborative Effort on Measuring the Health and Health Care of the Aging. We abbreviate this to the ICE on Aging: Some even abbreviate it to the ICE Age. Like its predecessor, the International Collaborative Effort on Infant and Perinatal Mortality, the ICE on Aging is designed to help NCHS meet its mandate to provide reliable and timely data to assess the health of the population and to track progress in promoting the Nation's health. We feel it is important to share our experience with others and, in turn, to learn from our colleagues in other countries how they are responding to their nations' requirements for high-quality data.

The aging of the population is an unprecedented worldwide phenomenon with major social and economic consequences. One important consequence is the need for increased efforts and resources to maintain the health of older people and to provide them with adequate health care.

Questions raised by researchers, care providers, and policymakers reflect the complexity of these health issues:

- Are the final years of life ones of quality?
- How can disability from chronic conditions be delayed or even prevented entirely?
- How can outcomes of care be improved?

These and many similar questions challenge us to improve our ability to measure the health of the aging.

In response to this challenge, NCHS has launched a major program on measuring the health and health care of the aging, of which this International Collaborative Effort on Aging is an essential component. The ultimate goal of the ICE on Aging is to strengthen the measurement of health and health care of the aging in both NCHS programs and international applications. The emphasis on international collaboration provides increased opportunity for comparing health data among nations and for sharing our accumulated knowledge and experience.

The focus of the ICE on Aging is on the health and wellness of older persons and, in particular, on several measurement issues that arise in assessing the many aspects of health and illness in this population. To make our task manageable, we have selected three themes for consideration within the scope of the International Collaborative Effort:

- Comparing diagnostic statistics.
- Measuring vitality.
- Assessing outcomes of health care.

Within these three overarching themes, a set of specific measurement issues has been selected for priority attention.

For the task of comparing diagnostic statistics, the two measurement topics selected are:

- Mortality statistics for cardiovascular disease and cancer.
- Morbidity measures for chronic diseases common in older persons.

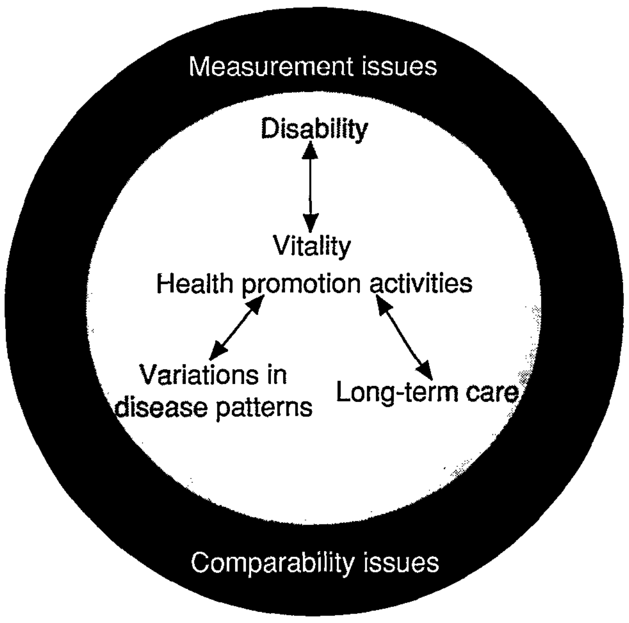
For the task of measuring vitality, the three measurement issues are:

- Assessment of vitality and aging.
- Defining and measuring functional disability.
- Appropriate measures relevant to health promotion and disease prevention among the aging.

In assessing outcomes of health care, a single area was selected, namely, measuring risk factors and outcomes of institutional long-term care.

Joan Van Nostrand has aptly summarized the interrelation of these topics in the form of a diagram (see figure 1) with vitality and health promotion at the core, indicating the focus on wellness and quality of life. Surrounding these two essential elements are three critical aspects of health for older persons—disability, variation in disease patterns, and long-term care. Each is connected to the others by two-way arrows, indicating the plasticity of aging: Older persons can shift from able to disabled and back again; disability can lead to a need for long-term care; good care can return one to improved vitality. Finally, surrounding all of these topics are the underlying issues on which the ICE on Aging concentrates—the measurement issues relating to health and use of care, and comparability issues for international studies.

To assist us in developing an agenda for further research in the six targeted areas, NCHS has organized this Symposium and has invited a group of distinguished international experts from a dozen different countries and a variety of organizations, including governmental offices, universities, foundations, and international agencies. They have been asked to participate in this Symposium as experts on particular research topics and as knowledgeable consultants on international research activities and data sets in the field of aging. They have not been asked to serve as formal or official representatives of their countries or organizations.



SOURCE: National Center for Health Statistics.

Figure 1. Interrelationship of International Collaborative Effort on Aging topics

This brings us to the specific objective of the International Symposium, and that is to develop a research agenda for each of the six targeted measurement topics. To do this, the Symposium has been organized into two types of activities—a plenary session for each topic, at which the international and domestic experts will raise pertinent research issues, and then workshops to discuss these issues and develop specific research proposals. The draft research proposals are presented in Part X.

In developing the research proposals, I ask you to concentrate on using existing data sets. Our experience from the first ICE on Infant and Perinatal Mortality has demonstrated that existing data, viewed from an international perspective, are a rich and relatively untapped source of valuable information. Furthermore, using existing data sets will facilitate the completion of the projects within a relatively short timeframe of about 3 to 4 years, so that the results can be incorporated into the programs of NCHS and other groups by the mid-1990's.

In the weeks following this Symposium, the research proposals will be reviewed for feasibility. Consideration will be given to technical, scheduling, and resource aspects. We hope to initiate the research projects in spring 1989. If this schedule is achieved, we hope to hold a second Symposium at which interim research results can be presented. Depending on the progress of the research, the Symposium is tentatively planned for summer 1991. We hope that the final results and recommendations from the selected projects will be presented at a third International Symposium in 1993.

In concluding, I would like to repeat my welcome to you and reaffirm my belief that conducting international collaborative research will allow us to build on existing knowledge and experience in measuring the health of the aging. Strengthening the measurement of health and health care of older persons will assist us all in meeting the diverse challenges that an aging world presents.

Chapter 2
My grandmother said, "If you have your health, you have everything." What did she mean?

by Harvey Jay Cohen, M.D., Director, Center for the Study of Aging and Human Development, Duke University Medical Center, and Geriatric Research Education and Clinical Center, Veterans Administration Medical Center, Durham, North Carolina

I am quite honored to have been asked to keynote this Symposium and, reflecting on it, I was a little puzzled as to why I was selected. I have tried to figure this out and have come up with a few possible answers.

Ordinarily, I would have thought that you would have selected an expert in some of the measurement issues that are to be discussed at length here today. I do not consider myself an expert in any of these issues. This is confirmed by the definition of an expert which I have heard proposed, that is, a person who comes from more than 50 miles away and shows slides. I do come from more than 50 miles away. However, heretical as it may be to admit at a symposium so steeped in data and statistics, I will show no slides and present no data.

So I am not an expert. In fact, I once defined a talk without slides or a paper without data as a philosophical discussion. I have never considered myself much of a philosopher either, but in a sense, I guess this will be a philosophical discussion.

Actually, I suspect that my presence has to do with a couple of things that are pertinent. I come from a clinical background and thus face the problems which we are going to discuss and see them acted out on an everyday, practical basis. So I see the actual clinical impact of topics which we are going to discuss for the next few days in terms of measurement issues. Finally, I have assumed that I am here, in a sense, as a representative of the history and tradition that are present at the Duke Center for the Study of Aging and Human Development and more recently in the Veterans Administration Geriatric Research Education and Clinical Center (GRECC) regarding a number of issues. I think that these issues are quite pertinent, and I consider them essential to the enterprise that is to be embarked upon in the next couple of days.

First, the Duke Center has a long history in data collection on health and longitudinal changes in health. The Duke longitudinal studies, the Duke Older Americans Resources and Services (OARS) methodologies, and more recently our studies of geriatric and functional assessment speak to some of those issues (1–5). Second, many of those aspects of data collection have involved targeted, specific measurements geared to provide information in the areas which we wish to understand better. Third, we have had a history of international collaboration, acting as one of the two World Health Organization collaborating centers on aging in the United States.

Investigators in the Duke Aging Center have a long history of purposive archiving and a long history of secondary data analysis through our survey data laboratory. Perhaps most important in this area, we have a multidisciplinary team of people available to help in the interpretation of data being collected and assessed; to know what questions can and cannot be answered with a particular data set, the purposes for which it was elicited, the alternative uses to which it can be put; and—of almost too obvious importance—the quality of the data.

I think such a team needs to contain people knowledgeable not only in data collection and analysis but in the substantive content issues of aging. If I can deliver any exhortation, it is that many of these sorts of principles will govern the interpretation and organization of the data to be collected and, in this context, to be interpreted, since we will largely be dealing with secondary data analysis.

This conference will delve heavily into measurement issues in health and health care in a number of important areas. Since I have already said I am not an expert in these, I will not address them specifically, even though some, such as the cancer statistics, are of particular interest to me.

Instead, I would like to address some of the general issues behind the conference—the overall aim of the International Collaborative Effort on Aging which you have already heard articulated, that is, the focus on the health and wellness of the elderly. Those words flow trippingly from the tongue—health and wellness of the elderly. They are almost as cute as the phrase that the geriatric education coordinator at Duke used the other day when I mentioned to her that I was speaking at this conference. She said, "Oh! You are going to talk about hippy dippy." I looked at her, a little confused, and said, "Hippy dippy? What's that?" She said, "Oh, that is what we call health promotion and disease prevention" (HPDP).

Those are catchy words, catchy phrases, almost as though we know what we are talking about. The question I would ask is, Do we? I would like to start and perhaps spend most of the time on the basics, really the basics.

We are planning to measure health. My grandmother said, "If you have it, you have everything." What did she mean? What is "it"? It seems as if this should be really easy, one of those things we seem to know when we see it. In our mind's eye, each of us has a picture of what it is and what those "healthy" older people look like.

But it seems much more difficult to get a handle on what health is when we start to characterize it, and especially when we start to quantify it. This may be complicated somewhat by different pictures of health carried around in our mind's eye and conditioned in different countries by different cultures. I am sure in the next few days, as we address some of these issues from the international perspective, some of these images will become clear. At least they may become obvious. Whether they will become clear is another issue.

How, then, do we define some of these concepts? I thought it would be fun to get really basic, so I consulted one of my favorite medical textbooks, Webster's Dictionary, and looked up some of the definitions. The dictionary defines "health" as a condition of being sound in body, mind, or spirit, especially freedom from physical disease or pain. It defined "healthy" as implying full strength and vigor, as well as freedom from signs of disease. The dictionary also provided some synonyms in that same definition. One of them was "well." Being well, as opposed to healthy, was said to imply *merely* (my emphasis) freedom from disease or illness.

Other interesting terms were provided. One was "robust," which was defined interestingly as the opposite of delicate and sickly. I love terms that are defined as the opposite of something, because then you have to go figure out what those other things were defined as in the first place. Another interesting term was "hale," which was defined particularly as robustness in old age.

So we have a spectrum of that mind's-eye picture of the healthy older individual. I think there are some problems with some of these definitions, especially the one of "healthy" as full strength. It reminds one of the story about the man walking along the street and meeting an old friend who came up to him and asked, "How are you and how is your wife?" The man replied, "Compared to what?" Full strength compared to what? For elderly people, if by full strength we mean compared to a 20-year-old's full strength, that is probably not what my grandmother meant.

For purposes of argument, I would like to propose that health of the elderly, by and large, is the absence of chronic illness. Note that I have used the term illness, not disease, and I will come back to that in a moment.

Many have noted the reciprocal relationship of health and disease. As far back as 500 B.C. Aeschylus wrote, "Of a truly lusty health, rest us not content with its due bounds, for disease ever presseth close against it, its neighbor with a common wall."

More recently, Ed Bierman and Bill Hazzard, in promoting preventive gerontology, have focused on prevention or attenuation of the chronic diseases of aging as a major goal of medical practice. Others, on the other hand, have claimed that the disease focus is too narrow and have set up a confrontational situation, a confrontation between a biomedical model and a social model. I believe that broadening the focus to illness—that is, both disease and its manifestations and functional effects on the individual—makes this moot, at least for the elderly. An old Russian proverb says, "One can always be healthy as long as one is not ill."

Clearly, economic, social, and many other factors play important roles. These same factors must be dealt with by people of any age. It is my view that a healthy, well older person—that is, one in the absence of chronic illness, which includes disease and disability—can do fine even in a setting of fairly limited resources. The crisis occurs when health fails, that is, illness occurs. I believe that this is what my grandmother wanted, to be free of chronic disabling illness.

Could we do more? Perhaps. We could strive for that full strength of youth. I suspect that this is probably not what we wish to do. However, perhaps once we have finished defining vitality, during these next 2 days and over the next few years, we might wish to strive for vitality as elderly individuals.

I would remind you, though, of the caution of the French writer of the 1600's who said, "To preserve one's health by too strict a regimen is, in itself, a tedious malady." As a confirmed nonjogger, I would have to agree with that.

Regarding measurement issues, I would like to stress a couple of points. First, as I have already indicated, I believe we must account for both disease and function. This is not an either-or situation, and these two concepts are not to be placed in conflict. These are complementary, noncompetitive concepts.

Recently in geriatric circles the talk of functional assessment has become so great and so dominant that I fear we sometimes tend to forget the importance that specific diagnostic information can provide. Previous studies, recently confirmed by analyses of national long-term care surveys done by investigators at Duke, have noted the additive importance played by diagnostic and functional information. Thus, although functional measures in these studies determined the level of services needed by the elderly population, diagnostic information—information about specific disease processes—often determined the duration of need of these services. For example, women with the same degree of functional impairment as men lived considerably longer with this degree of functional impairment, because the functional impairment in women was caused by different medical conditions, those with lower force of mortality. As a result, the women actually exhibited much greater resource need than did the men (6).

Some of our current studies of geriatric consultation team assessment at the Durham Veterans Administration Medical Center GRECC (5) noted, in following a cohort of elderly individuals, that despite the excellent overall functional status of many of these individuals, there was an extremely high mortality over the next 2 years. At first, we were surprised, because functional status has been said to be everything. We should not have been surprised. It is clear that we are looking at the same issue, the force of mortality of specific diagnoses: That is, we had a population, a hospitalized population, with a number of severe and high-mortality illnesses, such as cancer and late-stage cardiac disease, and these dominated the mortality picture.

This relates to the concept of health, the duality of function and disease. For example, is the elderly individual who presents with no functional impairment, perfect performance status, high level of activity, but with widely metastatic oat cell carcinoma of the lung, healthy? I think not. That person will likely be dead within 9 months as well.

We cannot ignore either facet of this complex issue of function and disease. It is my hope, in looking at the organization of this conference, that both of these areas will be addressed specifically.

Likewise, in the medical context, sometimes the best way to improve functional status is by addressing a specific diagnostic entity. There has been a lot of writing in recent years in geriatric circles on maintenance of functional status, as if this were some separable magic process.

It is clearly true that for many individuals with multiple chronic, irremediable medical problems, maintaining functional status by a variety of symptomatic measures is the appropriate way to go. However, it is probably best not to treat patients with aches and pains in their bones by symptomatic measures alone, if the origin of these aches and pains is, for example, multiple myeloma, which could be treated quite specifically with excellent relief of symptoms and rather dramatic functional status improvement. Again, I would emphasize that functional status, as determined by functional assessment, and disease-specific and diagnostic information are complementary and dually useful pieces of information.

Why, then, are we so eager to look at all these data and to collaborate and to analyze them so thoroughly? I suggest that it is precisely because health will be created if we can prevent or attenuate the chronic illnesses of aging, but that we have a very poor handle on what the predictors for many of these illnesses are and what the risk factors for them are. We clearly need to learn more about those aspects of health in the elderly if we are to achieve the goal.

If we learn more, can we do anything about it? Are health promotion and disease prevention for the elderly contradictions in terms? I do not believe so. However, I believe we must avoid being too "hippy dippy" about this. We have to avoid espousing popular and trendy causes too quickly in the absence of data. We have to watch out for the cereal manufacturers who like to pick up on every announcement of a potential dietary manipulation to avoid a chronic illness of aging and flash it across their cereal advertisements.

However, if we learn more, I believe there is some precedent for hopeful outcomes even in situations where one might not have thought them probable. I will give you two examples. Recent studies have demonstrated that even for older smokers, at least over the age of 65, smoking cessation can decrease morbidity and, translating that term, improve health (7,8).

An interesting study a few years ago in patients with lung cancer also demonstrated that even for patients undergoing treatment for lung cancer, smoking cessation was able to increase response to treatment, and survival. Even when it would seem that the horse is out of the barn, sometimes we have been premature in making that conclusion. I suggest that we need to continue to look at the information that will tell us where the appropriate emphasis is to be placed on health promotion and disease prevention.

If we can truly identify the risk factors for these chronic illnesses, perhaps we may be able to begin to modify them and create a more healthy elderly population. In a sense, this is the same concept as that of "successful aging," which in 1974, a decade prior to its more recent popularization as a phrase and as a project of the MacArthur Foundation, was a title of a monograph and conference at the Duke Aging Center (9). In that conference a number of speakers—George Maddox, Bernice Neugarten, and many others—wrestled with some of these same concepts: What is success in aging to be? One of the conclusions was that success in this context is largely in the eye of the beholder, that everything is relative.

My grandmother provided some insight for me in this area as well a number of years ago. I had talked with her while she was living in Miami Beach when she was 78, and I asked her if she went out on the boardwalk much. She replied, "Nah. Who wants to sit around with those old people?" Her concept of a healthy older age was clearly a little different from the "old" people out on the boardwalk.

I look forward to hearing how many of you propose to measure a variety of aspects of health. I suspect that there will be some lively discussions, but hope that we will all learn a great deal from each other and that we can help set an agenda for this most worthwhile goal of seeking ways to help our elderly, as the U.S. Army recruiting posters would suggest, "Be all that they and we can be."

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Part II

Comparing cardiovascular and cancer statistics

Introduction

by Harry M. Rosenberg, Ph.D., Chief, Mortality Statistics Branch, National Center for Health Statistics

It is a great pleasure and honor to be at this Symposium on Aging. The topic that I am dealing with is the international comparability of diagnostic statistics, with emphasis on cardiovascular disease and cancer. I would like to acknowledge my collaboration on this topic with Dr. Tamara Harris, who is also one of the organizers of the Symposium. Dr. Harris is a Medical Officer in the Office of Analysis and Epidemiology at the National Center for Health Statistics.

We are going to concern ourselves in our workshop sessions with an overarching issue that touches the substantive focuses of the Symposium overall: That is, the comparability of diagnostic statistics, with a particular emphasis on comparing diagnoses for the elderly population. Issues affecting the comparability of diagnoses are a problem not only for information on causes of death but also for medical conditions representing the morbidity of the population.

Proper interpretation of international differences in both morbidity and mortality patterns requires understanding the comparability of health data among countries. For example, reported differences in life expectancy among countries may be real, or they may be artifacts reflecting differences in definition or in vital registration practices. Again, reported differences among countries in the age curve of death from cancer may be real or may instead reflect differences in the way in which physicians report neoplasms on the death certificate or differences in processing the information on the death certificate, such as the application of international rules in selecting the underlying cause of death. Again, international differences in the prevalence of chronic respiratory problems such as emphysema, bronchitis, chronic obstructive pulmonary disease, or coronary heart disease may represent true and important geographic variation or they may reflect, in large measure, differences in patterns in health services utilization, diagnostic techniques, definitions, terminologies, or data processing.

Clearly, a variety of terminologies and measurement issues bear importantly on international comparisons of the health status of the elderly population. Considerable work has been done and continues to be done on the comparability of medical coding of the cause of death, led by the World Health Organization (WHO) and implemented in WHO and in many individual countries. Additional work is needed that focuses more attention on comparative data and measurement techniques. A number of initiatives are under way.

This International Collaborative Effort on Aging, the ICE Age, provides a forum in which information on comparability of diagnostic information can be investigated by identifying various aspects of the area, including measurement techniques for establishing diagnoses, cause-of-death validation studies, and possibly use of autopsy, clinical, and survey information to establish the reliability and validity of cause-of-death information on the death certificate.

Our long-term goal is to develop a research proposal that can explore some of these issues, using existing data bases and knowledge. The specific diagnoses for which comparability will be explored will dovetail to some extent with other ICE projects, with particular emphasis on cardiovascular diseases and cancer. Initial research efforts may focus on a specific age group, such as the population 65–74 years of age, with a view to ascertaining if the problems of the old old are but an extension of those in the younger population or if, instead, they represent an entirely different set of issues.

Chapter 3

Morbidity and mortality information on old age: Comments on availability, validity, and comparability

by Thomas Strasser, M.D., Ph.D., World Hypertension League and Department of Social and Preventive Medicine, University of Geneva

Introduction

Although the title of the present session refers to comparisons of statistics, I would prefer to comment in more general terms on both available and desirable information on cardiovascular morbidity and mortality in the elderly from the international point of view. Available information on international validity and comparability, referring specifically to this topic, is scarce (1). However, by taking a wider look at the problem, by reviewing the various possible sources that may yield data on the elderly, we may arrive at a composite and perhaps consistent picture, and eventually come to certain conclusions that might be of some use to the present International Collaborative Effort on Aging.

There are three main sources of such information: (a) cause- and age-specific mortality statistics; (b) epidemiological studies—more precisely, community- or population-based surveys and disease registers; and (c) anatomo-clinical comparisons.

Mortality statistics

It can be assumed a priori that the validity of non-medically certified causes of death is too limited to take such information into account. In 1989, out of more than 150 member countries of the World Health Organization (WHO), 35 countries reported that 96–100 percent of deaths were medically certified (2). This excludes from our considerations most, although not all, developing countries: For example, medically certified mortality information has become available from parts of China recently, covering about 10 percent of the total population of the country (2).

The question is, how valid, and thus how comparable, are statistics derived from medically certified death records in various countries. More precisely, how well is the validity of mortality statistics established in general, and what information is available on the validity of cause-of-death statistics in the older as compared with the younger age groups.

The Unit for Global Epidemiological Surveillance and Health Situation Assessment of WHO recently started a Cause of Death Validation Program (3). This program consists of four parts: Consistency checks, surveillance, coverage and quality checks, and time-series checks. The program is geared neither toward cardiovascular diseases nor toward older age groups but could easily be expanded to these problems. Consistency warnings could be issued for highly improbable conditions in the elderly, such as death coded as due to acute rheumatic fever or, for that matter, to congenital heart disease in the oldest age groups. While surveillance concerns infectious diseases, coverage checks could be introduced specifically with regard to old age, such as too low rates for pulmonary embolism, known to be a major cause of death in the elderly. By the same token, time-series checks could be useful for producing warnings on deviations from established trends in changing age-related mortality patterns.

WHO's International Classification of Diseases and Causes of Death promulgates worldwide uniform coding of the causes of death (4). Yet in the field much depends on how coders interpret the rules. Moriyama, one of the most prominent experts in this field, recently commented on the complexities of measurement of accuracy of cause-of-death statistics: "Although the notion of the underlying cause of death appears to be fairly simple and straightforward, the actual determination of the underlying cause-sequence may be difficult in practice where a number of diseases and conditions are involved in the death" (5). This applies most pertinently to old age, with its well-known polypathology.

So, how do we assess validity? One way is to have a panel "blindly" recode a sample of death certificates on the basis of all available clinical information and to compare the thus-established "reference causes of death" with those recorded on the death certificates. In this way a "detection rate" and a "confirmation rate" can be calculated. The first gives information on missed diagnoses or false negatives, as in the corresponding epidemiological concept of sensitivity. The second provides information on the proportion of false positives, an analogy to the notion of specificity in epidemiology.

As an example, a recent study from Spain (6) gives insight into the degree of concordance of underlying causes of death as recorded on the certificates and as assessed by a panel of internists. On a total of 1,454 cases, there was an overall concordance of around 80 percent of the certificates. For cardiovascular diseases, the detection rate was 88 percent; the confirmation rate, 80 percent. These figures are within the ranges observed earlier in some other countries (Sweden, United Kingdom, United States) and indicate an acceptable level of validity and of international comparability. It may be of interest to mention that the greatest proportions of miscodings pertained to respiratory and circulatory diseases, both for false positives and for false negatives; circulatory diseases were often coded as respiratory disease and vice versa.

How relevant are such findings to statistics for the elderly? Because the majority of cardiovascular deaths occur in elderly people, even in the absence of age-specific information, it should be surmised that such findings largely reflect the situation of the elderly (provided that, in developed countries, no age limits for review of death certificates are set). The absolute numbers of autopsies are greatest in the elderly, even if the proportion of autopsies of persons over 65 years of age is low in most countries. It can be assumed that validity checks on general mortality, and on cardiovascular deaths in particular, reflect mortality over 60 or 65 years of age reasonably well within the limits of the methods applied.

Epidemiological studies

The second possible source of information on morbidity is epidemiological studies, both population surveys and population-based registries. Population surveys could yield valuable information on cardiovascular health variables in the elderly, such as blood pressure distributions; they could but frequently do not, because many epidemiological studies stop at age 64, e.g., (7–9). Since the beginnings of cardiovascular epidemiology, older age groups were "orphan categories." The historical reasons of this fact can be understood. However, it cannot be justified if epidemiological surveys started recently still ignore the need for more and better information on the elderly. Demographers showed decades ago that the problem is with us. Omitting the elderly from epidemiological surveys is ostrich policy.

This applies particularly to international comparative epidemiological projects, such as the Multinational Monitoring of Trends and Determinants in Cardiovascular Diseases (MONICA) Study (9), in which an upper age limit of 64 years was established—as if the bulk of cardiovascular morbidity and mortality were not occurring past that age. The opportunity of obtaining comparable cardiovascular information on the elderly of some 40 populations has thus been missed. The lesson for epidemiological surveys to come is clear: The elderly must not be ignored.

Similar considerations apply to a number of community-based disease registers. The European Myocardial Infarction Registration Project, which in the 1970's yielded valuable comparative data on incidence rates of myocardial infarction in some 20 European centers, also stopped at age 64. Nevertheless, this study showed a good correlation between registered incidence rates of myocardial infarction in the studied communities and nationwide myocardial infarction mortality rates, thus validating indirectly the information on this disease obtained from the official vital statistics, at least for the age group 55–64 years (10).

A cooperative, multicenter stroke registration study coordinated by WHO (11), on the other hand, included men and women of all ages from 17 communities in 13 countries in Europe, Africa, and Asia. A common operating protocol was strictly observed, and the results were comparable. Geographical differences in the incidence of stroke were moderate. In the ongoing MONICA Study (9), stroke is being registered in 21 centers out of a total of 51, the others registering only myocardial infarction. However, in only 12 centers is the age limit over 64 years—in most of the 12 it is 74 years and in only 3 centers is there no upper age limit to registration. In view of the considerable quality-control efforts in this project, the information will be comparable.

Anatomo-clinical comparisons

In the hospital setting, systematical autopsies are the classical, and still best, means of validating clinical diagnosis. One should not, of course, extrapolate from selected hospital populations to deaths and death certification in the field. Still, the information from hospital-based autopsy studies can be useful, because the validity of cause-of-death information is unlikely to be better in the field than in the hospital.

Autopsy rates have been declining steadily over the past decades (12). In the elderly population of the United States, for instance, the average rate of autopsy is less than 8 percent (13). The most accurately diagnosed condition was found to be cerebrovascular accident, with a 92-percent ante mortem accuracy rate; the highest error rate was due to underdiagnosis of pulmonary embolism, with a 39-percent ante mortem accuracy rate. In data similar to these from U.S. hospitals, findings from Belgrade, Yugoslavia, indicate the highest diagnostic accuracy for cases of stroke (87 percent). For myocardial infarction, the accuracy rate was 76 percent, but again many cases of pulmonary embolism were misdiagnosed as myocardial infarction (14).

On what does the validity of clinical diagnoses depend? Battle et al. (15) analyzed factors influencing discrepancies between ante mortem and post mortem diagnoses in a study of 2,067 autopsies collected from 32 university and community hospitals of various sizes located throughout the United States. Age was such a factor. In adolescents and young adults, the discrepancy rates were around 20 percent. At ages 50–59 years, the rate was 35 percent; it was nearly 40 percent in the group ages 60–69 years and rose to 50 percent for those 90 years of age and over. Incidentally, pulmonary embolism, among all causes, had the highest discrepancy rate in this study, 47 percent. In myocardial infarction, the discrepancy rate was 28 percent. There was little uncertainty about stroke. Thus, the second factor influencing diagnosis validity was the disease category itself.

The third factor was the type and size of hospital. University hospitals had better results than community hospitals; bigger hospitals were better than smaller ones. In all likelihood, the higher the level of services, the better the diagnoses. Better medicine obviously yields better diagnoses.

Discussion

Vital statistics from countries where deaths are medically certified are useful, despite their moderate general reliability. Validation procedures could, and should, be complemented with special considerations targeted at deaths in old age. Validation procedures of samples of death certificates play a useful role, too. It is conceivable to apply the type of exercise described in the example of Valencia, Spain, in an international effort by sampling cases from multiple countries and having the death certificates reexamined by an international board of experts.

Another, more innovative approach is automation of the coding process. As a matter of fact, a system of Automated Classification of Medical Entities (ACME) was introduced in the United States in 1968, applied to the International Classification of Diseases, Eighth Revision (ICD–8). The system was used to process almost 2 million records per year during the currency of ICD–8 and was converted to ICD–9 for the coding of death records as of 1979 (16). The performance of ACME was remarkable: Only 3 percent of cases were referred for nosological review, and coding achieved an accuracy of 99.5 percent.

More recently, the MICAR system (Mortality Medical Indexing, Classification and Retrieval) was introduced. This automated system internally performs ICD multiple-cause coding from basic information. MICAR is not yet operative, but ACME is being used in the United States and Brazil. (It has been tried also in the United Kingdom but has been abandoned.) Despite the logistic difficulties, it may be possible to apply this system more generally. This would solve the problem of uniformity in interpreting underlying causes of death. Naturally, good-quality grassroots information remains a prerequisite.

From the epidemiologist's point of view, it becomes imperative to include old people in health surveys and disease registers, provided that classical registers still have a future. It is conceivable that in the not-too-distant future comprehensive morbidity information systems could be established by an electronic, computer-to-computer mailing system. Again, innovative approaches are needed if long-term efforts are being planned. By the same token, and much more easily, collection of autopsy versus clinical information could be processed by establishing nationwide electronic mailing networks in technically advanced countries.

How does all this relate to the validity and comparability of cardiovascular statistics in old age? It is my firm conviction that, in order to assess and upgrade cardiovascular statistics in the elderly, a systemic approach will yield, in the long run, better results than partial, fragmented action aimed specifically at the cardiovascular system of elderly persons. Better and more valid health statistics at all ages will result in more reliable information on the elderly as well. Prerequisites are good-quality medicine and comprehensive epidemiology.

Conclusions

Valid and comparable information on cardiovascular morbidity and mortality in old age is scarce. The main sources of such information are national vital statistics, epidemiological surveys and registers, and comparisons between clinical diagnoses and autopsies. The uses of these sources could be improved by paying more attention to older age groups, for example, by the introduction of consistency checks of mortality statistics relevant to old age and the inclusion of elderly subjects in epidemiological studies.

In general, there is need for innovative approaches. Though fraught with special problems, information on cardiovascular morbidity and mortality in the elderly is only part of the problem of quality of health information in general. Overall efforts to upgrade health information also should improve knowledge about the elderly population, provided due attention is paid to them.

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Chapter 4
Validity of diagnosis of cancer in the elderly

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Introduction

In simplistic terms the conquest of infectious disease in much of the world has resulted in a fall in infant mortality, an increase in the average age of populations, and hence an increasing proportion of elderly persons. As the strongest risk factor for malignant disease is age, it is axiomatic that, other things being equal, the numbers of people with cancer to be diagnosed and treated will grow.

Rational planning of health services demands sound statistics of the impact of cancer on the elderly, here defined as persons over the age of 65 years. Sound statistics require that cancer be accurately diagnosed and recorded. This paper examines the validity of the diagnosis of cancer in older persons.

Data available

The two main sources of information on cancer in a population are mortality (derived from death certificates) and incidence (collected by cancer registries). Although mortality information is more widely available (figure 1), this source is generally acknowledged to be less precise than incidence, practically never indicating the basis on which cancer was diagnosed. (In some countries, the death certificate may indicate whether an autopsy was performed.) Further, given the varying lethality of different cancers, death rates give an incomplete picture of the cancer burden. This paper thus deals with incidence data only.

The editors of successive volumes of *Cancer Incidence in Five Continents* (1) have requested contributing cancer registries to provide data on (a) the proportion of diagnoses reported to the registry with histological verification of diagnosis (HV), (b) the proportion of cases registered for which the existence of a cancer was known from a statement on a death certificate only (DCO), (c) the proportion of registered cases whose age was not known, and (d) the ratio of mortality to incidence. Volume V of *Cancer Incidence in Five Continents* (1) presents such data for all ages, 0–34 years, 35–64 years, 65–74 years, and 75 years and over. For Volume V, many contributors provided this information by 5-year age group up to 95 years of age and over. These unpublished data have been further analyzed and are presented below for selected type registries, being supplemented by material from the Surveillance, Epidemiology, and End Results (SEER) registries of the United States, the collection of which is coordinated by the National Cancer Institute (2) of the National Institutes of Health.

When examining these indexes (3), it should be borne in mind that the proportion of diagnoses with histological verification (HV percent) may vary by site as other reliable methods of diagnosis exist, e.g., radiology for cancer of the esophagus and serum alpha-fetoprotein for hepatocellular cancer. DCO percent, i.e., the proportion of all notifications for which the only underlying information available to the cancer registry was a statement on a death certificate that a deceased person had cancer, is usually less than 1 in 20 notifications in most registries for all ages combined. Higher values indicate that the registration process is incomplete or that the quality of death certification is poor. By definition, a person with cancer diagnosed microscopically cannot be in the DCO category (but see below). The relationship between mortality and incidence (M-I) for a given cancer in the registration area at a particular time varies substantially from site to site, being close to unity for rapidly fatal forms of malignancy such as those of the stomach, lung, and esophagus and very low for

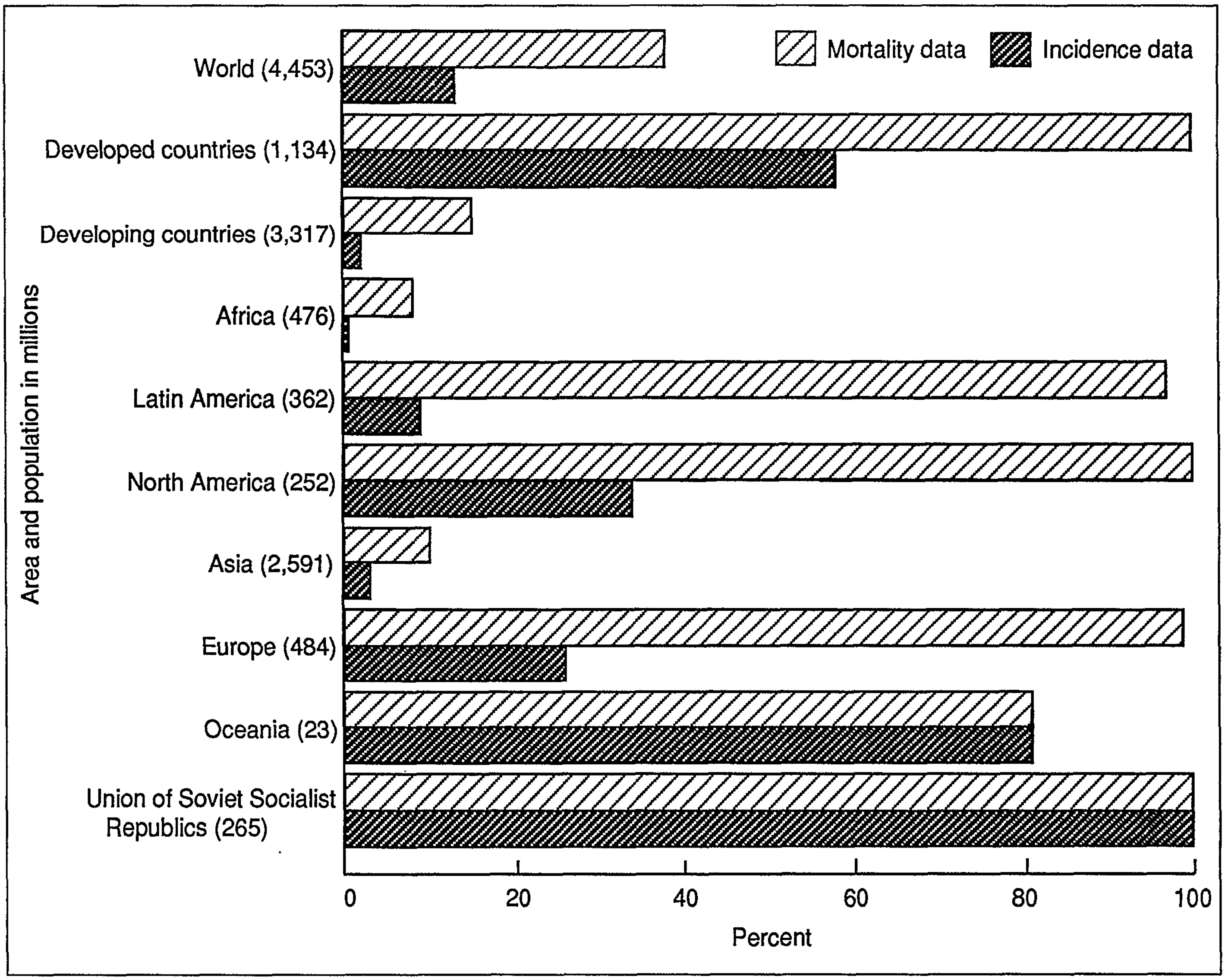


Figure 1. Percent of cancer mortality and incidence data available, by United Nations area and population: Circa 1980

nonmelanoma skin cancer. For a given cancer site, the ratio is likely to vary from center to center according to results of treatment and possibly the definition of what constitutes a cancer. The proportion of notifications of unknown age is usually very low other than for nonmelanoma skin cancer.

Results

Table A contains data for selected sites of cancer by age and sex for the SEER registries. Although the proportion of histological verification at ages 65–69 years and 70–74 years is much the same for the sites listed, after 75 years there is a gradual diminution in the proportion with HV, a rise in the proportion diagnosed on clinical grounds, and an increase in the proportion registered on the basis of a death certificate only.

Table B compares HV percent, DCO percent, and the M-I ratios for males in Connecticut and in Miyagi Prefecture in Japan for gastric cancer. The proportion with HV is substantially higher at any age in Connecticut and the proportion registered on the basis of DCO very low, whereas in the age group 85 years and over, over half of the cases in the Miyagi cancer registry had not been reported to the registry before death. As noted above, a DCO case cannot, by definition, have histological verification of diagnosis. Nonetheless, when the M-I ratios are compared up to the age of 79 years, these ratios are remarkably similar

Table A. Percent distribution of cancer diagnoses by mode of diagnosis, according to age, cancer site, and sex, as reported in Surveillance, Epidemiology, and End Results (SEER) registries: United States, 1983–86

Site of cancer and sex	*65–69 years*				*70–74 years*				*75–79 years*				*80–84 years*				*85 years and over*			
	HV	*A*	*C*	*DCO*	*HV*	*A*	*C*	*DCO*	*HV*	*A*	*C*	*DCO*	*HV*	*A*	*C*	*DCO*	*HV*	*A*	*C*	*DCO*
Total									Percent distribution											
Male	95.5	0.9	2.6	0.9	94.0	1.0	1.9	0.8	91.6	1.2	5.6	1.1	87.4	1.3	8.8	1.9	79.2	1.7	14.5	3.7
Female ..	96.6	0.3	2.2	0.6	94.6	0.4	3.7	1.0	92.3	0.6	5.3	1.4	87.2	0.7	9.4	2.2	76.6	0.7	16.7	4.9
Esophagus																				
Male	97.5	0.2	1.6	0.2	93.9	0.5	4.3	0.5	92.5	1.6	4.0	2.0	91.8	0.8	5.2	1.5	80.6	1.0	15.3	3.1
Female ..	98.8	---	---	0.6	95.6	0.6	1.9	1.2	92.7	0.7	2.9	3.7	93.0	---	7.5	3.5	79.1	---	16.3	4.7
Stomach																				
Male	97.6	0.4	0.9	0.9	96.5	1.0	1.0	1.0	94.5	0.6	3.9	0.5	92.8	1.2	4.0	1.4	84.6	1.3	11.2	2.4
Female ..	98.5	---	---	0.5	94.4	0.4	3.3	2.0	92.8	0.6	4.2	2.0	90.0	1.6	7.5	0.7	70.9	1.8	20.4	5.7
Liver																				
Male	73.9	5.1	17.1	2.3	72.5	8.2	13.0	4.8	71.5	7.8	16.8	3.4	69.0	6.0	18.1	6.9	58.6	8.6	20.7	10.3
Female ..	81.1	2.1	12.6	4.2	76.7	1.9	13.6	4.9	71.1	4.4	18.9	5.6	72.6	5.5	19.2	2.7	52.9	2.9	25.7	11.4
Pancreas																				
Male	80.5	1.7	14.3	2.2	77.8	1.7	17.7	1.8	69.9	2.0	23.6	3.3	54.6	1.2	39.8	3.6	43.1	1.5	45.2	7.5
Female ..	83.4	1.1	13.8	1.1	77.3	0.9	19.2	1.9	69.7	1.0	24.5	4.1	57.7	1.1	36.7	3.9	34.7	1.7	55.5	6.8
Lung																				
Male	93.8	0.9	3.8	1.0	91.3	1.0	6.2	1.1	86.8	1.4	9.4	1.9	77.1	1.0	18.1	3.1	58.5	2.0	31.8	6.8
Female ..	93.3	0.7	4.3	1.1	90.8	0.8	6.2	1.7	85.6	1.1	10.6	2.0	70.3	2.0	23.7	3.5	54.8	1.3	32.9	4.1
Breast																				
Female ..	99.3	---	0.4	0.2	98.3	0.1	1.0	0.5	97.5	0.1	1.5	0.7	94.7	0.2	3.6	1.5	85.8	0.1	9.4	8.9
Prostate																				
Male	97.5	1.4	0.9	0.2	97.1	1.4	1.2	0.2	95.2	1.4	2.5	0.5	92.2	1.8	4.6	0.9	83.6	2.6	10.6	2.4
Brain																				
Male	90.2	0.3	8.3	0.9	82.1	---	14.9	3.1	69.9	2.9	28.3	1.7	56.1	---	36.6	6.1	42.9	---	47.6	7.1
Female ..	83.3	---	15.7	0.4	80.5	---	17.5	1.6	71.4	0.5	22.9	3.7	44.1	2.5	46.9	5.9	35.3	---	52.9	5.9

NOTE: Totals are less than 100 percent due to small numbers of cases diagnosed in hospital for which the record did not indicate whether diagnosis was histologically confirmed. HV is histological verification, A is diagnosed at autopsy, C is clinical diagnosis only, DCO is known from death certificate only.

SOURCE: Basic data were provided by V. Van Holten and C. Percy of the U.S. National Cancer Institute.

in both areas, suggesting that despite the high level of DCO, most cases in Japan were in fact recognized although not reported to the cancer registry before death. Fujimoto and Hanai (4) discuss the reasons for the very high proportion of DCO cases in registries in Japan and demonstrate that in Osaka Prefecture, when a special effort was made to follow up DCO cases, the diagnosis proved to be highly reliable. Of 345 such DCO notifications, 7.2 percent had been diagnosed at autopsy, 37.1 percent had HV of diagnosis, 10.4 percent cytology, 19.4 percent radiology, and 10.2 percent ultrasound or other tests.

Comparison in the same table of similar data for males in the German Democratic Republic reveals a very low percentage of DCO and a somewhat greater proportion with HV of diagnosis than in Japan, which should indicate more reliable data than in Japan. Yet in the older age groups in the German Democratic Republic, more deaths were stated to be due to gastric cancer than there were incident cases, reflecting either underregistration or poor death certification.

The overall proportions of HV in male Japanese in Miyagi and in Los Angeles were 67 percent and 95 percent, respectively. The overall M-I ratios were 0.67

Table B. Percent of males diagnosed with gastric cancer, by age, mode of diagnosis, and ratio of mortality to incidence: Connecticut, Miyagi, Japan, and German Democratic Republic, 1978–82

Area and item	*All ages*	*0–34 years*	*35–64 years*	*65–69 years*	*70–74 years*	*75–79 years*	*80–84 years*	*85 years and over*
Connecticut[1]								
HV percent	93	100.00	98.30	94.30	96.20	92.20	88.80	70.20
DCO percent ...	1	-	1.10	1.70	-	1.50	2.00	4.80
M-I ratio	66	0.80	0.59	0.66	0.65	0.80	0.70	0.75
Miyagi, Japan								
HV percent	75	89.90	85.30	78.60	69.20	50.00	30.80	[2]17.30
DCO percent ...	14	5.10	6.80	11.00	18.40	29.90	41.40	[2]59.70
M-I ratio	59	0.46	0.47	0.62	0.70	0.82	0.91	[2]0.98
German Democratic Republic								
HV percent	77	97.90	89.00	82.30	75.80	68.10	58.70	[2]55.10
DCO percent ...	1	-	0.10	0.30	0.70	1.00	2.10	[2]0.80
M-I ratio	91	0.77	0.80	0.88	0.92	1.01	1.05	[2]1.40

[1] Data are for white males.
[2] Data available for age groups up to 95 years of age and over.

NOTE: HV percent is percent histologically verified, DCO percent is percent known from death certificate only, M-I ratio is ratio of mortality to incidence.

SOURCE: Muir CS, Waterhouse J, Mack T, et al., eds. Cancer incidence in five continents, vol V. International Agency for Research on Cancer scientific publications no 88. Lyon, France: International Agency for Research on Cancer. 1987.

and 0.60, respectively; i.e., survival appeared to be slightly better in Japanese living in Los Angeles. Comparison of these indicators of data quality by sex showed that females in Miyagi also had a much lower proportion of HV, 69 percent compared with 96 percent in Los Angeles; a much higher proportion of DCO only, 15 percent compared with 2 percent; and somewhat poorer survival, the M-I ratios being 0.60 and 0.43. Comparing male lung cancer and female breast cancer in Connecticut and Miyagi (table C), survival at any age tends to be slightly better in Connecticut than Miyagi for lung cancer, the M-I ratios being 0.78 and 0.83, respectively. For breast cancer, the M-I ratios were 0.34 and 0.25, findings in consonance with observed survival for white persons and Japanese in the SEER program (5). The consistency of these data suggests that, despite the lower proportion with HV in Japan, the diagnosis was reasonably reliable.

Table C. Ratio of mortality to incidence for male lung cancer and female breast cancer, by age: Connecticut and Miyagi, Japan, 1978–82

Site of cancer and area	*All ages*	*0–34 years*	*35–64 years*	*65–69 years*	*70–74 years*	*75–79 years*	*80–84 years*	*85 years and over*
Lung[1]				Ratio				
Connecticut	0.78	0.65	0.72	0.76	0.83	0.84	0.92	0.92
Miyagi, Japan ...	0.83	0.86	0.72	0.86	0.82	0.92	0.99	[3]1.00
Breast[2]								
Connecticut	0.34	0.15	0.31	0.36	0.36	0.38	0.44	0.50
Miyagi, Japan ...	0.25	0.17	0.24	0.28	0.28	0.63	0.41	[3]0.50

[1] Data are for males.
[2] Data are for females.
[3] Data available for age groups up to 95 years of age and over.

SOURCE: Muir CS, Waterhouse J, Mack T, et al., eds. Cancer incidence in five continents, vol V. International Agency for Research on Cancer scientific publications no 88. Lyon, France: International Agency for Research on Cancer. 1987.

Discussion

Indexes of reliability

While the indexes of reliability are useful guides to data quality, they cannot be used without some knowledge of local circumstances. A high proportion of HV may reflect complete reporting by pathologists and lesser degrees of reporting by other sources. A low proportion of HV may reflect inadequate provision of pathologists, a high proportion of cancer that can be diagnosed by other means, failure to notify the registry that biopsy and/or autopsy were performed, or an unwillingness to investigate elderly persons exhaustively. A high proportion of DCO may, as in Japan, reflect the inability of cancer registration systems to link hospital records with death certificates. The M-I ratio may be distorted by poor or imprecise death certification; for example, there are usually more deaths attributed to unspecified leukemias than there are incident cases, as the more precise data on cell type available to the clinician and cancer registry do not appear on the death certificate. Similarly, a neoplasm reported to a cancer registry as arising in the rectum may appear as cancer of the large bowel on a death certificate and, following current coding rules, be classified with cancer of the colon (see also (6)). The mechanical application of these indexes can be misleading—all available information has to be taken into account.

Use of cumulative rate

Believing that the detection and diagnosis of cancer were optimal for ages 35–64 years, Doll and Cook (7) introduced the Truncated Standardized Rate (TSR) for the comparison of international incidence and mortality data. Yet in many populations the cumulative rate (8) for cancer for ages 65–74 years is about the same as that for ages birth to 64 years (table D and figures 2–6), and that for ages 75–84 years is likely to be substantially larger, although based on smaller numbers of persons. The TSR, in effect, "writes off" older persons.

Treatment of cancer in elderly persons

The precision of cancer diagnosis may depend on the attitude of physicians toward treatment of older persons. If treatment is not contemplated, investigation is likely to be less thorough. While there is no reason why the elderly person with cancer should not be treated as energetically as those who are younger (and indeed, as the neoplasms often grow more slowly, with success), physicians are often reluctant to submit elderly patients to the discomfort of invasive diagnostic procedures and aggressive therapy. It is probable that in several cultures permission to do so would be refused. Such considerations may be at least in part responsible for the large differences among selected areas seen around 1980 in the indexes of data reliability

Table D. Cumulative incidence rate for several common cancers, by site of cancer, age, and area: Selected areas, circa 1980

	Site of cancer									
	Stomach[1]		*Colon*[1]		*Lung*[1]		*Breast*[2]		*Prostate*[1]	
Area	*0–64 years*	*0–74 years*	*0–64 years*	*0–74 years*	*0–64 years*	*0–74 years*	*0–64 years*	*0–74 years*	*0–64 years*	*0–74 years*
	Rate									
Cali	2.4	5.2	1.3	1.5	1.2	3.1	2.4	3.8	0.8	3.5
Detroit:										
Black	0.9	2.0	1.3	3.5	7.4	14.0	4.5	7.0	3.0	11.1
White	0.5	1.2	1.3	3.2	5.0	10.7	5.4	8.5	1.3	5.9
Shanghai	3.0	7.4	0.5	1.0	2.7	7.3	1.5	2.1	0.0	0.2
Osaka	3.4	9.1	0.6	1.4	1.4	4.5	1.6	2.1	0.1	0.5
Denmark	0.6	1.6	0.8	2.2	3.0	7.5	4.6	6.9	0.7	3.1
Warsaw	1.1	2.8	0.5	1.3	3.4	7.0	2.5	3.7	0.2	1.3

[1] Data are for males.
[2] Data are for females.

SOURCE: Muir CS, Waterhouse J, Mack T, et al., eds. Cancer incidence in five continents, vol V. International Agency for Research on Cancer scientific publications no 88. Lyon, France: International Agency for Research on Cancer. 1987.

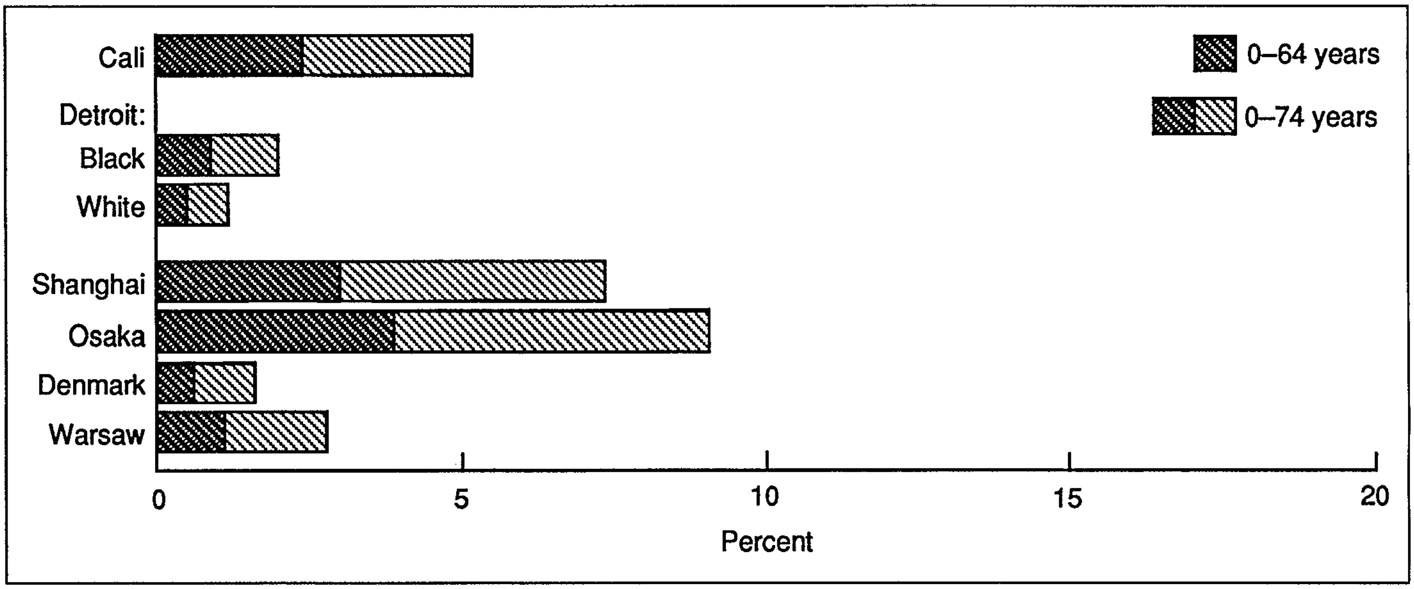


Figure 2. Cumulative incidence rate for stomach cancer among males, by age: Selected areas, circa 1980

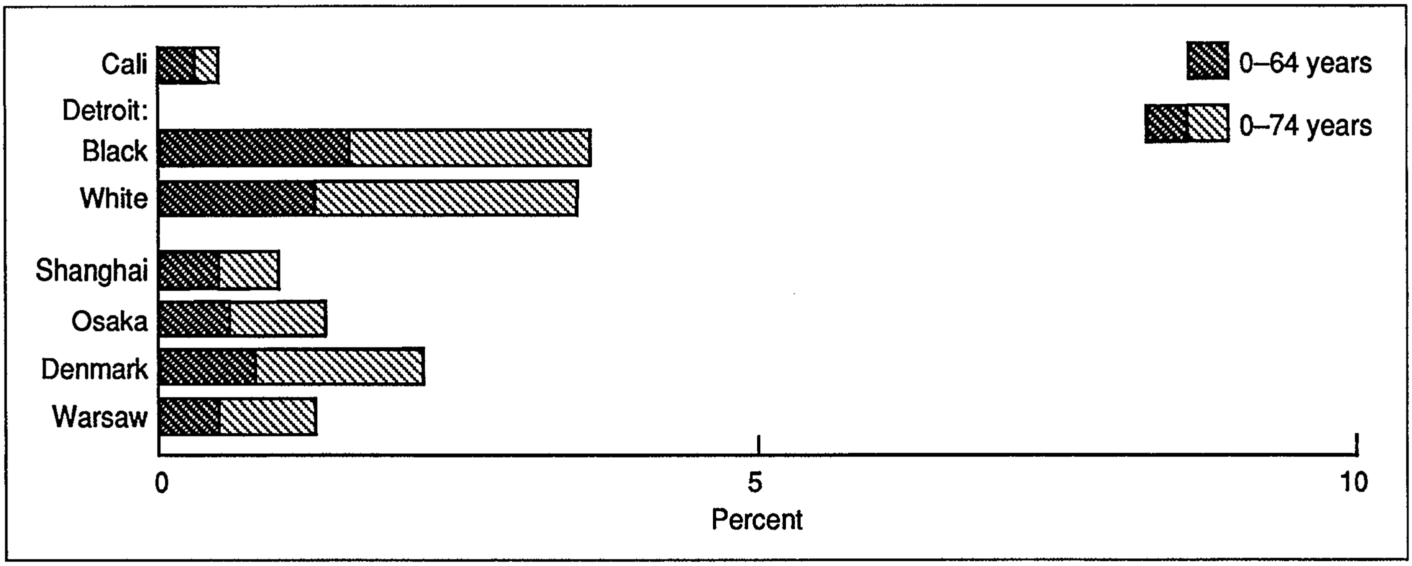


Figure 3. Cumulative incidence rate for colon cancer among males, by age: Selected areas, circa 1980

for persons 80–84 years (table E). The substantially lower M-I ratios in North America (the United States and Canada only) demand further study, as it is unlikely that standards of medical care are higher than in, say, Geneva. For a proportion of the elderly, the presence of concomitant cardiovascular, cardiorespiratory, or other disease may in effect rule out therapy for the cancer. Nonetheless, results are often better than might be imagined, although not as favorable as in younger patients. This type of information is rarely available but was published in 1980 by the Norwegian Cancer Registry (9). Table F gives 5-year relative survival for colon cancer by stage, sex, and age group. Breast cancer survival data from the same source are presented in table G. Given the accessibility of this site, the quality of diagnosis, including staging, is likely to be fairly uniform across ages. At any stage, survival is poorer in the age group 75 years and over; at any age, stage at diagnosis is a more important prognostic factor than age per se. The use of the relative survival rate takes the effect of the weight of other causes of death into account.

Unfortunately, in many countries it is not possible to estimate cancer survival for the population as a whole, as to do so requires three items of information: Knowledge of all persons with newly diagnosed cancer,

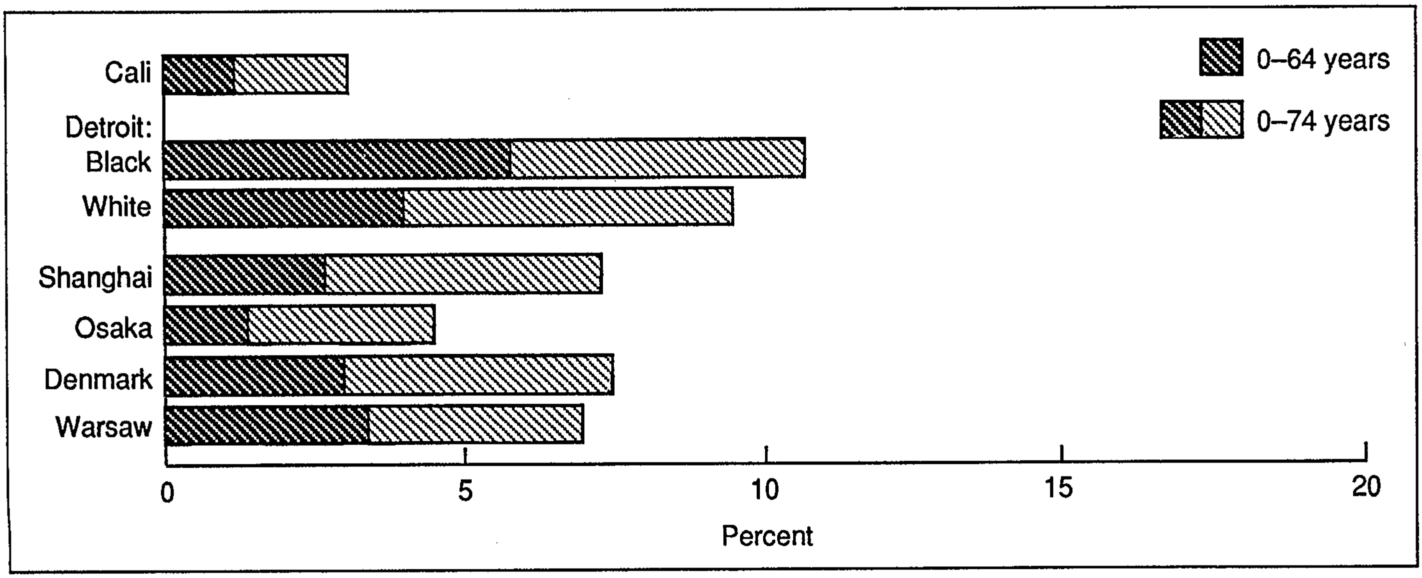


Figure 4. Cumulative incidence rate for lung cancer among males, by age: Selected areas, circa 1980

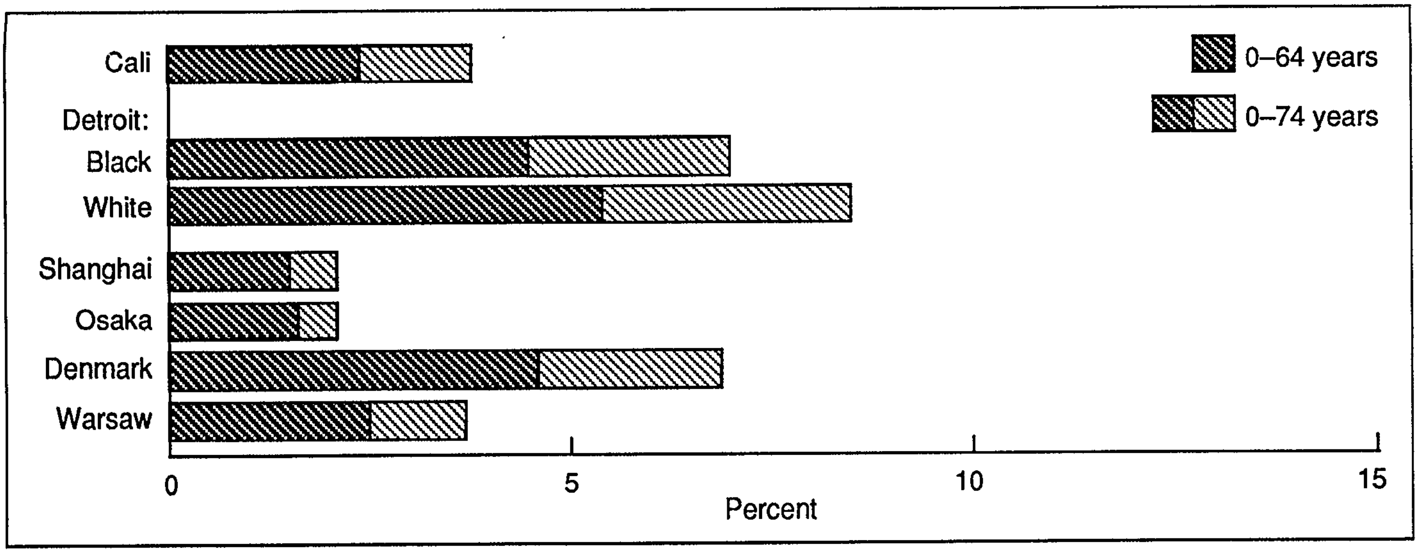


Figure 5. Cumulative incidence rate for breast cancer among females, by age: Selected areas, circa 1980

their date of diagnosis, and their date of death. This implies either national cancer registration or, if registration covers only part of the country, the ability to determine whether registered cancer patients are alive or dead, no matter where they happen to reside at the time of death. Unfortunately, in several Western European countries, considerations of so-called confidentiality prevent such matches being made. (The Western European countries referred to in this paper are Austria, Belgium, France, the Federal Republic of Germany, Luxembourg, The Netherlands, and Switzerland.) It must be stressed that the survival figures emerging from controlled clinical trials are in no way representative of the cancer survival of a given population, in that patients entered in these trials rightly are highly selected so that valid comparisons can be made between treatment regimens.

While there have been very substantial improvements in survival for Hodgkin's disease, acute lymphocytic leukemia in childhood, choriocarcinoma, and testis cancer, these rather uncommon forms of malignancy are unusual in older persons. Survival for

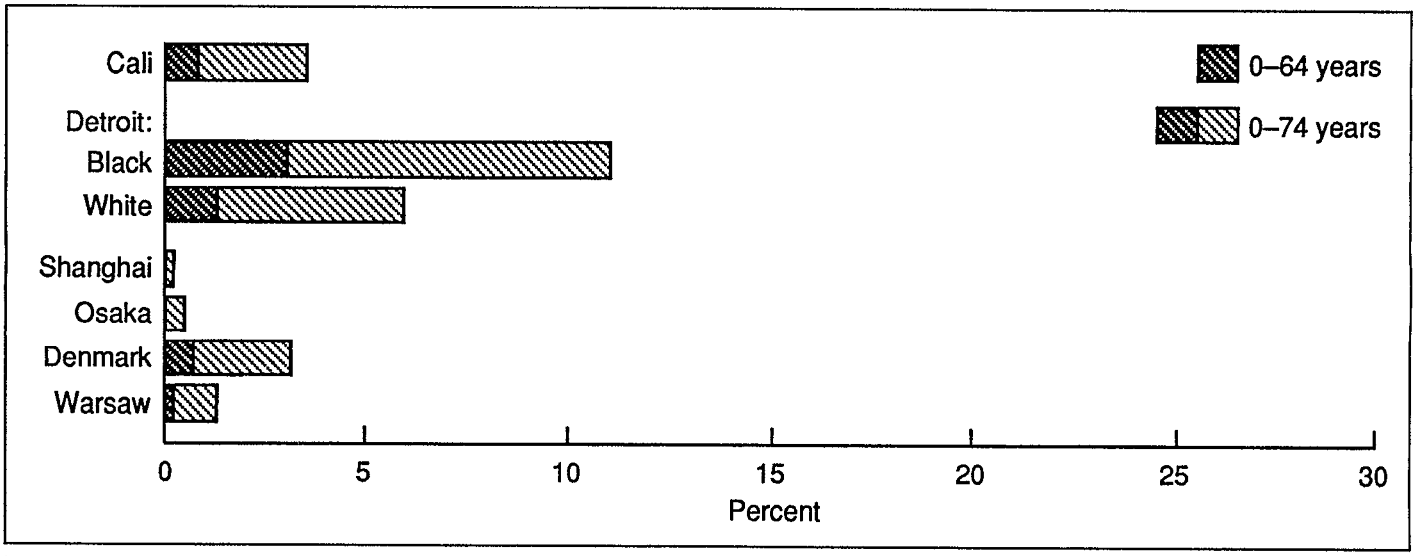


Figure 6. Cumulative incidence rate for prostate cancer among males, by age: Selected areas, circa 1980

Table E. Percent of persons 80–84 years of age with cancer, by mode of diagnosis, ratio of mortality to incidence, and sex: Selected areas, circa 1980

	Percent histologically verified		*Percent known from death certificate only*		*Mortality-incidence ratio*	
Area	*Male*	*Female*	*Male*	*Female*	*Male*	*Female*
North America[1]	80+	80+	5	4	0.70	0.60
Shanghai	20	15	50	60	0.96	0.57
Japan	40	30	40	45	0.93	0.93
Geneva	90	90	2	4	0.88	0.91
Scotland	60	60	11	14	0.81	0.78
Victoria, Australia	70	70	8	9	0.84	0.93

[1] United States and Canada only.

Table F. Rate of 5-year relative survival for persons with colon cancer, by age, stage, and sex: Norway, 1968–75

Stage and sex	*0–54 years*	*55–74 years*	*75 years and over*
Localized		Rate	
Male	0.77	0.69	0.60
Female	0.79	0.71	0.56
Regional spread			
Male	0.48	0.42	0.35
Female	0.45	0.42	0.36
Distant spread			
Male	0.05	0.04	0.08
Female	0.08	0.06	0.05

SOURCE: The Cancer Registry of Norway. Survival of cancer patients: Cases diagnosed in Norway, 1968–1975. Oslo: Norwegian Cancer Registry. 1980.

stomach, lung, and large bowel cancer has improved very little over the past decades (10).

The world cancer burden

Parkin et al. (11) estimated the global cancer burden around 1980 in terms of numbers of cases of cancer. These estimates were based on incidence and mortality data, when available, and on relative frequency, usually based on series of histologically diagnosed cancers, for the very large parts of the world without such data (figure 1). The top 10 ranking cancers are given in table H. It will be seen from figures 7–10 that the cancer patterns are quite different for the 4 of the 24 demographic regions recognized by the United Nations (U.N.) that are presented.

Not only are patterns different, but the degree of

Table G. Rate of 5-year relative survival for persons with breast cancer, by stage and age: Norway, 1968–75

Age	*All cases*	*Stage I*	*Stage II*	*Stage III*	*Stage IV*
			Number		
Total cases	10,591	4,743	3,305	772	912
			Rate		
All ages	0.67	0.86	0.58	0.46	0.12
0–44 years	0.72	0.90	0.60	0.48	0.14
45–54 years	0.71	0.89	0.62	0.47	0.16
55–74 years	0.65	0.86	0.56	0.48	0.12
75 years and over	0.58	0.76	0.48	0.40	0.09

SOURCE: The Cancer Registry of Norway. Survival of cancer patients: Cases diagnosed in Norway, 1968–1975. Oslo: Norwegian Cancer Registry. 1980.

Table H. Number and percent of the 10 most frequent cancers worldwide, by sex and site of cancer: 1980

Sex and site of cancer	*Number in thousands*	*Percent*
Male		
1. Lung	513.6	15.8
2. Stomach	408.8	12.6
3. Colon/rectum	286.2	8.8
4. Mouth/pharynx	257.3	7.9
5. Prostate	235.8	7.3
6. Esophagus	202.1	6.2
7. Liver	171.7	5.3
8. Bladder	167.7	5.2
9. Lymphoma	139.9	4.3
10. Leukemia	106.9	3.3
Female		
1. Breast	572.1	18.4
2. Cervix	465.6	15.0
3. Colon/rectum	285.9	9.2
4. Stomach	260.6	8.4
5. Corpus uteri	148.8	4.8
6. Lung	146.9	4.7
7. Ovary	137.6	4.4
8. Mouth/pharynx	121.2	3.9
9. Esophagus	108.2	3.5
10. Lymphoma	98.0	3.2

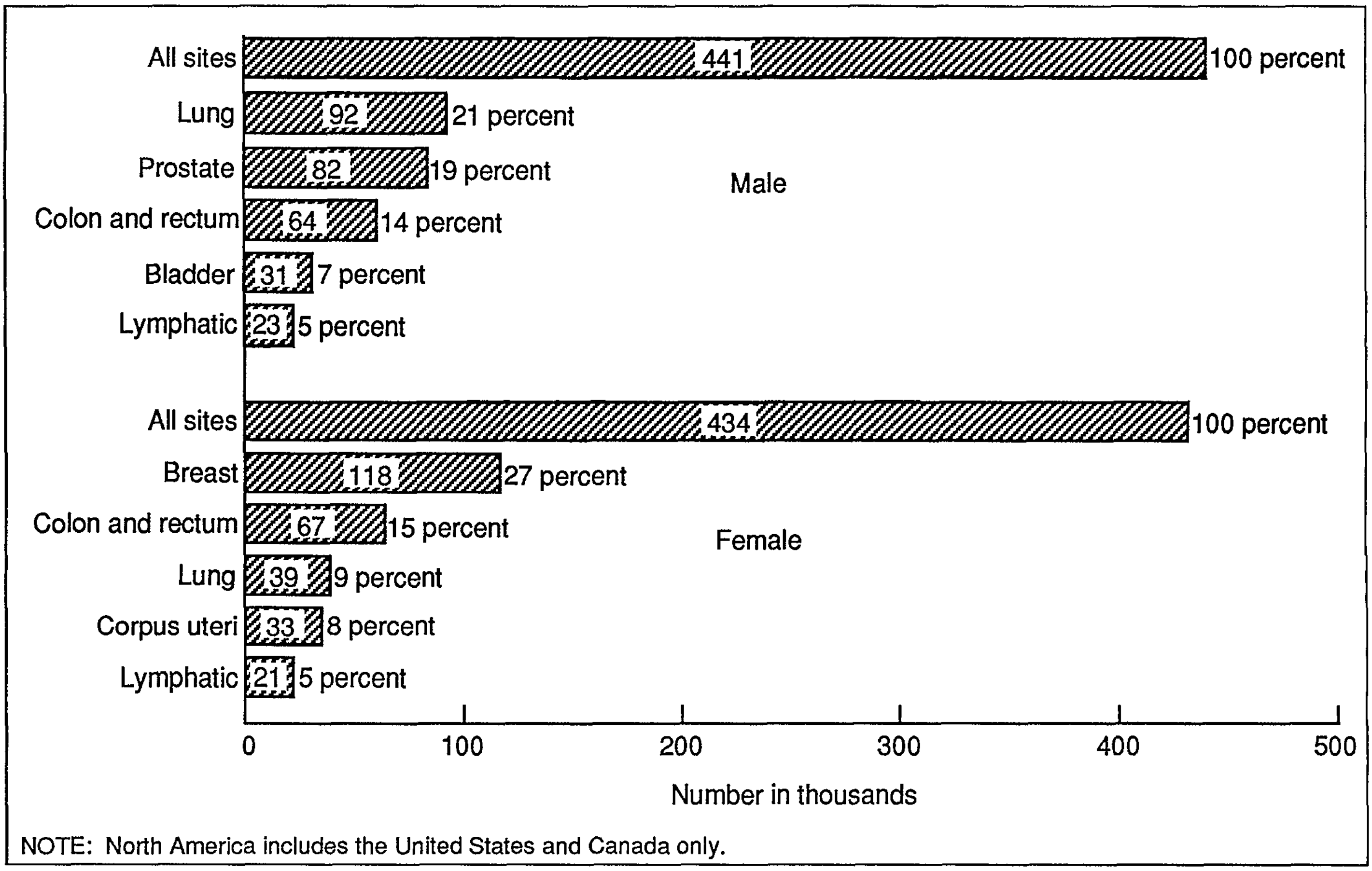
SOURCE: Parkin DM, Läära E, Muir CS. Estimates of the worldwide frequency of sixteen major cancers in 1980. Int J Cancer 41:184–97. 1988.

sophistication of medical services required to diagnose these cancers varies considerably. Cancers of the mouth and pharynx can be readily diagnosed with fairly simple apparatus, as can those of the cervix; cancers of the breast are also readily accessible. The detection of prostate and ovary cancer and the accurate diagnosis of lymphoma demand another level of complexity and expertise, a further factor to be considered when comparing data from different parts of the world.

The effect of aging populations: The future

While somewhat outside the scope of this paper, it is nonetheless sobering to examine what is likely to happen in the future. The increasing average age of the many populations means that, should present cancer patterns and levels of risk be "frozen," the total cancer burden would nonetheless substantially increase. The U.N. in 1986 (12) calculated that there would be a 15-percent increase in total population in southern Europe between 1975 and the year 2000. Further, the proportion of the male population over 60 years of age would increase by 24 percent; the female, by 27 percent, in contrast to northern Europe, where population size and age structure were considered to be virtually stable. The ratio of the cancer burden in the year 2000 compared with that in 1975, assuming that the projected population rises and change in age structure take place and taking into account likely secular trends in cancer risk, has been assessed (13). While the numbers of northern Europe would show little change, there would be increases of 60–80 percent in eastern and southern Europe, these increases being smaller, although still substantial (10–30 percent), in the western part of that continent.

The World Health Organization (14) has recently examined the impact of demographic trends on health, publishing the median age for the world as a whole and for major demographic areas for the years 1950, 1975, and 1985, with projections for 2000 and 2025. This



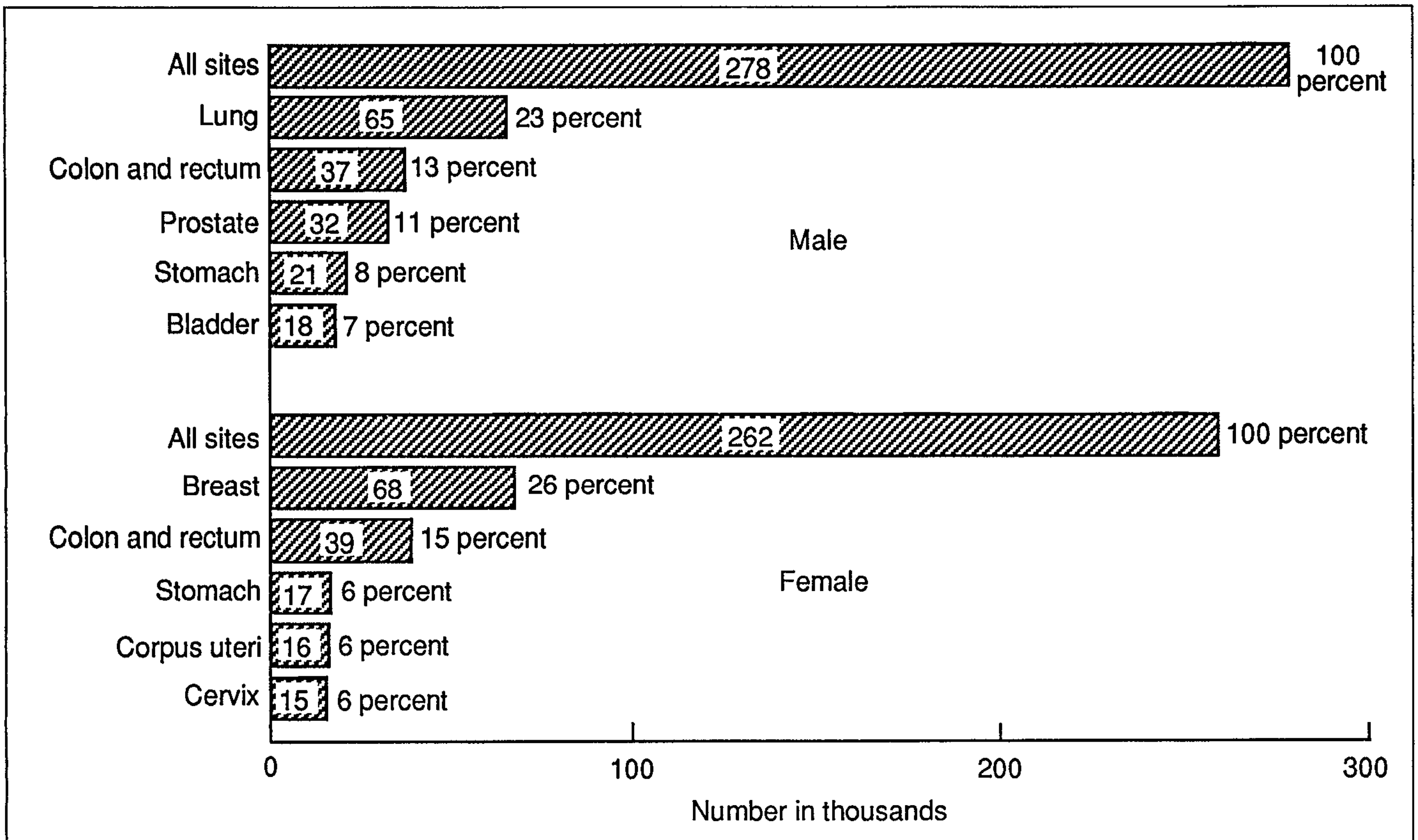
NOTE: North America includes the United States and Canada only.

Figure 7. Number and percent of cases of the 5 most frequent cancers, by sex and cancer site: North America, 1980

figure is perhaps not as informative as the dependency ratio (defined as the number of persons under 15 years and of those 65 years and over, divided by the number of persons aged 15–64 years and multiplied by 100), which provides an indicator of the relative sizes of the non-working-age and working-age populations. Noting that at present two out of five persons in the world are urban residents, the proportion of those living in cities is projected to exceed 50 percent sometime during the first decade of the 21st century. While this concentration of the population should, in theory, make it easier for the elderly in the population to have access to good-quality medical care, this is currently not so for many megacities.

Changes in cancer risk

Changes in the risk of cancer in either direction are often first observed in younger age groups, as change in exposures is frequently a reflection of changes in the habits of a particular generation or birth cohort (15,16). As most cancers are the result of lifelong exposures, the risk of developing malignant disease after the age of 65 (and it will be recalled that there are normally as many cancers at ages 65–74 as there are from birth to 64) is probably largely already determined on reaching the age of 65 and is frequently characteristic for a given birth cohort. Thus, successive birth cohorts, on reaching, say, the age of 65 in many fair-skinned populations, have higher age-specific incidence rates for malignant melanoma than those born previously, rates that in turn are lower at the same age in those born subsequently. While it would currently appear very difficult to undo or reverse the cellular damage already sustained on reaching older ages, nonetheless, for the initiated cells to be transformed, it is believed that prolonged exposure to promoting agents is needed. If exposure to promoters can be avoided or reduced (and, indeed, antipromoters given), then the malignant transformation may not take place or may be delayed. Although Berenblum (17) stated that "interference with the promoting phase of carcinogenesis would seem to offer the best prospects



NOTE: Western Europe includes Austria, Belgium, France, the Federal Republic of Germany, Luxembourg, The Netherlands, and Switzerland.

Figure 8. Number and percent of cases of the 5 most frequent cancers, by sex and cancer site: Western Europe, 1980

for cancer prevention, if only because the promoting phase covers most of the latent period of carcinogenesis (which, in humans, may be 30 years or more)," it is only recently that extensive work, including search for short-term tests of promoting activity, has begun on this topic. It is currently believed that fresh fruits and vegetables may contain antipromoters, and their use by elderly persons should be encouraged. Unfortunately, dietary habits are often set at a much younger age, and it may not be easy to persuade older persons of the need to change. In terms of lung cancer risk, it is probable that ceasing to smoke would be helpful at any age. The beneficial effect of small quantities of alcohol need not be abandoned.

Comment

Even in the absence of change in cancer risk, increasing longevity will result in many more cancers in elderly persons to be diagnosed and treated. The results of therapy for common cancers, such as large bowel, lung, and stomach, show little improvement. The burden of medical care budgets, with an ever-decreasing productive population base, is likely to be such that no nation, however prosperous, will be able to cope. Prevention is surely to be preferred. Tobacco is responsible for at least 10 percent of the global cancer burden and viruses (liver and cervix uteri) for another 10 percent (18). The major enigma remains the etiology of cancers of breast, large bowel, and prostate: It is here that research effort should be concentrated. Rational prevention is easier when cause is known.

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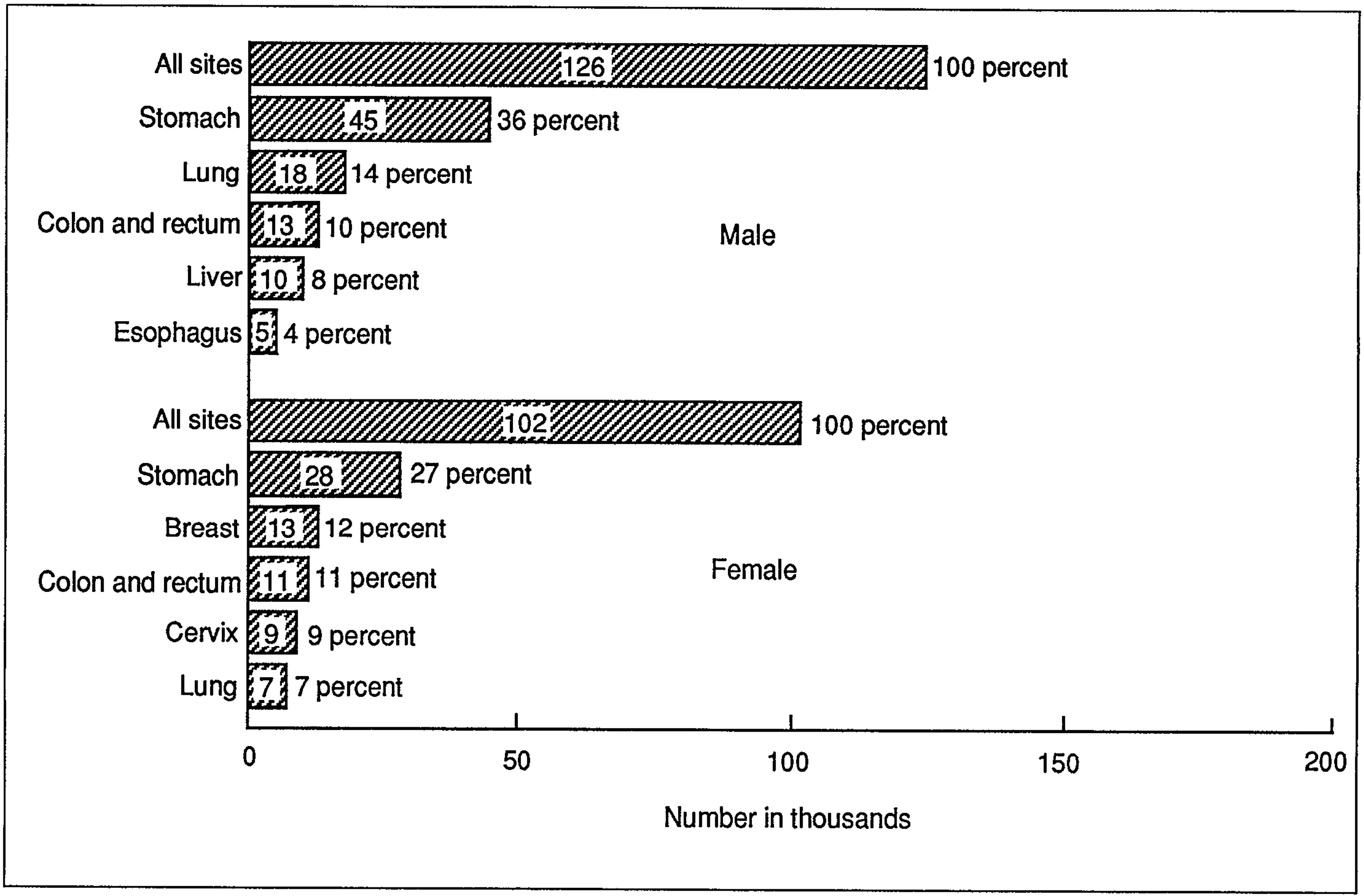

Figure 9. Number and percent of cases of the 5 most frequent cancers, by sex and cancer site: Japan, 1980

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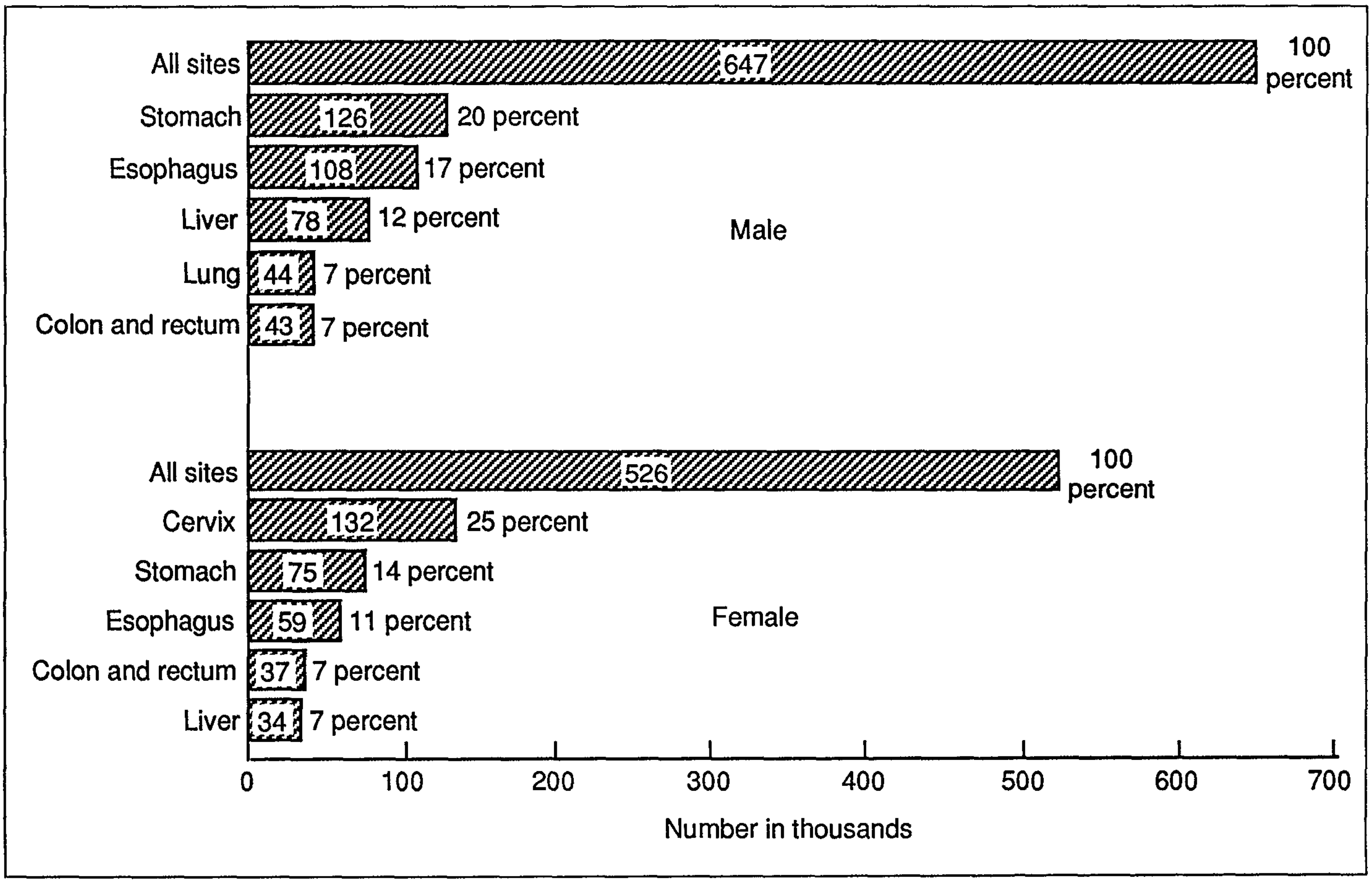

Figure 10. Number and percent of cases of the 5 most frequent cancers, by sex and cancer site: China, 1980

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Chapter 5
Causes of death among the elderly: Information from the death certificate

by Harry M. Rosenberg, Ph.D., Chief, Mortality Statistics Branch; Frances Chevarley, Ph.D., Eve Powell-Griner, Ph.D., and Kenneth Kochanek, M.A.; and Manning Feinleib, M.D., Dr.P.H., Director, National Center for Health Statistics

The leading causes of death among the elderly in the United States are heart disease, cancer, and stroke. In 1986, these three conditions accounted for 41.6, 20.7, and 8.7 percent of deaths, respectively, to persons 65 years of age and over, based on the causes of death reported by physicians on death certificates and collected through the national vital statistics system (1) (table A).

Such a health profile of the elderly, based on cause-of-death information from the death certificate, reflects the ready availability of mortality data from the national vital statistics system, as well as its uniqueness as a health data source that is comparable at the national, State, and local levels (2). Cause-of-death data from the death certificate are a key statistical resource for describing the health problems of the general population as well as the health of the elderly (3).

Two questions arise in using these data for describing and studying the health of older persons. The first, not limited to the elderly population, is the persistent issue of the validity of cause of death reported on the death certificate. This has been examined over the years in numerous studies, which are summarized in an annotated bibliography prepared by the National Center for Health Statistics (NCHS) (4) and in other studies (5,6). It was also the focus of a recent workshop convened under the auspices of the U.S. National Committee on Vital and Health Statistics (7). A related question, noted by others (8,9), is the ability of the medical certification on the death certificate to capture the complexity of the morbid process leading to death in elderly persons, who often have several concurrent chronic conditions, any or a combination of which could lead to death.

Table A. Number and percent distribution of deaths for the 10 leading causes of death for persons 65 years of age and over in rank order: United States, 1986

Rank order	*Cause of death*[1]	*Number*	*Percent distribution*
All causes		1,488,161	100.0
1	Diseases of heart 390–398, 402, 404–429	619,009	41.6
2	Malignant neoplasms, including neoplasms of lymphatic and hematopoietic tissues 140–208	308,184	20.7
3	Cerebrovascular diseases 430–438	129,357	8.7
4	Chronic obstructive pulmonary diseases and allied conditions 490–496	62,649	4.2
5	Pneumonia and influenza 480–487	60,801	4.1
6	Diabetes mellitus 250	27,256	1.8
7	Accidents and adverse effects E800–E949	25,134	1.7
	Motor vehicle accidents E810–E825	6,410	0.4
	All other accidents and adverse effects E800–E-807, E826–E949	18,724	1.3
8	Atherosclerosis 440	21,555	1.4
9	Nephritis, nephrotic syndrome, and nephrosis 580–589	17,851	1.2
10	Septicemia 038	14,821	1.0
11	All other causes ...Residual	201,544	13.5

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[1] Includes code numbers of Ninth Revision International Classification of Diseases.

SOURCE: National Center for Health Statistics. National Vital Statistics System. 1986.

The second question is the extent to which cause-of-death patterns really reflect patterns of illness and serious disability in the population; in other words, how good a proxy mortality is for morbidity. This issue, which has been raised by others (10), accounts in part for the creation of the national health surveys conducted by NCHS.

The studies that examine these broad questions do so by comparing information from the death certificate with another source. In the case of studies of "validity" of cause of death reported on the death certificate, the comparisons are between the report on the death certificate and a report of clinical findings, autopsy, or correlation of clinical and pathological findings. To make such comparisons, a variety of methodologies have been used, including using a panel of physicians to construct a hypothetical death certificate from available diagnostic information and then comparing the hypothetical certificate with the death certificate that was actually filed for the same decedent. The feasibility of adapting such a methodology for national evaluations of cause of death on the death certificate is currently being explored by NCHS (11).

In this paper, a somewhat similar approach is used. Data on cause of death from the death certificate are compared with those from another source of information to enhance our understanding of what cause-of-death statistics, particularly those for the elderly population, really mean.

The independent source is a survey of informants who were asked to respond to questions about the health history of the decedent. By correlating the responses from the survey with the reported cause of death, the study provides information on both the extent to which the death certificate reflects aspects of the medical history of the decedent and, further, whether this correlation is stronger for some age groups than others. Because the independent source of information is not clinical or autopsy information or physicians' independent assessment of cause of death, results of this study should not be construed as measures of the validity of cause of death on the death certificate in the classical sense, but rather as indicators of how well cause of death on the death certificate reflects prior medical history and whether this association changes with age of the decedent.

The paper also addresses two related questions bearing on the nature of the cause of death reported on the death certificate. It examines statistical evidence for the association between quality and completeness of reporting cause of death and age of decedent, using a cause-of-death classification category that can represent the adequacy of the medical certification on the death certificate. The paper also uses multiple cause-of-death data to ascertain whether medical certifiers report more medical conditions at the time of death for elderly decedents than for younger decedents. Such a finding would be consistent with Kohn's description of death in the elderly as "an increasing collection of diseases" (9), and it would suggest that medical certifiers of cause of death are attempting to record some of the increasing complexity of the morbid process leading to death with increasing age of decedent.

Methods

Death certificates and survey comparisons

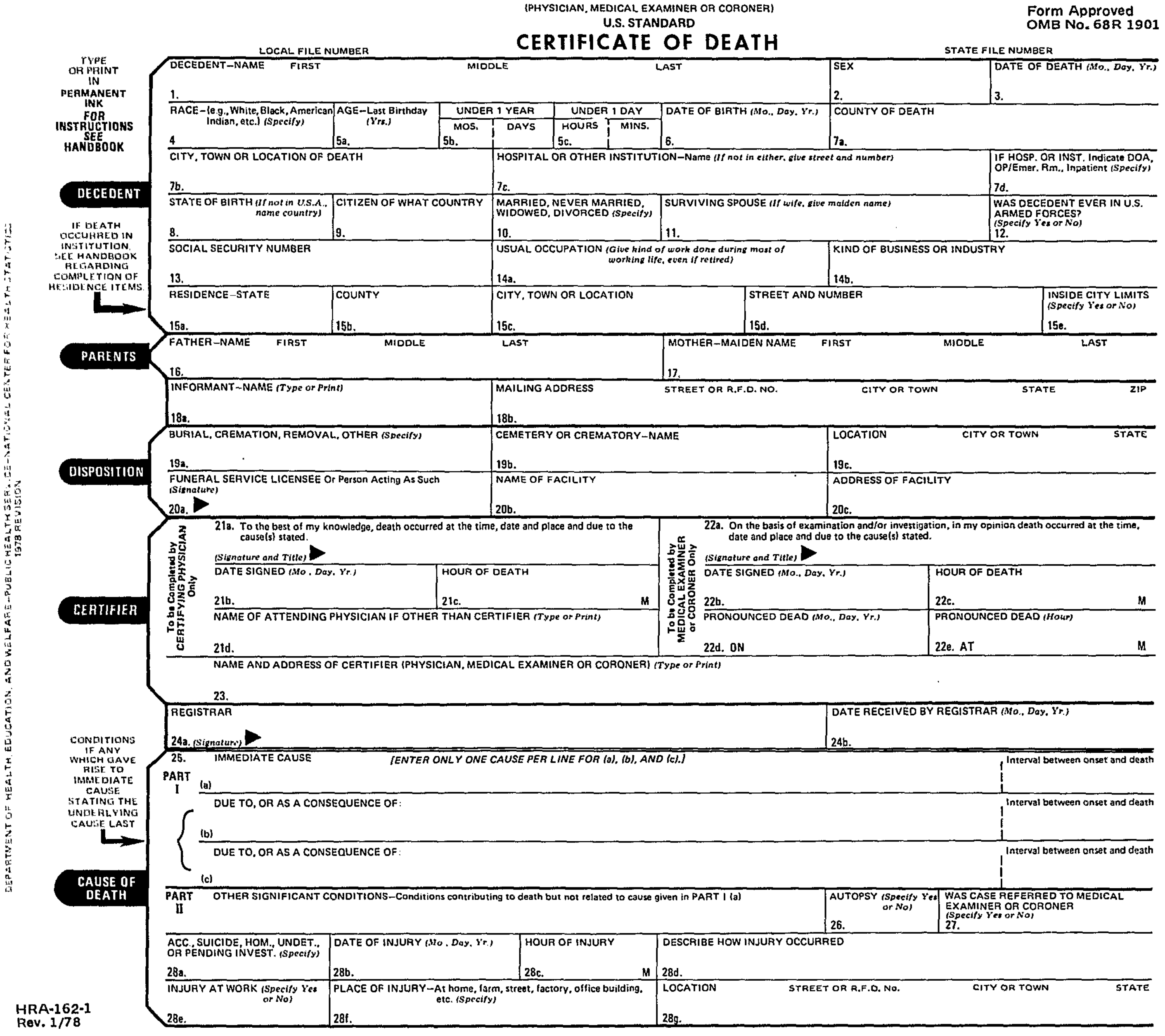
To compare cause of death and medical history for decedents, two sources of NCHS data were used: (a) underlying cause-of-death data for U.S. deaths in 1986 compiled from the Current Mortality Sample, a 10-percent systematic sample of death certificates received each month in the vital statistics offices in the 50 States, the District of Columbia, and the independent registration area of New York City and coded by NCHS (12) and (b) medical data from the 1986 National Mortality Followback Survey (NMFS), a survey used to augment information from a large sample of U.S. death certificates for 1986 (13). Comparisons were made between underlying cause of death reported on death certificates and selected information on the health history of the same decedents from the NMFS. Below are described the sources of the data—mortality data from the national vital statistics registration system and medical history information from the 1986 NMFS—and the principal analytical procedure, contingency table analysis.

Cause of death—Mortality data in comparisons between the underlying cause on the death certificate and medical history from the 1986 NMFS are based on underlying cause-of-death coding procedures used by

NCHS for the Current Mortality Sample (12). The single underlying cause of death is from the medical conditions reported on the death certificate by the attending physician, medical examiner, or coroner as contributing to death (figure 1). The underlying cause is selected using a set of medical coding rules specified by the World Health Organization (WHO) in the Ninth Revision International Classification of Diseases (ICD–9) (14), which ensure consistency in coding, particularly when medical certifications are reported incompletely, incorrectly, or ambiguously.

The underlying cause is defined as "(a) the disease or injury which initiated the train of morbid events leading directly to death, or (b) the circumstances of the accident or violence which produced the fatal injury" (14). The sequence of conditions can be etiological as well, as when there is no direct causation but an antecedent condition is believed to have prepared the way for the direct cause by damage to tissues or impairment of function even after a long interval.

The use of a single underlying cause of death to characterize each death is an obvious oversimplification of the morbid process that culminated in death, particularly deaths resulting from natural causes and at advanced ages. The widespread and institutionalized use of underlying cause-of-death information represents adoption of the WHO procedures for mortality



DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE—PUBLIC HEALTH SERVICE—NATIONAL CENTER FOR HEALTH STATISTICS
1978 REVISION

(PHYSICIAN, MEDICAL EXAMINER OR CORONER)
U.S. STANDARD
CERTIFICATE OF DEATH

Form Approved
OMB No. 68R 1901

LOCAL FILE NUMBER
STATE FILE NUMBER

TYPE OR PRINT IN PERMANENT INK
FOR INSTRUCTIONS SEE HANDBOOK

DECEDENT

DECEDENT–NAME FIRST MIDDLE LAST 1.
SEX 2.
DATE OF DEATH *(Mo., Day, Yr.)* 3.
RACE–(e.g., White, Black, American Indian, etc.) *(Specify)* 4
AGE–Last Birthday *(Yrs.)* 5a.
UNDER 1 YEAR MOS. DAYS 5b.
UNDER 1 DAY HOURS MINS. 5c.
DATE OF BIRTH *(Mo., Day, Yr.)* 6.
COUNTY OF DEATH 7a.
CITY, TOWN OR LOCATION OF DEATH 7b.
HOSPITAL OR OTHER INSTITUTION–Name *(If not in either, give street and number)* 7c.
IF HOSP. OR INST. Indicate DOA, OP/Emer. Rm., Inpatient *(Specify)* 7d.
STATE OF BIRTH *(If not in U.S.A., name country)* 8.
CITIZEN OF WHAT COUNTRY 9.
MARRIED, NEVER MARRIED, WIDOWED, DIVORCED *(Specify)* 10.
SURVIVING SPOUSE *(If wife, give maiden name)* 11.
WAS DECEDENT EVER IN U.S. ARMED FORCES? *(Specify Yes or No)* 12.
SOCIAL SECURITY NUMBER 13.
USUAL OCCUPATION *(Give kind of work done during most of working life, even if retired)* 14a.
KIND OF BUSINESS OR INDUSTRY 14b.

IF DEATH OCCURRED IN INSTITUTION, SEE HANDBOOK REGARDING COMPLETION OF RESIDENCE ITEMS.

RESIDENCE–STATE 15a.
COUNTY 15b.
CITY, TOWN OR LOCATION 15c.
STREET AND NUMBER 15d.
INSIDE CITY LIMITS *(Specify Yes or No)* 15e.

PARENTS

FATHER–NAME FIRST MIDDLE LAST 16.
MOTHER–MAIDEN NAME FIRST MIDDLE LAST 17.

INFORMANT–NAME *(Type or Print)* 18a.
MAILING ADDRESS STREET OR R.F.D. NO. CITY OR TOWN STATE ZIP 18b.

DISPOSITION

BURIAL, CREMATION, REMOVAL, OTHER *(Specify)* 19a.
CEMETERY OR CREMATORY–NAME 19b.
LOCATION CITY OR TOWN STATE 19c.
FUNERAL SERVICE LICENSEE Or Person Acting As Such *(Signature)* 20a. ▶
NAME OF FACILITY 20b.
ADDRESS OF FACILITY 20c.

CERTIFIER

To be Completed by CERTIFYING PHYSICIAN Only

21a. To the best of my knowledge, death occurred at the time, date and place and due to the cause(s) stated.
(Signature and Title) ▶
DATE SIGNED *(Mo., Day, Yr.)* 21b.
HOUR OF DEATH 21c. M
NAME OF ATTENDING PHYSICIAN IF OTHER THAN CERTIFIER *(Type or Print)* 21d.

To be Completed by MEDICAL EXAMINER or CORONER Only

22a. On the basis of examination and/or investigation, in my opinion death occurred at the time, date and place and due to the cause(s) stated.
(Signature and Title) ▶
DATE SIGNED *(Mo., Day, Yr.)* 22b.
HOUR OF DEATH 22c. M
PRONOUNCED DEAD *(Mo., Day, Yr.)* 22d. ON
PRONOUNCED DEAD *(Hour)* 22e. AT M

NAME AND ADDRESS OF CERTIFIER (PHYSICIAN, MEDICAL EXAMINER OR CORONER) *(Type or Print)* 23.

REGISTRAR 24a. *(Signature)* ▶
DATE RECEIVED BY REGISTRAR *(Mo., Day, Yr.)* 24b.

CAUSE OF DEATH

CONDITIONS IF ANY WHICH GAVE RISE TO IMMEDIATE CAUSE STATING THE UNDERLYING CAUSE LAST

25. IMMEDIATE CAUSE *[ENTER ONLY ONE CAUSE PER LINE FOR (a), (b), AND (c).]*
PART I (a) — Interval between onset and death
DUE TO, OR AS A CONSEQUENCE OF: (b) — Interval between onset and death
DUE TO, OR AS A CONSEQUENCE OF: (c) — Interval between onset and death
PART II OTHER SIGNIFICANT CONDITIONS–Conditions contributing to death but not related to cause given in PART I (a)
AUTOPSY *(Specify Yes or No)* 26.
WAS CASE REFERRED TO MEDICAL EXAMINER OR CORONER *(Specify Yes or No)* 27.
ACC., SUICIDE, HOM., UNDET., OR PENDING INVEST. *(Specify)* 28a.
DATE OF INJURY *(Mo., Day, Yr.)* 28b.
HOUR OF INJURY 28c. M
DESCRIBE HOW INJURY OCCURRED 28d.
INJURY AT WORK *(Specify Yes or No)* 28e.
PLACE OF INJURY–At home, farm, street, factory, office building, etc. *(Specify)* 28f.
LOCATION STREET OR R.F.D. No. CITY OR TOWN STATE 28g.

HRA-162-1
Rev. 1/78

Figure 1. U.S. Standard Certificate of Death (1989 version)

data collection and tabulation, especially at the international level—procedures that at once embody simplicity, logic, and recognition of the inherent limitations of the medical certification of cause of death on the death certificate. The limitations, in turn, reflect the dual nature of the death certificate, which is, on the one hand, a concise legal document required for disposition of a body and settlement of legal and financial matters attendant to death and, on the other hand, a statistical document that in limited space summarizes the facts of death. The procedures assume that, for public health purposes, a single cause of death for each death may be a sufficient and possibly the only available descriptor of the medical conditions responsible for death.

To some degree the dual purposes of the document result in a competition in which pressures for expeditious disposal of the body tend to outweigh those for detailed, multifactorial, and well-substantiated diagnostic information on cause of death. Further limiting the information on cause of death is the known difficulty of ascribing a natural death to a single cause, particularly for persons at advanced ages (8). Some of the limitations of underlying cause-of-death data can be addressed by using multiple cause-of-death data, that is, data on all of the conditions reported on death certificates (15). Multiple-cause data are not a panacea, however. They are subject to, and may be more seriously affected by, the limitations of the present WHO form used to certify causes of death, which is designed to elicit a single underlying cause of death, not multiple causes.

National Mortality Followback Survey—The other major source of information in this study is the 1986 NMFS (13). The NMFS is designed to fill a key research gap by supplementing the information obtained from death records in the vital statistics mortality file with information on important characteristics of the decedent that may have affected mortality. These characteristics include patterns of lifetime behavior, health services experienced prior to death, socioeconomic status, and many other aspects of life that affect when and how death occurs.

The NMFS is a 1-percent stratified random sample nationally representative of adults 25 years of age and over who died in the United States during 1986. The sample, which was selected from the Current Mortality Sample of NCHS, consists of data for 18,753 decedents. The Current Mortality Sample is the basis for provisional estimates of mortality by underlying cause of death and selected demographic characteristics for the United States published monthly and annually (12). The survey data on social, demographic, and behavioral characteristics of decedents were obtained from a mailed questionnaire or interview with the person identified on the death certificate as the informant. The response rate for the 1986 NMFS was 89 percent.

Information on the decedents' age, race, sex, and underlying cause of death was obtained from statistical records of the Current Mortality Sample. The survey data were weighted to produce unbiased estimates. The weight for each sample certificate is the product of the reciprocal of the probability of sample selection and an adjustment for nonresponse. Weighted data are used in this study. While all 50 States and the District of Columbia granted approval for use of a sample of their death certificates in the NMFS, the State of Oregon was not included because of respondent consent requirements. Thus, the data in this study are representative of deaths in the United States, excluding Oregon.

Twelve items pertaining to the health conditions and history of the decedent were available for this study. These items, shown in appendix I, concerned whether the decedent had ever had hypertension; a heart attack; angina pectoris; stroke; Alzheimer's disease or other chronic brain syndrome; other mental, nervous, or emotional problems; diabetes; cancer; asthma; other lung conditions; or cirrhosis of the liver. The analysis was limited to six conditions—hypertension, heart attack, stroke, cancer, diabetes, and asthma—for which sample numbers in the survey were sufficiently large.

Comparison of survey and death certificate information—The presence of each of these conditions in the health history of the decedent according to survey data was compared with selected underlying causes of death from the death certificate. The categories of cause of death were selected on the basis of their similarity to the survey condition or because of a known etiological relationship, as follows:

- Hypertension on survey was compared separately with two different broad cause-of-death categories: Diseases of heart and Major cardiovascular diseases.
- Heart attack was compared with three categories: Deaths related to heart attacks (a specially constructed category comprising International Classification of Diseases (ICD) codes that include such terms as "heart attack," "heart attack, 8 weeks or more," "healed or old heart attack," "coronary failure," "cardiac arrest," and "cardiovascular disease, unspecified"); Diseases of heart; and Major cardiovascular diseases.
- Stroke was compared with two categories: Cerebrovascular diseases and Major cardiovascular diseases.
- Diabetes was compared with two categories: Diseases of heart and Major cardiovascular diseases.
- Cancer was compared with two categories of Malignant neoplasms.
- Asthma was compared with Chronic obstructive pulmonary disease (COPD) and allied conditions.

The questions on the NMFS related to these medical conditions and the names of the compared causes of death with ICD–9 category names and code numbers are shown in appendix II.

Because older individuals generally have more morbid conditions present from which to select the underlying cause of death for the death certificate, it was hypothesized that the associations between cause-of-death categories would diminish by age. Therefore, each association was examined by age, as it was conjectured that the underlying cause-of-death information is less informative for older persons than for younger persons.

The degree of association between the medical history obtained in the NMFS and the cause of death on the death certificate is measured using the "odds ratio" applied to data arrayed as contingency tables (16,17). In table B is shown the construction of an odds ratio for cardiovascular disease (CVD) as an underlying cause of death on the death certificate and a reported history of hypertension from the NMFS, by age of decedent. Thus, for the age group 25–64 years, 46.8 percent of persons dying from CVD were reported as having a history of hypertension, compared with 53.2 percent of persons dying from other causes who also were reported as having a history of CVD.

The ratio of these percents—46.8 to 53.2, or 0.88—represents the "odds" of dying from CVD rather than another disease for decedents in this age group reported as having a history of hypertension. This ratio of 0.88 can be compared with the ratio of the percent dying of CVD (23.7 percent) or other causes (76.3 percent) when there was no reported history of hypertension, which is 23.7/76.3, or 0.31. The odds ratio is the ratio of the first odds quantity, 0.88, to the second odds quantity, 0.31—that is, 0.88/0.31, or 2.83. This odds ratio means that a history of hypertension increased the odds about three times that a person aged 25–64 years died of CVD rather than another cause of death in 1986. Data from which odds ratios were constructed are shown in appendix III.

Diagnostic completeness

Data on diagnostic completeness are based on final mortality data for all deaths occurring to residents of the United States in 1985, as published in *Vital Statistics of the United States, 1985,* Volume II, Part A (18). Final data for 1986 were not readily available for this analysis. Diagnostic completeness was measured using the number of deaths assigned to ICD–9 category Nos. 780–799, Symptoms, signs, and ill-defined conditions. To this category are assigned deaths whose underlying cause is characterized by such terms as "natural causes," "stopped breathing," or "old age." More generally, the category includes a range of medical terms and conditions that cannot be classified to other parts of the ICD that are more precise with respect to anatomical characterization or disease.

Multiple cause-of-death analysis

The multiple cause-of-death analysis is also based on final mortality data for all U.S. resident deaths occurring in 1985 (18). Multiple causes of death represent all conditions reported by the medical certifier as contributing to death, regardless of whether they were selected as the underlying cause (19). The source of the multiple-cause data are the multiple

Table B. Number and percent of deaths and odds and odds ratio of dying from Cardiovascular disease (death certificate compared with survey reports of Hypertension), by age: United States, 1986

	Age and cause of death on death certificate							
	25–64 years		*65–74 years*		*75–84 years*		*85 years and over*	
History of hypertension on survey	*Cardiovascular diseases*	*Other*	*Cardiovascular diseases*	*Other*	*Cardiovascular diseases*	*Other*	*Cardiovascular diseases*	*Other*
	Number							
Yes	93,150	105,990	128,060	109,030	159,460	112,780	118,800	58,540
No	68,590	221,060	80,140	135,340	122,600	136,560	128,190	88,030
Unknown	6,990	16,920	11,920	11,640	16,690	15,160	17,410	10,560
	Percent							
Yes	46.8	53.2	54.0	46.0	58.6	41.4	67.0	33.0
No	23.7	76.3	37.2	62.8	47.3	52.7	59.3	40.7
Unknown	29.2	70.8	50.6	49.4	52.4	47.6	62.2	37.8
	Odds							
Yes	0.88		1.17		1.41		2.03	
No	0.31		0.59		0.90		1.46	
Unknown	0.41		1.02		1.10		1.65	
Odds ratio	2.83		1.98		1.57		1.39	

NOTE: Calculation of odds ratio:

	With specified cause of death	Without specified cause of death
With mention of condition	A	B
Without mention of condition	C	D

$$\text{Odds ratio} = \frac{A/B}{C/D} = \frac{AD}{BC}$$

SOURCE: National Center for Health Statistics. National Mortality Followback Survey. 1986.

cause-of-death public use data tapes for 1985 (20). Multiple-cause data for 1986 were not available for the analysis. In this analysis each medical condition reported on the death certificate was counted once; for example, if for the same death, Coronary atherosclerosis and Aneurysm of heart were reported, each would be counted once. If a physician reported three nonredundant conditions in Part I and two conditions in Part II of the certificate, this death would be tabulated as having a total of five reported conditions. Excluded from the analysis were external causes, that is, conditions coded to trauma such as accidents, homicides, and suicides; however, for these deaths the nature of trauma, such as fracture, was counted as a condition.

Results

Death certificate and survey comparisons

Comparison of cause of death on the death certificate with medical history information from the NMFS can shed light on the degree to which cause of death is associated retrospectively with reported medical history of the decedent. One can also see if the correlation between diagnostic information from the death certificate and from the survey changes with the age of the decedent. For only one cause of death in the NMFS—cancer—was the informant actually asked the main cause of death of the decedent. The reply can be used as a rough indicator of the validity of the cause of death reported on the death certificate. However, the respondent's answer cannot be viewed as a rigorous standard for assessing the reported cause of death on the death certificate; for that, a clinical or pathological determination assessed by a physician is required.

Comparison between survey and death certificate information is shown for selected causes of death in tables C–F and figures 2–8 and is discussed below for major cardiovascular diseases, heart attacks, cancer, stroke, and COPD, conditions for which the NMFS reported medical history and for which the sample size was sufficient to ensure statistically reliable measures.

Major cardiovascular diseases—In table C is shown the relationship between CVD reported on the death certificate and related medical history reported from the NMFS. Within the broad category CVD is the subcategory Diseases of heart and a more specific component called Heart attack related in this study. Compared with CVD on the death certificate are the medical items on the survey for hypertension, heart attack, diabetes, and stroke.

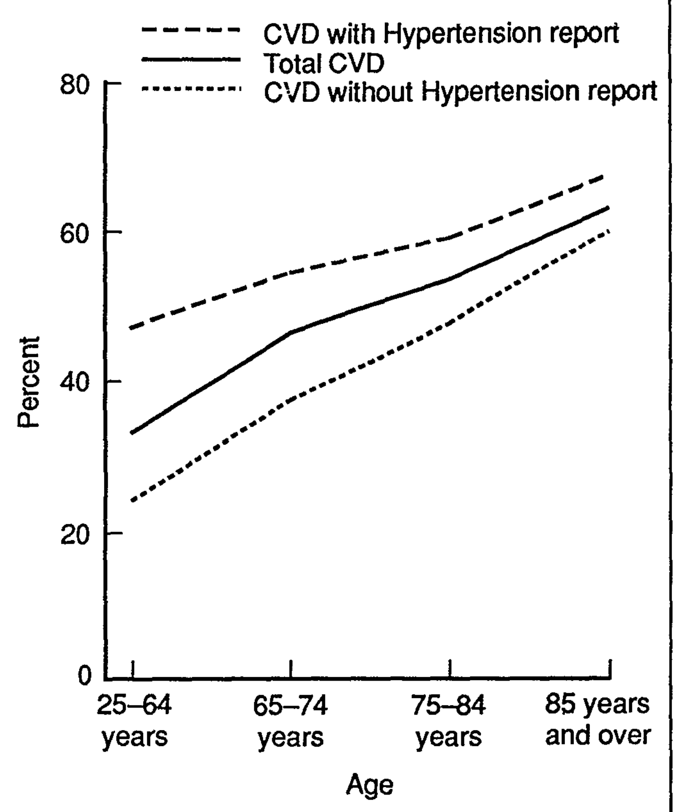
CVD accounts for a large share of the deaths annually in the United States; of the 2,105,361 deaths in the United States in 1986, a total of 968,240 were due to these conditions. In 1986, CVD was selected as the underlying cause of death for 48.2 percent of the decedents who were 25 years of age and over. In 1986, CVD's prevalence as an underlying cause of death increased gradually with age, from about one-third (32.9 percent) of deaths at ages 25–64 years to two-thirds (62.7 percent) at ages 85 and over (table C). The first association examined is between the CVD as the underlying cause of death and a reported history of high blood pressure, or hypertension. Hypertension, according to the NMFS, is a highly prevalent condition: 44.9 percent of the decedents 25 years of age and over in 1986 had this condition at some point in their life, while 49.7 percent were reported as never having had high blood pressure; for the remaining 5.4 percent, information about hypertension was not available (table B).

The data in table C show that the percent dying of CVD increases gradually with age for decedents both with and without a reported history of hypertension. For those with reported hypertension, the percent dying of CVD increased from 46.8 percent at ages 25–64 years to 67.0 percent at ages 85 years and over (figure 2); for those without, from 23.7 to 59.3 percent. The odds of dying from cardiovascular disease compared with other causes also increased with age for decedents regardless of their history of hypertension. For those with such a history, the odds increased from 0.88 at 25–64 years to 2.03 at 85 years and over (table C). For those without a history of hypertension, the odds increased more slowly, from 0.31 to 1.46. As a consequence of the differential rate of increase in the odds, the odds ratio—the measure chosen to represent

Table C. Percent of deaths and odds and odds ratios of dying from Cardiovascular disease (death certificate compared with survey reports of selected conditions), by age: United States, 1986

Underlying cause of death on death certificate with or without history of specified condition reported on survey	*Percent dying of Cardiovascular disease on death certificate*					*Odds and odds ratios*			
	25–64 years	*65–74 years*	*75–84 years*	*85 years and over*		*25–64 years*	*65–74 years*	*75–84 years*	*85 years and over*
Cardiovascular disease	32.9	46.2	53.0	62.7	Odds ratio	2.83	1.98	1.57	1.39
With Hypertension	46.8	54.0	58.6	67.0	Odds	0.88	1.17	1.41	2.03
Without Hypertension	23.7	37.2	47.3	59.3		0.31	0.59	0.90	1.46
Cardiovascular disease:					Odds ratio	7.58	4.65	3.37	1.67
With Heart attack	66.2	69.4	72.4	71.4	Odds	1.95	2.27	2.62	2.50
Without Heart attack	20.5	32.8	43.7	59.9		0.26	0.49	0.78	1.50
Cardiovascular disease:					Odds ratio	1.90	1.61	1.61	0.84
With Diabetes	45.4	55.7	62.7	59.3	Odds	0.83	1.26	1.68	1.46
Without Diabetes	30.5	43.8	51.1	63.4		0.44	0.78	1.04	1.73
Cardiovascular disease:					Odds ratio	2.12	1.61	2.00	1.82
With Stroke	47.8	54.8	64.8	71.7	Odds	0.91	1.21	1.84	2.53
Without Stroke	30.2	43.0	47.9	58.1		0.43	0.75	0.92	1.39

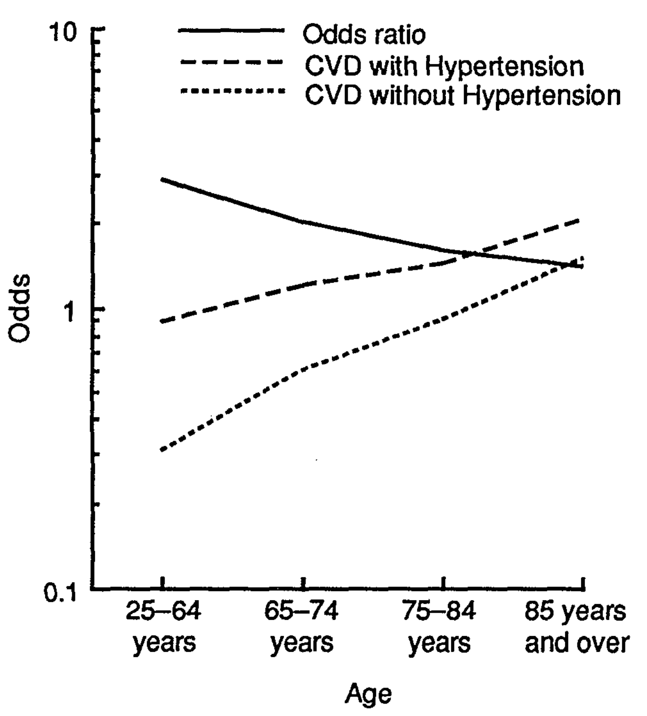
SOURCE: National Center for Health Statistics. National Mortality Followback Survey. 1986.



NOTE: CVD is cardiovascular disease.

SOURCE: National Center for Health Statistics. National Mortality Followback Survey. 1986.

Figure 2. Percent of deaths from Cardiovascular disease, survey reports of Hypertension and age: United States, 1986



NOTE: CVD is Cardiovascular disease.

SOURCE: National Center for Health Statistics. National Mortality Followback Survey. 1986.

Figure 3. Odds and odds ratio of dying from Cardiovascular disease (death certificate compared with survey reports of Hypertension), by age: United States, 1986

the association between CVD reported on the death certificate and a history of hypertension on the NMFS—diminishes from 2.83 to 1.39 with increasing age (table C and figure 3).

The relatively large odds ratio for the youngest age group represents a statistical association between a reported history of hypertension on the survey and the report of CVD as the underlying cause of death on the death certificate for this broad age group. However, for the oldest old—those aged 85 years and over—the odds ratio of close to 1.0 indicates essentially no relationship between CVD cause of death and a history of hypertension.

The association between CVD as a cause of death and a history of heart attack on the NMFS is even stronger than the association of CVD with a history of hypertension. Of persons aged 25–64 years who died in 1986, more than two of three with a history of heart attack died of CVD, while only one of five who had not had a heart attack died of CVD rather than from another underlying cause of death (table C). For that broad age group, a reported history of heart attack was associated with odds of dying from CVD of 1.95, as compared with odds for other causes of 0.26, resulting in an odds ratio of 7.58. The odds ratio for dying of CVD in relation to a history of heart attack decreased rapidly with increasing age to 1.67 for the oldest age group (table C).

Another condition expected to be associated with deaths from CVD is diabetes. A total of 17.2 percent of persons 25 years of age and over who died in 1986 had a reported medical history of diabetes. By broad age group, the percent did not vary greatly. For the youngest age group of decedents, 25–64 years, the percent was 15.7; for those aged 65–74 years, 75–84 years, and 85 years and over, the percents were 20.6, 18.6, and 13.4, respectively.

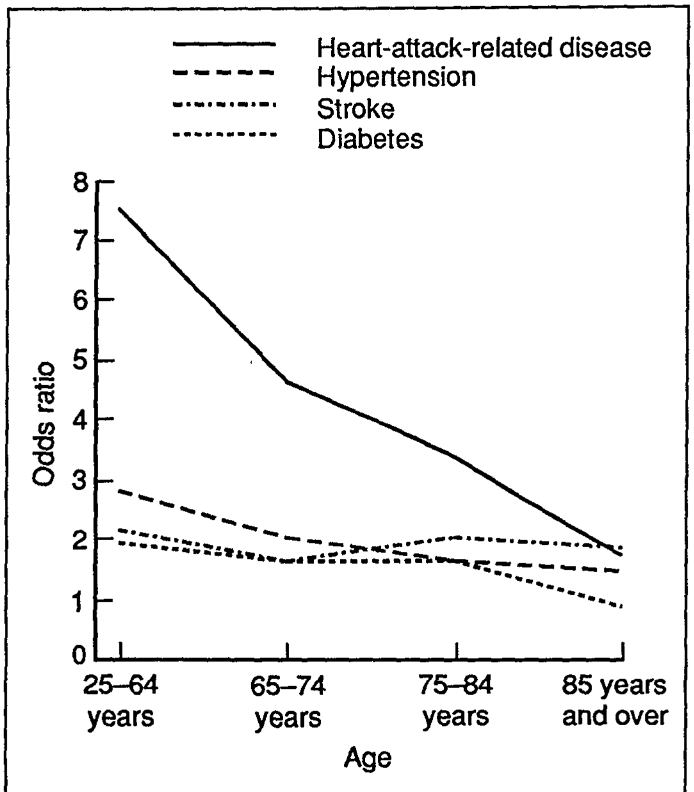
A history of diabetes increased the probability of dying from CVD compared with other causes for every age group. The odds ratio was 1.9 at ages 25–64 years, indicating that persons in this age group who died in 1986 were twice as likely to die from CVD as from other causes if they had a reported prior history of diabetes (table C). By 85 years and over, the odds ratio was about 1.0, indicating essentially no association between these conditions at that age.

The association between CVD as an underlying cause and stroke reported on the NMFS for 1986 is also shown in table C. As with the previously discussed medical conditions reported on the survey, the odds of dying from CVD as an underlying cause on the death certificate increased for those both with and without a reported history of stroke. The rate of increase in the odds for the two groups remained about the same throughout the age span, with odds of persons with stroke being about twice those of persons without stroke. Thus, stroke as a risk factor contrasts with hypertension and heart attack, for which the odds ratio diminished sharply with increasing age; for stroke the ratio remained relatively constant.

In sum, the likelihood of CVD as an underlying cause increased if the decedent had a medical history of one of the reported conditions—hypertension, heart attack, diabetes, or stroke. The strongest association was with a reported history of heart attack, which increased the odds of dying from this cause rather than another cause by an average factor of 4.31 for all ages combined (the simple average of the odds ratios at each age). In order of strength of association, this was followed by the impact of stroke, with an average odds ratio of 1.89, then by hypertension (1.94) and diabetes (1.49).

For each of these conditions, the effect of the prior history of disease decreased with increasing age. The sharpest reduction was for heart attack, for which the odds ratio diminished by an average of 0.099 points per year of age between ages 25 and 85 years and over, compared with 0.024 for hypertension, 0.018 for diabetes, and 0.005 for stroke—differentials that are illustrated in figure 4.

Heart disease—Heart disease, or Diseases of heart, is a subcategory of Major cardiovascular diseases, accounting for 765,490 deaths, or 79 percent of all CVD deaths in the United States in 1986. Table D shows the association between death due to heart disease and a history of hypertension and heart disease reported in the NMFS.



SOURCE: National Center for Health Statistics. National Mortality Followback Survey. 1986.

Figure 4. Odds ratio of dying from Cardiovascular disease for survey reports of Hypertension, Heart-attack-related disease, Diabetes, and Stroke, by age: United States, 1986

Deaths from heart disease as an underlying cause increased from 27.8 percent at ages 25–64 years to 46.5 percent at ages 85 years and over. For ages 25–64 years, a history of hypertension raised the percent dying of heart disease by a factor of 2.45 compared with persons without a history of hypertension. By 85 years and over, the odds ratio decreased to 1.15.

A history of heart attack was strongly associated with death from heart disease, as it was for CVD. The odds ratio was 9.63 for the youngest age group, decreasing to 2.17 for decedents in the oldest age group.

The pattern of association between heart disease and CVD as underlying causes of death on the death certificate in relation to a reported history of hypertension or heart attack in the NMFS was, not surprisingly, similar in terms of both order of magnitude and rate of change with increasing age of decedent (table G).

Table D. Percent of deaths and odds and odds ratios of dying from Heart-attack-related diseases or Heart disease (death certificate compared with survey reports of selected conditions), by age: United States, 1986

Underlying cause of death on death certificate with or without history of specified condition reported on survey	*Percent dying of specified underlying cause of death on death certificate*				*Odds and odds ratios*				
	25–64 years	*65–74 years*	*75–84 years*	*85 years and over*		*25–64 years*	*65–74 years*	*75–84 years*	*85 years and over*
Heart-attack-related diseases	22.7	32.2	35.4	39.7	Odds ratio	8.63	5.59	3.61	1.92
With Heart attack	53.0	56.1	55.4	51.7	Odds	1.13	1.28	1.24	1.07
Without Heart attack	11.6	18.6	25.6	35.8		0.13	0.23	0.34	0.56
Heart disease	27.8	38.4	41.3	46.5	Odds ratio	2.45	1.59	1.29	1.15
With Hypertension	38.6	43.2	44.4	48.4	Odds	0.63	0.76	0.80	0.94
Without Hypertension	20.4	32.4	38.2	44.9		0.26	0.48	0.62	0.81
Heart disease:					Odds ratio	9.63	5.71	3.73	2.17
With Heart attack	62.6	63.8	62.6	61.0	Odds	1.67	1.76	1.67	1.57
Without Heart attack	14.8	23.6	31.0	41.9		0.17	0.31	0.45	0.72

SOURCE: National Center for Health Statistics. National Mortality Followback Survey. 1986.

Heart attack has a greater impact on the underlying cause of death than a history of hypertension, as well as a much more rapidly declining ratio with increasing age of decedent.

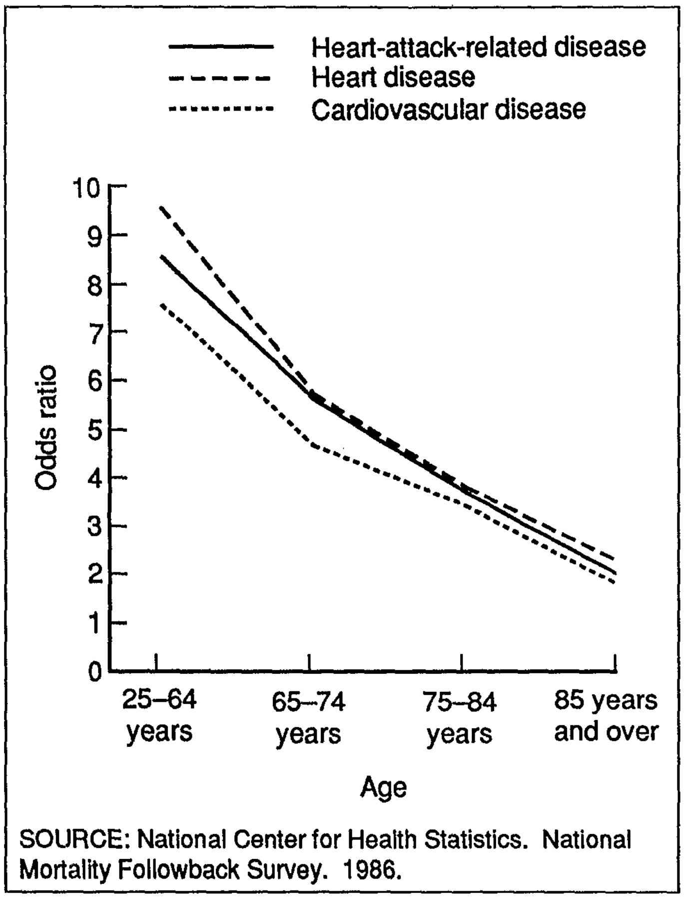
Heart attack—According to the 1986 NMFS, an estimated 29.2 percent of decedents in 1986 had had a heart attack prior to death. The percent varied by age as follows: For decedents aged 25–64 years, 26.2 percent had had a heart attack; for those aged 65–74 years, 35.5 percent; for 75–84, 31.9 percent; and for those aged 85 years and over, 22.1 percent.

The percent of deaths attributed to the underlying cause-of-death category Heart attack related (see appendix II) increased from 22.7 percent at ages 25–64 years to 39.7 percent at ages 85 years and over (table D). The percent was affected by a reported history of heart attack such that the odds ratio for the youngest age group was 8.63. The odds ratio declined to 1.92 for the oldest group, a pattern similar to the impact of prior heart attack on death due to CVD and heart disease, as shown in figure 5 and table H.

The analysis of the association between heart attack reported on the NMFS and heart attack reported as an underlying cause on death certificates was carried out in three different ways, once for the broad category CVD; then for its subcomponent Diseases of heart; and finally, within that category, for the specially constructed category Heart-attack-related deaths. For each of these, the relationship was similar (tables C and D, and figure 5). For CVD and heart attack, the odds ratios ranged with increasing age from 7.58 to 1.67; for Diseases of heart, from 9.63 to 2.17; and for Heart-attack-related deaths, from 8.63 to 1.92. Generally, the associations are stronger for the more specific categories of cause of death than for the broader categories.

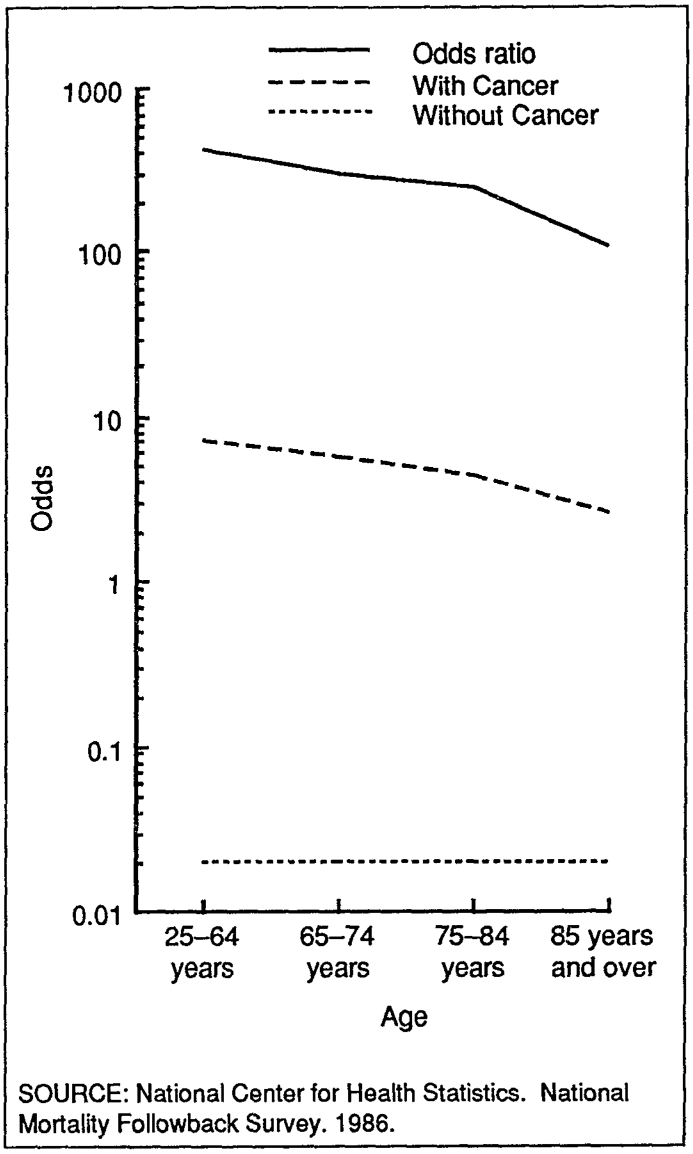
Cancer—In the NMFS, the question about medical history related to cancer differed from that for the other conditions. For the other conditions, the question on medical history was couched in terms of, "At any time during the person's life did he or she have [the condition]," thus providing information on the medical history of the decedent regarding the specified condition. In contrast, the question for cancer—"Was cancer the main condition leading to death?"—is directed more at confirming the diagnosis reported on the death certificate or, conversely, determining the knowledge of the informant regarding the cause of death reported by the physician. The analysis was carried out using alternative sets of ICD categories for Malignant neoplasms, one including ICD Nos. 140–209, the other including a broader range of ICD Nos. 140–239. Results were about the same for the two definitions.

Cancer is the second leading cause of death in the United States. In 1986, it accounted for a total of 469,376 deaths, or 22.3 percent of all deaths. The proportion of deaths due to cancer decreased with



SOURCE: National Center for Health Statistics. National Mortality Followback Survey. 1986.

Figure 5. Odds ratio of dying from Cardiovascular disease, Heart disease, and Heart-attack-related disease for survey reports of Heart attack, by age: United States, 1986



SOURCE: National Center for Health Statistics. National Mortality Followback Survey. 1986.

Figure 6. Odds and odds ratio of dying from Cancer (death certificate compared with survey report of Cancer as main condition leading to death), by age: United States, 1986

increasing age of the decedent, from about 31 percent at ages 25–64 years to about 11 percent at ages 85 years and over (table E). For a very high percent of decedents for whom cancer was reported as the underlying cause on the death certificate, cancer was also reported on the NMFS as the condition leading to death. Of those aged 25–64 years, the NMFS figure was close to 90 percent; it decreased gradually to 72 percent by ages 85 years and over. Conversely, of those not reported on the death certificate as dying of cancer, the percent reported on the NMFS as dying of cancer was only 1.6 percent for the youngest age group and increased to 2.3 percent for the oldest group (table E). As a consequence, the odds ratios for cancer were very high—about 400 at ages 25–64 years, declining to about 100 at ages 85 years and over (table E and figure 6).

Stroke—Cerebrovascular disease, or stroke, is the third leading cause of death in the United States, accounting for 149,643 deaths, or 7.1 percent of the total in 1986. For decedents aged 25 years and over, stroke was selected as the underlying cause of death for 7.5 percent of the deaths in 1986. The proportion of deaths due to stroke increased rapidly with age, from about 4 percent at ages 25–64 years to 12 percent at ages 85 years and over (table F).

According to the NMFS, 25.4 percent of the decedents in 1986 had a stroke during their lifetime; 70.9 percent had not had a stroke; and information regarding stroke was not available for 3.6 percent of the decedents. The percent who had had a stroke increased with age of the decedent from 14.2 percent for persons

Table E. Percent of deaths and odds and odds ratios of dying from Cancer (death certificate compared with survey reports of selected conditions), by age: United States, 1986

Underlying cause of death on death certificate with or without Cancer as main cause of death reported on survey	Percent dying of specified Cancer on death certificate					Odds and odds ratios			
	25–64 years	65–74 years	75–84 years	85 years and over		25–64 years	65–74 years	75–84 years	85 years and over
Cancer (ICD–9 Nos. 140–208)	30.9	29.7	20.3	10.5	Odds ratio	421.26	304.71	252.99	106.79
With Cancer	87.6	84.9	81.6	71.8	Odds	7.07	5.60	4.43	2.54
Without Cancer	1.6	1.8	1.7	2.3		0.02	0.02	0.02	0.02
Cancer (ICD–9 Nos. 140–239)	31.3	30.1	20.5	10.8	Odds ratio	381.15	280.09	251.52	102.85
With Cancer	88.2	85.4	82.4	72.7	Odds	7.49	5.86	4.67	2.67
Without Cancer	1.9	2.0	1.8	2.5		0.02	0.02	0.02	0.03

NOTE: ICD–9 is Ninth Revision International Classification of Diseases.

SOURCE: National Center for Health Statistics. National Mortality Followback Survey. 1986.

Table F. Percent of deaths and odds and odds ratios of dying from Cerebrovascular disease or Chronic obstructive pulmonary disease (death certificate compared with survey reports of selected conditions), by age: United States, 1986

Underlying cause of death on death certificate with or without history of specified condition reported on survey	Percent dying of specified underlying cause of death on death certificate					Odds and odds ratios			
	25–64 years	65–74 years	75–84 years	85 years and over		25–64 years	65–74 years	75–84 years	85 years and over
Cerebrovascular disease	3.9	5.6	9.1	12.0	Odds ratio	10.52	8.55	8.72	4.64
With Stroke	16.2	15.7	22.3	22.9	Odds	0.19	0.19	0.29	0.30
Without Stroke	1.8	2.1	3.2	6.0		0.02	0.02	0.03	0.06
Chronic obstructive pulmonary disease	2.1	5.2	5.1	2.3	Odds ratio	7.20	5.52	4.49	2.35
With Asthma	9.8	19.2	16.1	5.0	Odds	0.11	0.24	0.19	0.05
Without Asthma	1.5	4.1	4.1	2.2		0.02	0.04	0.04	0.02

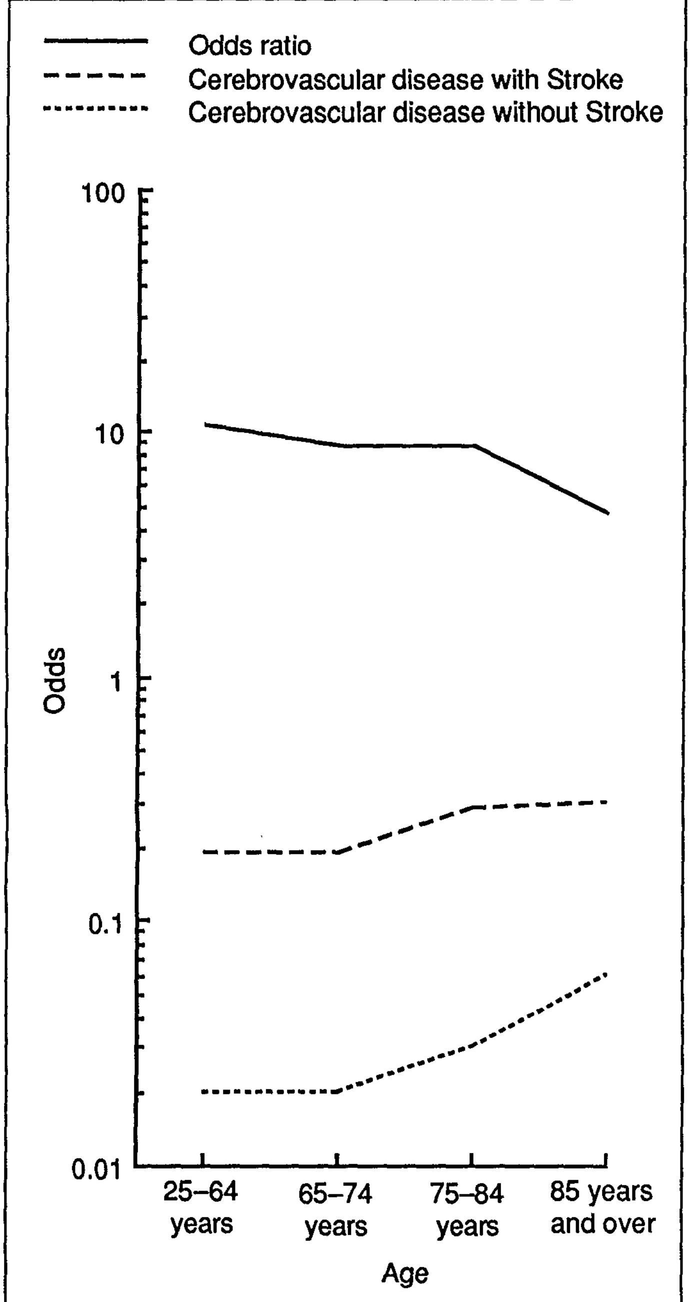
SOURCE: National Center for Health Statistics. National Mortality Followback Survey. 1986.

aged 25–64 years to 33.3 percent for those aged 85 years and over.

For each age group, the percent of decedents for whom stroke rather than another cause was selected as the underlying cause of death was higher if they had a history of stroke than if they did not (table F). As with reported cancer, report of a stroke in the survey is strongly associated with stroke as an underlying cause of death; that is, the odds of dying from stroke are much larger for those reporting a history of stroke than for those who did not, resulting in large odds ratios. The odds ratio is almost 11 for the youngest age group, decreasing to 4.6 at ages 85 years and over (figure 7). The high odds ratio for even the oldest old indicates a strong association between a history of stroke and death from stroke throughout the age range.

Chronic obstructive pulmonary disease—COPD was the fifth leading cause of death in the United States in 1986, accounting for 76,559 deaths, 3.6 percent of deaths from all causes combined. The category COPD includes bronchitis, emphysema, asthma, and other chronic respiratory diseases that are difficult to differentiate from one another in the elderly population. In the NMFS, information was collected not on COPD but on asthma (appendix I). The percent of deaths due to COPD in 1986 ranged among the age groups from 2 to 5 percent (table F).

Asthma was not reported as a highly prevalent

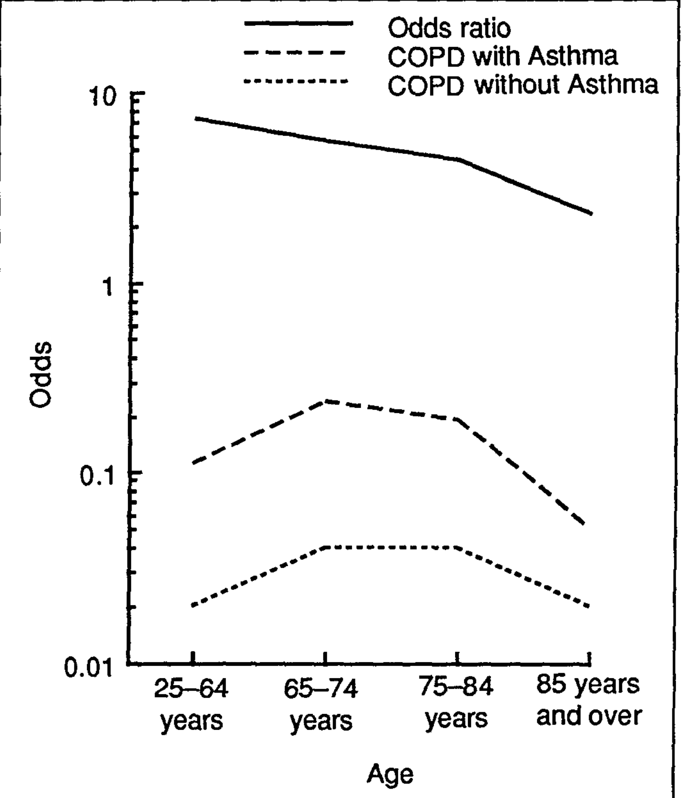


SOURCE: National Center for Health Statistics. National Mortality Followback Survey. 1986.

Figure 7. Odds and odds ratio of dying from Cerebrovascular disease (death certificate compared with survey report of Stroke as main condition leading to death), by age: United States, 1986

medical condition for persons who died in 1986. Only 6.3 percent of all decedents 25 years or older in 1986 were reported to have ever had a history of this respiratory condition. The percent was about the same throughout the age span, except for the oldest age group, for whom the percent declined to about 4.

The odds of dying from COPD as an underlying cause were greatly affected by the reported presence



NOTE: COPD is chronic obstructive pulmonary disease.

SOURCE: National Center for Health Statistics. National Mortality Followback Survey. 1986.

Figure 8. Odds and odds ratio of dying from Chronic obstructive pulmonary disease (death certificate compared with survey report of Asthma as main condition leading to death), by age: United States, 1986

of asthma during the decedent's lifetime. For the youngest group, the percent dying of COPD who had a reported history of asthma was almost 10 percent, compared with only 1.5 percent for those without a history of the condition—a fivefold difference that diminished only slightly with increasing age. The odds ratio, which was over 7 at ages 25–64 years, declined to a low of just over 2 for persons 85 years and over (figure 8).

Summary—A comparison of underlying cause on the death certificate with reported medical history on the NMFS for the same decedents in 1986 shows significant associations, although the strength and variation by age differ among the selected conditions. Excluding cancer, for which the item on the NMFS differed from the other conditions, the strongest association was for stroke. The odds ratio was close to

Table G. Odds ratio of dying from Cardiovascular disease or Heart disease (death certificates compared with survey reports of Hypertension and Heart attack) and average change in odds ratio per year of age: United States, 1986

Survey history	*Underlying cause of death on death certificate* *Cardiovascular disease*	 *Heart disease*
Hypertension		
Average odds ratio	1.94	1.62
Average change in odds ratio per year of age	-0.024	-0.022
Heart attack		
Average odds ratio	4.31	5.31
Average change in odds ratio per year of age	-0.099	-0.124

SOURCE: National Center for Health Statistics. National Mortality Followback Survey. 1986.

8.0 for all ages combined for this condition. In terms of strength of association between the two sources of information, stroke was followed by heart attack. Heart attack listed on the NMFS was related to death from heart attack, heart disease, and CVD reported on the death certificate; the odds ratios were in the range of 4–5, as was the association between asthma on the survey and COPD reported on the death certificate. The odds ratio was about 2.0 for the association between stroke on the survey and CVD on the death certificate.

The odds ratio diminished with increasing age for all of the combinations of conditions from the two sources. The sharpest declines were for a history of heart attack in combination with any of the causes of death with which it was paired. The smallest change was for stroke as a factor associated with death from CVD.

Diagnostic completeness

It has been suggested that the precision of diagnostic information on the death certificate may decline with increasing age of decedent; that is, as the age of the decedent increases, the medical certifier is more likely to characterize the cause of death on the death certificate with imprecise and vague terms such as "natural causes" or "old age" (9). This can be examined by determining the proportion of deaths at an age assigned to the category Symptoms, signs, and ill-defined conditions, ICD–9 Nos. 780–799.

Table H. Odds ratio of dying from Cardiovascular disease, Heart disease, and Heart attack (death certificates compared with survey reports of Heart attack) and average change in odds ratio per year of age: United States, 1986

Underlying cause of death on death certificate	*Average odds ratio*	*Average change in odds ratio per year of age*
Cardiovascular disease	4.31	-0.099
Heart disease	5.31	-0.124
Heart attack	4.94	-0.112

SOURCE: National Center for Health Statistics. National Mortality Followback Survey. 1986.

Table J shows the number and percent of deaths in 1985 to persons 25 years of age and over classified to this category, by age, race, and sex. The percents are about the same for males as for females and slightly higher for black decedents than for white decedents. By age, the percent is highest for the age group 25–34 years (3.19 percent), but it declines rapidly to 0.98 percent at ages 75–84 years and increases only slightly thereafter (figure 9). Using this as an index of the quality and completeness of reporting cause of death, there is no indication of a decline in the quality of reporting with increasing age. However, the index represents the physician's use of medical terms that are codable to informative diagnostic categories in the ICD, not the reliability or validity of these terms in relation to the actual diagnosis of cause of death.

Multiple causes of death

Death among the oldest old appears to have a somewhat opportunistic character, with many chronic conditions competing to be the precipitating cause. The particular cause of death is less the result of a clearly defined etiological path than the random result of a more generalized deterioration of the capacity for life. Data on the reported number of chronic conditions contributing to death, by age of decedent, are available from multiple cause-of-death data from NCHS.

Table K and figure 10 show the average number of conditions reported on death certificates in the United States in 1985 for persons 25 years and over, by age,

Table J. Number of deaths and number and percent of deaths due to Symptoms, signs, and ill-defined conditions, by sex, race, and age: United States, 1985

	Both sexes			Male			Female		
Race and age	*Total deaths*	*Ill-defined deaths*	*Percent*	*Total deaths*	*Ill-defined deaths*	*Percent*	*Total deaths*	*Ill-defined deaths*	*Percent*
All races	Number			Number			Number		
25–34 years	51,852	1,655	3.19	37,354	1,133	3.03	14,498	522	3.60
35–44 years	65,815	1,490	2.26	43,494	1,041	2.39	22,321	449	2.01
45–54 years	116,634	1,731	1.48	73,320	1,154	1.57	43,314	577	1.33
55–64 years	286,480	3,331	1.16	177,711	2,245	1.26	108,769	1,086	1.00
65–74 years	482,646	4,832	1.00	283,017	2,957	1.04	199,629	1,875	0.94
75–84 years	568,848	5,581	0.98	279,872	2,821	1.01	288,976	2,760	0.96
85 years and over	419,051	5,160	1.23	141,653	1,710	1.21	277,398	3,450	1.24
Not stated	877	92	...	491	63	...	386	29	...
White									
25–34 years	38,463	1,113	2.89	28,102	791	2.81	10,361	322	3.11
35–44 years	49,608	1,017	2.05	32,907	712	2.16	16,701	305	1.83
45–54 years	92,204	1,219	1.32	58,347	804	1.38	33,857	415	1.23
55–64 years	241,237	2,553	1.06	151,038	1,723	1.14	90,199	830	0.92
65–74 years	422,956	3,849	0.91	249,919	2,385	0.95	173,037	1,464	0.85
75–84 years	513,954	4,592	0.89	253,056	2,319	0.92	260,898	2,273	0.87
85 years and over	389,513	4,481	1.15	130,583	1,428	1.09	258,930	3,053	1.18
Not stated	702	76	...	377	53	...	325	23	...
Black									
25–34 years	12,144	512	4.22	8,415	320	3.80	3,729	192	5.15
35–44 years	14,779	442	2.99	9,724	307	3.16	5,055	135	2.67
45–54 years	22,486	492	2.19	13,821	337	2.44	8,665	155	1.79
55–64 years	41,836	747	1.79	24,657	502	2.04	17,179	245	1.43
65–74 years	55,032	940	1.71	30,310	546	1.80	24,722	394	1.59
75–84 years	50,000	942	1.88	23,804	473	1.99	26,196	469	1.79
85 years and over	26,675	633	2.37	9,780	257	2.63	16,895	376	2.23
Not stated	158	16	...	106	10	...	52	6	...

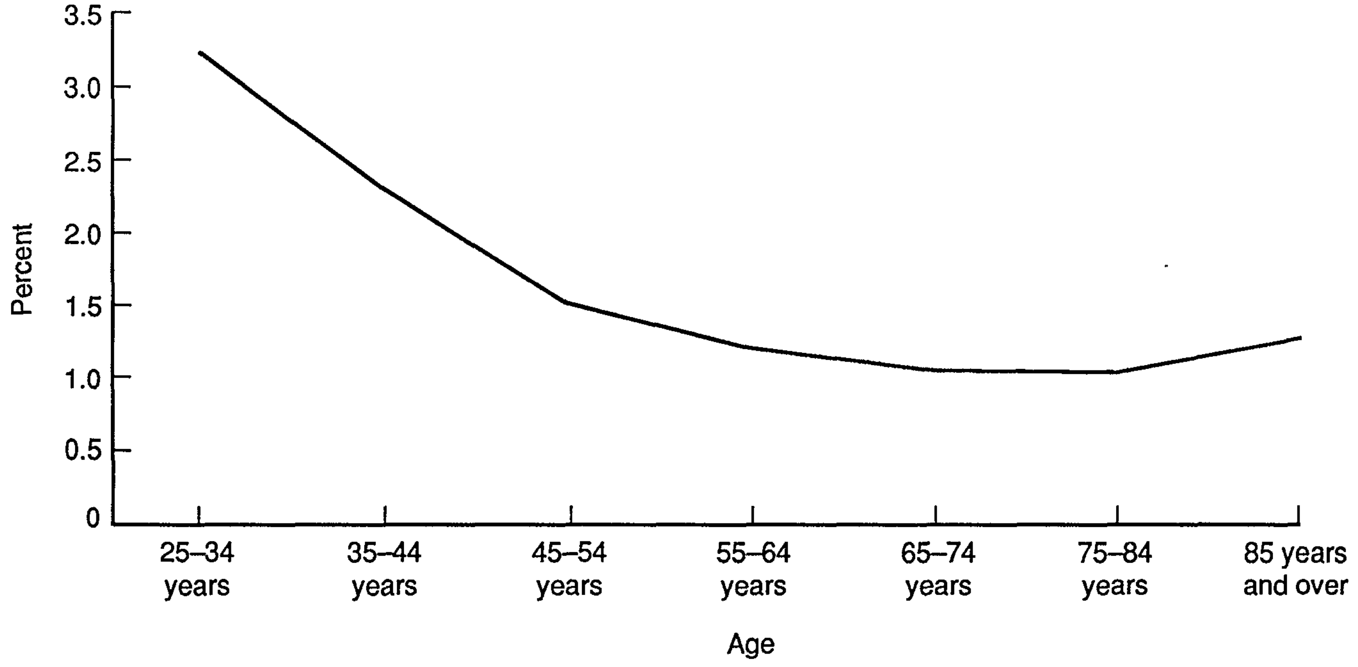
SOURCE: National Center for Health Statistics. National Vital Statistics System. 1985.

race, and sex of the decedent. Excluded from these counts are "external" causes, that is, accidents, suicides, and homicides, because these causes are also represented by the "nature of the injury," that is, whether the injury was a fracture, cut, abrasion, etc. The average number of reported conditions was fairly constant at about 2.5 for the age groups 25–34 years to 45–54 years, then increased steadily to 2.89 for persons aged 75–84 years old and over. The number of conditions by age was about the same for males and females and for white and black decedents.

The increasing number of conditions reported with increasing age presented as a percent distribution is shown in table L and figure 11. For each broad age group—25–64 years, 65–84 years, and 85 years and over—the number and percent of death certificates on which one, two, three, or four or more conditions were reported in 1985 is shown in table L. The percent with one condition decreases from about 24 percent for decedents 25–64 years to about 14 percent for deaths at ages 85 years and over. The percent with four or more conditions increases between these ages from 22 to 28 percent.

Discussion

Several sources were used to examine the nature of cause-of-death data from the death certificate with respect to the health of the elderly population. One of these was the 1986 National Mortality Followback



SOURCE: National Center for Health Statistics. National Vital Statistics System. 1985.

Figure 9. Percent of deaths due to Symptoms, signs, and ill-defined conditions, by age: United States, 1985

Survey. Survey responses on the medical history of decedents were correlated with their reported underlying cause of death on the death certificate. Another approach was examining whether statistical indicators of imprecise diagnosis of cause of death on the death certificate as classified under the ICD changed systematically with increasing age of decedent. Finally, multiple cause-of-death data were examined to determine whether more contributing conditions were reported for the older population than for the younger population.

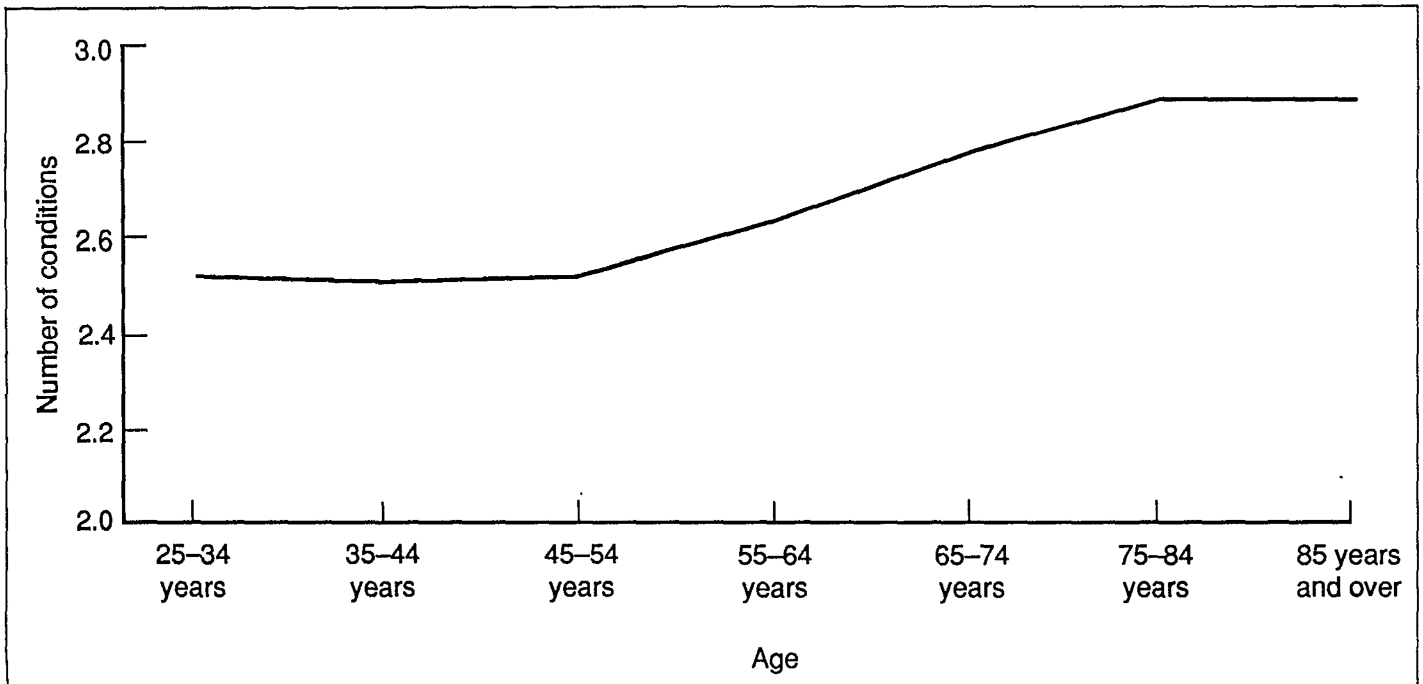
The study shows an association between medical history on the survey and underlying cause of death from the death certificate for each of the conditions selected from the NMFS. A medical history of conditions hypothesized to be associated with the fatal outcome did increase the risk of death for the selected cause, as measured by the odds ratio. The degree to

Table K. Average number of medical conditions reported on death certificates, by race, sex, and age: United States, 1985

	All races			*White*			*Black*			*All other*		
Age	*Total*	*Male*	*Female*	*Total*	*Male*	*Female*	*Total*	*Male*	*Female*	*Total*	*Male*	*Female*
25–34 years	2.52	2.52	2.53	2.51	2.51	2.52	2.54	2.53	2.54	2.59	2.58	2.60
35–44 years	2.51	2.50	2.52	2.48	2.48	2.50	2.57	2.56	2.58	2.59	2.64	2.52
45–54 years	2.52	2.50	2.56	2.50	2.49	2.52	2.58	2.52	2.67	2.69	2.65	2.73
55–64 years	2.63	2.62	2.66	2.63	2.62	2.65	2.66	2.61	2.73	2.76	2.74	2.80
65–74 years	2.78	2.77	2.80	2.79	2.78	2.80	2.75	2.70	2.81	2.96	2.95	2.97
75–84 years	2.89	2.88	2.89	2.89	2.89	2.89	2.82	2.78	2.85	3.02	3.02	3.03
85 years and over	2.89	2.91	2.88	2.89	2.92	2.88	2.81	2.79	2.82	3.03	3.04	3.03

NOTE: Excludes external "E" codes listed as underlying cause.

SOURCE: National Center for Health Statistics. National Vital Statistics System. 1985.



NOTE: Excludes external "E" codes listed as underlying cause.

SOURCE: National Center for Health Statistics. National Vital Statistics System. 1985.

Figure 10. Average number of medical conditions reported on death certificates, by age: United States, 1985

which the history raised the likelihood of death from a particular cause compared with all other causes combined varied considerably.

While the presence of the antecedent condition increased the likelihood of dying from this or a closely related condition, the relationship was far from perfect; that is, proportions increase at each age, sometimes severalfold, but are never close to 100 percent (except for cancer, which is not comparable with other conditions on the survey). With increasing age, the association for every condition weakens. At the very oldest ages, the underlying cause of death was fairly invariant to the antecedent condition, except for stroke. A large proportion of deaths at each age were due to cardiovascular diseases. However, this proportion was only weakly associated with the conditions reported on the survey, especially among the elderly, suggesting that deaths from heart disease among the oldest old do not reflect the antecedent prevalence of serious chronic illness from this or related conditions.

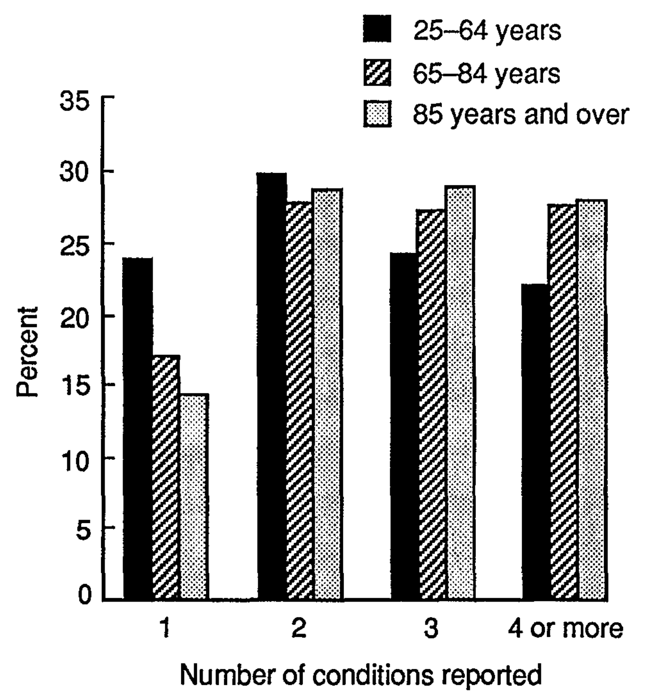
In summary, with increasing age of decedent, the relationship between the reported medical history in the NMFS and the physician's report of underlying cause of death diminished considerably. Several

Table L. Number and percent distribution of deaths by number of conditions reported on death certificate, according to age: United States, 1985

Number of conditions reported per certificate	25–64 years Number	 Percent distribution	65–84 years Number	 Percent distribution	85 years and over Number	 Percent distribution
Total	446,558	100.00	1,026,737	100.00	411,486	100.00
1	106,348	23.82	175,573	17.10	59,005	14.34
2	133,235	29.84	285,770	27.83	117,997	28.68
3	108,423	24.28	280,924	27.36	118,936	28.90
4 or more	98,552	22.07	284,470	27.71	115,548	28.08

NOTE: Excludes external "E" codes listed as underlying cause.

SOURCE: National Center for Health Statistics. National Vital Statistics System. 1985.



SOURCE: National Center for Health Statistics. National Vital Statistics System. 1985.

Figure 11. Percent distribution of deaths by number of conditions reported on death certificate, according to age: United States, 1985

factors may account for this. One is that, for younger persons, antecedent medical conditions may be more acute and directly associated with the death. Thus, a history of hypertension may indicate a much more intensive disease process for a younger person dying of CVD than for an elderly person dying of CVD. This interpretation could be tested by introducing another variable into the analysis, namely, duration of the condition; this is because persons dying at a younger age usually had the reported medical conditions for a shorter period than persons dying at more advanced ages.

Another possible reason for the weakening association with increasing age of decedent is poorer diagnoses of cause of death for the elderly population as compared with younger decedents. For the elderly, particularly those dying in long-term care institutions, medical certification of cause of death may be handled with less precision, with less knowledge about the decedent's medical history, and with less diagnostic information from laboratory tests and autopsy than for younger decedents. Another possible factor accounting for the change in association with increasing age is that the informant on the NMFS was simply less knowledgeable about the health history of older decedents compared with younger decedents.

With respect to completeness of medical certification, underlying cause-of-death data show little deterioration with increasing age. The percent of deaths assigned to the category Symptoms and ill-defined conditions as an underlying cause of death was very small and increased little with advancing age. This suggests that certifying physicians are about equally likely to provide an unambiguous, specific, and codable cause of death at any age. However, the comparisons with survey data suggest that the reported causes are more informative with respect to medical history for younger decedents than for older decedents.

Multiple cause-of-death data show that the reported number of medical conditions increases with age, a pattern consistent with deaths of elderly persons being multifactorial and more difficult to capture with a single underlying cause of death than deaths of younger decedents are. For 1985, the average number of reported conditions on the death certificate increased systematically with age, from 2.51 at ages 35–44 years to 2.89 for persons 85 years and over.

The results of the study all support the usefulness of underlying cause-of-death data at younger ages; however, the results do lend credence to concerns about its validity as an indicator of the health status of the very old, whose health may be compromised by more than one serious chronic condition. Verbrugge questioned the correspondence between cause of death and major illness or disability proximate to death for the elderly (10). Moriyama was concerned about the loss of useful information on current diseases and conditions because of the emphasis in the medical certification on a single underlying cause of death (8). Kohn, taking the most extreme position, recommended that the cause of death for the elderly be reported as "senescence" when "deaths in debilitated members of the aged population cannot be ascribed to a disease process that would cause death in a middle-aged person" (9). While Kohn's recommendation is impractical as well as at odds with the need for more care and specificity in medical certification of death rather than less, it nevertheless serves as a caution with respect to interpreting cause-of-death data for the elderly population. As such, it is consistent with the concerns of Moriyama, Verbrugge, and others and with the findings of this study.

One approach to more effective use of cause-of-death data from the death certificate for studying the health of elderly people is increased reliance on multiple cause-of-death data, a statistical resource available in the United States but not in many other countries on a routine basis (15). Most death certificates have more than one reported medical condition cited as contributing to death; this study shows that the average number of causes reported for deaths in the United States is now close to 3.0 and that the number increases systematically with increasing age of decedent. Were the present study to be repeated using multiple-cause data, greater concordance might be found between reported medical history from the NMFS and reported causes of death from the death certificate. Such results would strengthen the use of cause-of-death data for studying the health of the elderly.

Further, duration of the medical condition reported in the survey may also affect the association between cause of death on the death certificate and a history of a related medical condition, on the assumption that death at an earlier age might reflect a more severe condition. In a future study, duration since onset of the major medical condition could be used as a control for severity of illness. This, too, may result in a more consistently strong association between cause of death and prior medical history with increasing age.

While the results of this study pose questions about the validity of underlying cause of death as an indicator of health status of the elderly, additional research taking into account multiple causes of death and duration of illness is needed to further clarify the way in which death certificates reflect the prior health status of decedents and how well mortality data measure the health of our older population.

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Appendix I
Questions from the National Mortality Followback Survey

The following questions from the National Mortality Followback Survey provided information used in the study. The respondent was asked to check boxes for "yes" or "no" for each item.

- At any time in the person's life, did he or she ever have high blood pressure (hypertension)?
- At any time in the person's life, did he or she ever have a heart attack?
- At any time in the person's life, did he or she ever have angina pectoris?
- At any time in his or her life, did the person have a stroke in which any resulting conditions (such as paralysis, loss of vision or speech) lasted AT LEAST ONE DAY OR LONGER?
- At any time in the person's life, did a doctor say that the person had Alzheimer's disease, chronic brain syndrome, dementia, senility, or any other serious memory impairment?
- At any time in the person's life, did he or she have OTHER mental, nervous, or emotional problems?
- At any time during the person's life, did he or she have diabetes?
- Was cancer the main condition leading to death?
- At any time during the person's life, did he or she have cancer of any kind, except skin cancer?
- At any time during the person's life, did he or she have asthma?
- At any time during the person's life, did he or she have any other lung condition, such as emphysema or bronchitis, lasting 3 months or longer?
- At any time in the person's life, did he or she have cirrhosis of the liver?

Appendix II
Selected underlying causes of death that were compared with specified conditions identified in the National Mortality Followback Study (NMFS)

NMFS question	Underlying cause of death
Hypertension—At any time in the person's life, did he or she have high blood pressure (hypertension)?	1. Diseases of heart (ICD–9 Nos. 390–398, 402, 404–429) 2. Major cardiovascular diseases (ICD–9 Nos. 390–448)
Heart attack—At any time in the person's life, did he or she ever have a heart attack?	1. Heart attack related (ICD–9 Nos. 410–414, 427.5, 429.2) 2. Diseases of heart (ICD–9 Nos. 390–398, 402, 404–429) 3. Major cardiovascular diseases (ICD–9 Nos. 390–448)
Stroke—At any time in his or her life, did the person have a stroke in which any resulting conditions (such as paralysis, loss of vision or speech) lasted AT LEAST ONE DAY OR LONGER?	1. Cerebrovascular diseases (ICD–9 Nos. 430–438) 2. Major cardiovascular diseases (ICD–9 Nos. 390–448)
Diabetes—At any time during the person's life, did he or she have diabetes?	1. Diseases of heart (ICD–9 Nos. 390–398, 402, 404–429) 2. Major cardiovascular diseases (ICD–9 Nos. 390–448)
Cancer—Was cancer the main condition leading to death?	1. Malignant neoplasms, including neoplasms of lymphatic and hematopoietic tissues (ICD–9 Nos. 140–208) 2. Neoplasms (ICD–9 Nos. 140–239)
Asthma—At any time during the person's life, did he or she have asthma?	1. Chronic obstructive pulmonary diseases and allied conditions (ICD–9 Nos. 490–496)

NOTE: ICD–9 is Ninth Revision International Classification of Diseases.

Appendix III
National Mortality Followback Survey and death certificate comparisons

Table I. Number of deaths with underlying cause of cardiovascular disease and other causes, by age and survey response: United States, 1986

Survey response	*Age and underlying cause of death on death certificate*							
	25–64 years		*65–74 years*		*75–84 years*		*85 years and over*	
	Cardiovascular disease	*Other*	*Cardiovascular disease*	*Other*	*Cardiovascular disease*	*Other*	*Cardiovascular disease*	*Other*
Hypertension	Number							
Yes	93,150	105,990	128,060	109,030	159,460	112,780	118,800	58,540
No	68,590	221,060	80,140	135,340	122,600	136,560	128,190	88,030
Unknown	6,990	16,920	11,920	11,640	16,690	15,160	17,410	10,560
Heart attack								
Yes	88,930	45,490	117,380	51,780	129,970	49,640	66,680	26,670
No	74,990	290,670	96,640	198,240	159,630	205,540	188,020	125,620
Unknown	4,810	7,800	6,090	6,000	9,150	9,310	9,690	4,850
Diabetes								
Yes	36,680	44,060	54,550	43,400	65,720	39,180	33,530	22,970
No	127,530	290,810	159,940	205,000	226,380	217,000	223,120	128,650
Unknown	4,520	9,100	5,620	7,620	6,650	8,310	7,750	5,520
Stroke								
Yes	34,780	38,020	66,450	54,700	109,060	59,300	100,750	39,810
No	127,910	296,290	145,280	192,690	179,900	195,540	151,990	109,430
Unknown	6,050	9,640	8,380	8,620	9,800	9,650	11,650	7,910

Table II. Number of deaths with underlying cause of heart-attack-related diseases and other causes, by age and survey response: United States, 1986

Survey response	*Age and underlying cause of death on death certificate*							
	25–64 years		*65–74 years*		*75–84 years*		*85 years and over*	
	Heart-attack-related diseases	*Other*	*Heart-attack-related diseases*	*Other*	*Heart-attack-related diseases*	*Other*	*Heart-attack-related diseases*	*Other*
Heart attack	Number							
Yes	71,290	63,130	94,900	74,260	99,510	80,100	48,240	45,110
No	42,330	323,330	54,880	240,000	93,520	271,650	112,250	201,390
Unknown	2,910	9,700	3,750	8,340	6,160	12,300	6,650	7,890

Table III. Number of deaths with underlying cause of heart disease and other causes, by age and survey response: United States, 1986

Survey response	Age and underlying cause of death on death certificate							
	25–64 years		65–74 years		75–84 years		85 years and over	
	Heart disease	Other	Heart disease	Other	Heart disease	Other	Heart disease	Other
	Number							
Hypertension								
Yes	76,840	122,300	102,350	134,740	120,960	151,280	85,840	91,500
No	59,200	230,450	69,760	145,720	99,070	160,090	97,010	119,210
Unknown	6,470	17,440	10,780	12,780	12,320	19,530	13,250	14,720
Heart attack								
Yes	84,080	50,340	107,960	61,200	112,450	67,160	56,970	36,380
No	54,070	311,590	69,610	225,270	113,150	252,020	131,420	182,220
Unknown	4,360	8,250	5,330	6,760	6,750	11,710	7,710	6,830

Table IV. Number of deaths with underlying cause of cancer—International Classification of Diseases (ICD) Nos. 140–208—and other causes, by age and survey response: United States, 1986

Survey response	Age and underlying cause of death on death certificate							
	25–64 years		65–74 years		75–84 years		85 years and over	
	Cancer (ICD Nos. 140–208)	Other	Cancer (ICD Nos. 140–208)	Other	Cancer (ICD Nos. 140–208)	Other	Cancer (ICD Nos. 140–208)	Other
	Number							
Cancer								
Yes	152,120	21,530	134,140	23,950	104,710	23,650	35,260	13,860
No	5,420	323,150	5,550	301,940	7,230	413,120	8,400	352,610
Unknown	910	9,550	1,910	8,630	2,140	12,390	570	10,830

Table V. Number of deaths with underlying cause of cancer—International Classification of Diseases (ICD) Nos. 140–239—and other causes, by age and survey response: United States, 1986

Survey response	Age and underlying cause of death on death certificate							
	25–64 years		65–74 years		75–84 years		85 years and over	
	Cancer (ICD Nos. 140–239)	Other	Cancer (ICD Nos. 140–239)	Other	Cancer (ICD Nos. 140–239)	Other	Cancer (ICD Nos. 140–239)	Other
	Number							
Cancer								
Yes	153,190	20,460	135,040	23,050	105,740	22,620	35,720	13,400
No	6,330	322,240	6,300	301,190	7,670	412,680	9,120	351,890
Unknown	910	9,550	1,910	8,630	2,190	12,340	570	10,830

Table VI. Number of deaths with underlying cause of cerebrovascular disease and other causes, by age and survey response: United States, 1986

Survey response	Age and underlying cause of death on death certificate							
	25–64 years		65–74 years		75–84 years		85 years and over	
	Cerebrovascular disease	Other	Cerebrovascular disease	Other	Cerebrovascular disease	Other	Cerebrovascular disease	Other
Stroke				Number				
Yes	11,760	61,040	18,970	102,180	37,590	130,770	32,120	108,440
No	7,630	416,570	7,180	330,790	11,980	363,460	15,690	245,730
Unknown	400	15,290	690	16,310	1,910	17,540	2,980	16,580

Table VII. Number of deaths with underlying cause of chronic obstructive pulmonary disease and other causes, by age and survey response: United States, 1986

Survey response	Age and underlying cause of death on death certificate							
	25–64 years		65–74 years		75–84 years		85 years and over	
	Chronic obstructive pulmonary disease	Other	Chronic obstructive pulmonary disease	Other	Chronic obstructive pulmonary disease	Other	Chronic obstructive pulmonary disease	Other
Asthma				Number				
Yes	3,460	31,840	6,320	26,660	6,350	33,170	810	15,510
No	6,870	455,030	17,530	408,500	20,620	483,520	8,510	382,510
Unknown	400	15,090	980	16,140	1,680	17,900	220	13,970

Chapter 6
Diagnosis of cardiovascular disease in elderly populations

by Millicent W. Higgins, M.D., Associate Director for Epidemiology and Biometry Program, National Heart, Lung and Blood Institute, National Institutes of Health

This paper provides a brief overview of studies of cardiovascular disease (CVD) in the elderly sponsored by the National Heart, Lung and Blood Institute. I will emphasize international collaborative studies but will present information about the magnitude of the problem in the United States as background.

The prevalence of cardiovascular diseases and the numbers of physician's office visits, hospitalizations, and deaths from cardiovascular disease among people ages 65 and over are shown in table A (1–6). The elderly make up only 12 percent of the population but account for a disproportionately large amount of prevalent illness, use of medical services, and expenditures for cardiovascular disease.

Mortality rates for cardiovascular disease rise steeply with increasing age in men and women (figure 1), but rates provide an incomplete estimate of the magnitude of the problem of cardiovascular disease in the elderly. Morbidity data are also available and provide (a) additional information about the frequency and distribution of these conditions by age and (b) help to measure the burden of illness in the elderly.

The Framingham Heart Study initially began with a cohort of middle-aged men and women (30–62 years). For over 40 years, this study has provided unique information about the incidence of different kinds of fatal and nonfatal cardiovascular disease by age and sex for the white population. In both sexes, incidence of cardiovascular disease rises dramatically with increasing age. The most frequent condition is coronary heart disease followed by stroke and congestive heart failure, all of which increase steeply with increasing age. Intermittent claudication is less frequent and does not increase with age after about age 60 (figure 2) (7).

Table A. Selected measures of impact of cardiovascular disease among persons 65 years of age and over: United States, 1980's

Item	*Number*	*Percent*
With hypertension[1]	18,500,000	32
With heart disease	8,900,000	40
With cerebrovascular disease	1,400,000	57
Annual hospitalizations	3,200,000	61
Physician's office visits	27,000,000	48
Annual deaths	800,000	83
Health care expenditures in 1980	$20 billion	60
Population	30 million	12

[1] Blood pressure ≥ 140/90 mmHg or on antihypertensive medication.

SOURCES: Joint National Committee on Detection, Evaluation, and Treatment of High Blood Pressure. Hypertension prevalence and the status of awareness, treatment, and control in the United States. January 11, 1984.

Adams PF, Hardy AM. Current estimates from the National Health Interview Survey, 1988. National Center for Health Statistics. Vital Health Stat 10(173). 1989.

Graves EJ. 1988 Summary: National Hospital Discharge Survey. Advance data from vital and health statistics; no 185. Hyattsville, Maryland: National Center for Health Statistics. 1990.

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At ages over 65, many individuals have more than one of these conditions, and having one cardiovascular condition increases the risk of developing another. Coronary heart disease, congestive heart failure, and atrial fibrillation are strong predictors of stroke

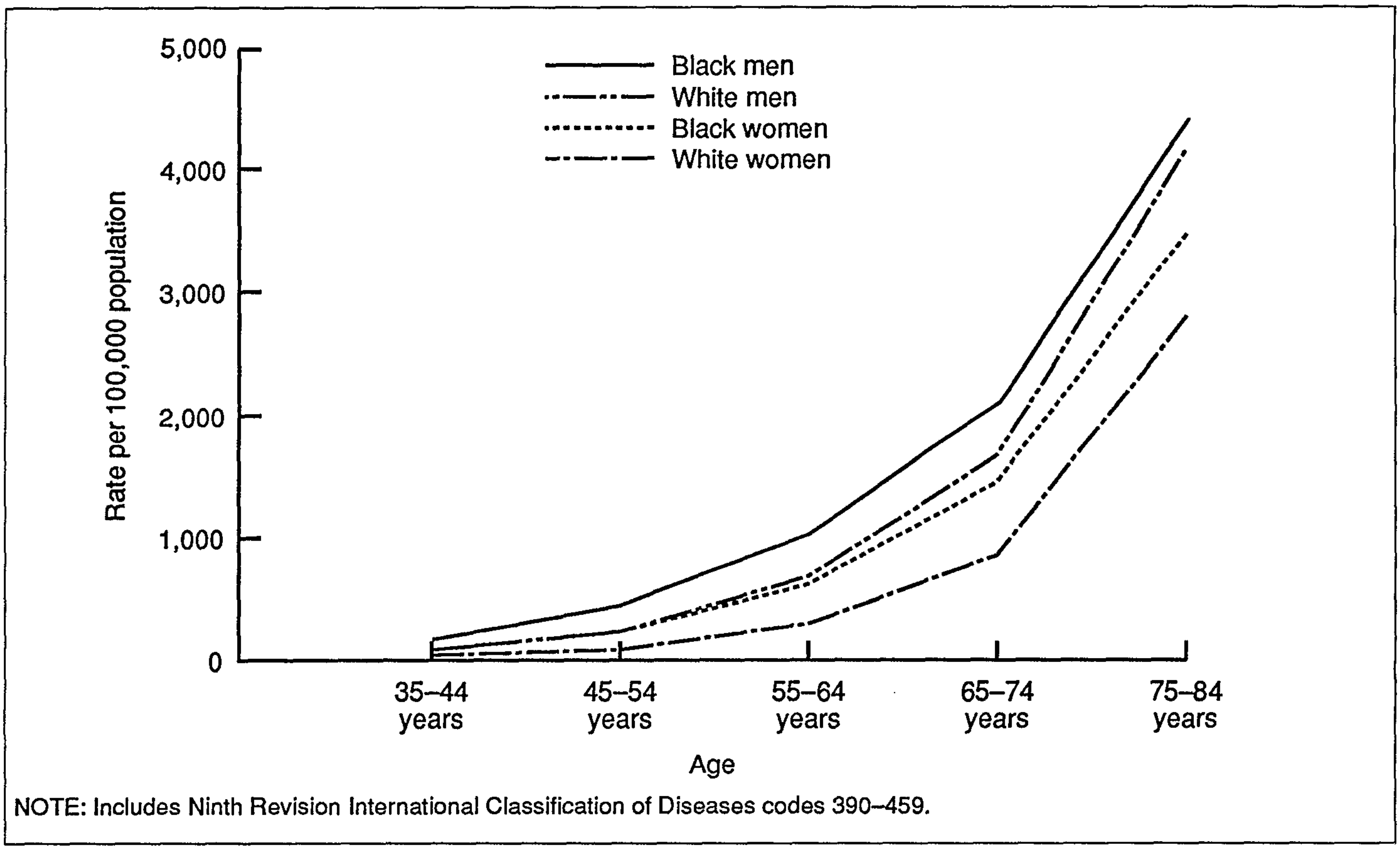
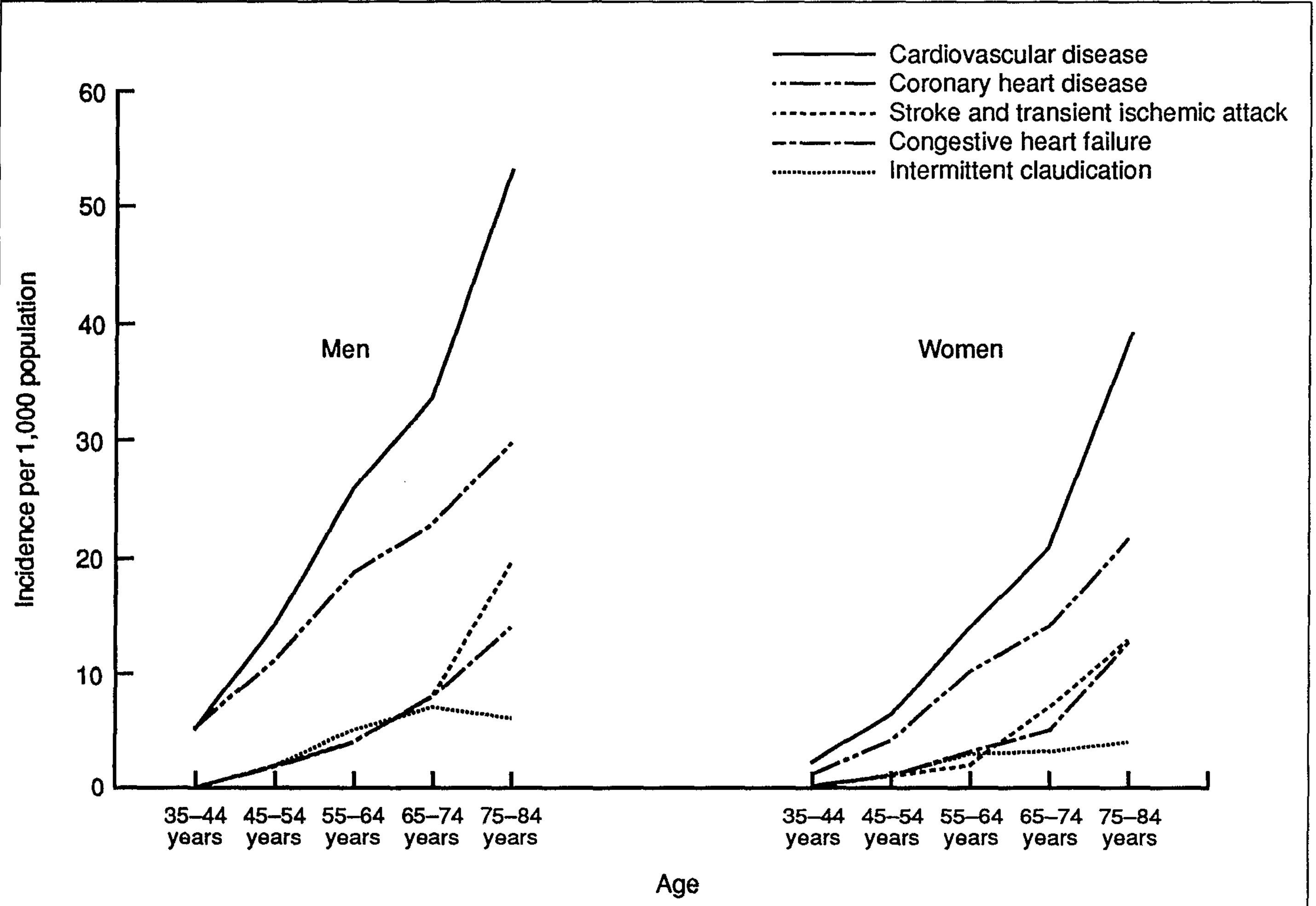


Figure 1. Death rates for cardiovascular disease for persons 35–84 years of age, by age, race, and sex: United States, 1987

occurring at a later age (8). Recently, attention has been drawn to the substantial proportion of myocardial infarctions that are not recognized at the time but are detected when routine electrocardiograms are obtained later. Rates of unrecognized myocardial infarction are higher in women than in men and occur with increasing frequency at older ages in both sexes (9). In the Framingham experience, more than 40 percent of first myocardial infarctions were unrecognized in women, and about 33 percent were unrecognized in men. In interview surveys such as the National Health Interview Survey, information can be obtained only on events that have been diagnosed clinically and are reported by the respondents or their family members. Thus, this measure of the prevalence of coronary heart disease is incomplete.

The Framingham Heart Study was the model for a number of other studies that were added later. These include the Honolulu and Puerto Rico Heart Studies and the Yugoslavia Heart Study. These studies have participated in domestic and international comparisons, as well as in comparisons with U.S. mainland populations, whose experience of cardiovascular disease is substantially different. Similar methods were used in these studies so that comparisons could be made with populations whose mortality rates were lower and whose risk factor levels and distributions provided a broader range of experiences than was available in the United States.

One of the earliest international studies of cardiovascular disease was the Seven Countries Study, which has been reported extensively in the literature (10). The Ni-Hon San Study can be used to illustrate some of the methodologic issues that are important in studies of the elderly. The study of Atherosclerosis Risk in Communities (ARIC), which shares some features in common with the Multinational Monitoring of Trends and Determinants in Cardiovascular Diseases (MONICA) Study, promises to provide new opportunities for international collaboration (11,12). Intersalt is a recent collaborative effort to evaluate blood pressure and its relationship with obesity, sodium and



SOURCE: National Institutes of Health. The Framingham Study: an epidemiological investigation of cardiovascular disease, section 34. NIH publication no. 87–2703. 1987.

Figure 2. Average annual incidence of cardiovascular disease for persons 35–84 years of age, by age and sex: Framingham Heart Study 30-year followup

potassium, and other electrolytes. This study also encompasses a broad range of prevalence rates of hypertension, obesity, and electrolyte intake and excretion (13).

In 1950 mortality statistics indicated that there were substantial differences in death rates for atherosclerotic heart disease and stroke for Japanese men in Japan, Hawaii, and California, as shown in table B (14,15). (For the white population in the United States, rates for coronary heart disease, not shown, were even higher.) Across the Japanese populations, we see that the pattern for stroke is in the reverse direction; death rates were highest for those in Japan, intermediate for those in Hawaii, and lower for Japanese in the United States. Some of the questions that have already been raised about the validity of differences in death certificate entries led to the design of studies that would provide more accurate information about relationships between mortality and morbidity rates and risk factor levels. A major emphasis of the study of coronary heart disease and stroke in Japanese men in Japan, Honolulu, and San Francisco was an attempt to use comparable methods. Although this effort has not been entirely successful, some valid comparisons have made use of information on autopsy findings, morbidity, mortality, and risk factors.

Comparison of electrocardiogram evidence of myocardial infarction showed no significant differences in prevalence between the Japanese in Japan and Honolulu, but there is a substantial difference between these populations and those on the U.S. mainland. The pattern of angina pectoris is similar to that for

Table B. Rate of mortality, incidence, and prevalence of coronary heart disease and stroke for Japanese men ages 55–64 years: Japan, Hawaii, and California

Item	*Japan*	*Hawaii*	*California*
Mortality[1]		Rate	
Coronary heart disease	160	300	464
Stroke	525	300	230
Incidence[2]			
Fatal coronary heart disease	1.0	1.4	---
Hemorrhagic stroke	1.7	0.6	---
Thromboembolic stroke	3.0	0.9	---
Prevalence[3]			
Myocardial infarction confirmed by electrocardiogram	5.3	5.2	10.8
Angina pectoris	11.2	14.3	25.3
Stroke	35.4	10.7	10.4

[1] Mortality per 100,000 in 1950.
[2] Average annual incidence per 1,000.
[3] Prevalence per 1,000.

SOURCES: Yano K, MacLean CJ, Reed DM, et al. A comparison of the 12-year mortality and predictive factors of coronary heart disease among Japanese men in Japan and Hawaii. Am J Epidemiol 127:476–87. 1988.

Takeya Y, Popper JS, Shimizu Y, et al. Epidemiologic studies of coronary heart disease and stroke in Japanese men living in Japan, Hawaii and California: Incidence of stroke in Japan and Hawaii. Stroke 15:15–23. 1984.

coronary heart disease. Stroke prevalence rates were similar for the Japanese populations in Honolulu and California, contrary to expectations; however, there is a major discrepancy between these populations and the Japanese in Japan, who have stroke prevalence rates more than three times as high. Over the course of time, as this originally middle-aged population has advanced in years, we have gained information on incidence in the elderly. The comparisons must be restricted to fatal coronary heart disease and hemorrhagic and thromboembolic stroke, because these conditions could be detected using comparable criteria in the two populations. Again, there are differences in stroke rates between the Japanese residents and the other two cohorts and between coronary heart disease in U.S. mainland residents and the other two cohorts (14). More atherosclerosis was found in the coronary arteries of men in Honolulu than in Japan, but also there was more atherosclerosis in the circle of Willis in Honolulu than in Japan, which was not expected. However, small cerebral artery disease is more frequent in Japan. Investigations are continuing in Japan and Hawaii in the hope that the differences can be explained.

Clearly, comparable methods in examining people and specimens are an important advance. However, it is also important to consider the participation rates and the frequency with which examinations are done, since these aspects of a study can have a marked impact on ability to detect disease, to generalize the results to the populations from which the study subjects come, and to make comparisons between populations living in different areas.

The ARIC Study was established as a collaborative study in the United States to investigate the epidemiology and natural history of atherosclerosis and clinical atherosclerotic diseases in cohorts using new methods of measurement and detection of atherosclerosis by a noninvasive method. New risk factors as well as the established risk factors are being measured (11). Preliminary information is available about variation in cardiovascular disease risk factors, medical care, and disease, by race, sex, and place and over time. The important contribution that this study can make to our understanding of disease in populations is that information about cohorts undergoing detailed examination to detect all manifestations of cardiovascular disease can be related to information from surveillance of the populations from which the cohorts come. Approximately 10 times as many people are included in the community surveillance as in the cohort examinations. Thus, the number of new events is much larger for the community, but the completeness and accuracy of this information may not be as good as information resulting from repeated examinations of the cohort. The goal for surveillance is more circumscribed and is restricted to the investigation of hospitalized myocardial infarctions and fatal coronary heart disease. Approaches to community surveillance for the fatal events include identification of possible coronary heart disease deaths from vital statistics records supplemented by information from the next of kin or other informants and from hospital and physicians' records. Standardized criteria are used to classify the events. Both cohort and surveillance data will be related to national vital statistics information to compare the more detailed information with what is routinely available for the U.S. population.

A pilot study known as the Cardiovascular Community Surveillance Project (CCSP) investigated the ability to use readily available mortality and hospital statistics to identify cases of coronary heart disease and stroke. Potential cases were identified through an initial screening, and variable sampling rates were developed for International Classification of Diseases (ICD) codes. In ARIC sampling, rates are highest for codes with the highest probability of identifying coronary heart disease or stroke events. The sampling fraction for death certificates is 100 percent for ICD codes 410–414 and 429.2, but only 25 percent for codes where ischemic heart disease is less likely to be present (11). Hospital records are abstracted according to primary or secondary discharge diagnoses. The sampling fractions are 100 percent for acute myocardial infarction (ICD–9 code 410); 50 percent for other acute and subacute ischemic heart disease (ICD–9 code 411); 25 percent for old myocardial infarction, angina pectoris, and other forms of chronic ischemic heart disease (codes 412–414); and 10 percent for conditions less likely to yield cases of acute myocardial infarction (ICD–9 codes 402, 427, 428, and 518.4). Diagnostic criteria are based on information about chest pain, cardiac enzymes, and electrocardiograms, which are classified according to the Minnesota code. This strategy is designed as a cost-efficient approach to monitoring cardiovascular events in defined communities.

The National Heart, Lung and Blood Institute qualifies as an associate member of the MONICA Study, sponsored by the World Health Organization, through its ARIC Study. MONICA's objectives are to monitor trends and determinants in cardiovascular mortality, coronary heart disease, and cerebrovascular disease morbidity in participating countries and to relate the trends to changes in risk factors, living habits, health care, and socioeconomic characteristics (12). This study includes 26 countries, many of which are European. There are two sites in North America: One in Canada and one in the United States. There are also centers in New Zealand, Australia, Japan, and China, but developing countries, unfortunately, are not represented adequately. Opportunities certainly exist for extending international collaborative studies of cardiovascular disease to include participants from developing as well as developed countries.

Collaborative studies have provided data not previously available. In addition, these studies have led to the development and use of standardized methods that other researchers can adopt. Greater attention has been paid to quality control and to the training of personnel who can participate in epidemiologic studies. Analyses of performance at different sites over time have shown that agreement was not very good initially, but training and practice and circulation of case histories to all MONICA participants led to improved agreement on classifying events (16).

In conclusion, I would like to comment on trends in cardiovascular disease in the United States, where the elderly population is increasing disproportionately. Despite declining death rates, these diseases continue to be the leading cause of death and a major cause of morbidity. The percentage of various cardiovascular and noncardiovascular diseases that occur among the elderly has increased especially at ages 75 and over (table C). While these trends are favorable, they indicate that cardiovascular diseases will continue to be a major health problem in the older members of the U.S. population. Opportunities for international studies are probably better now than they have ever been. We are aware of opportunities and pitfalls, and we can focus our efforts on collaborative investigations in elderly populations to take advantage of knowledge gained from previous studies of middle-aged populations and to take advantage of new technologies to address unanswered questions.

Table C. Percent of deaths occurring after age 75, by year and cause of death: United States, 1950 and 1988

Cause of death	*1950*	*1988*
	Percent	
Heart disease	36	59
Coronary heart disease	33	59
Stroke	42	68
Cancer	22	36
Chronic obstructive pulmonary disease	26	49
Diabetes	26	46
Pneumonia	32	74
All causes	29	49

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Part III

Health promotion and disease prevention among the aged

Introduction

by Gerry E. Hendershot, Ph.D., Chief, Illness and Disability Statistics Branch, National Center for Health Statistics

In this international collaborative effort on aging for health promotion and disease prevention statistics, our goal is to improve measures of health-related behaviors and use of preventive services among the aged population, and to standardize measures across nations so that comparative analyses can be undertaken. We hope these analyses will reveal some important determinants of the success and failure of health promotion and disease prevention programs.

The countries that are prospectively involved are The Netherlands and the United States. The Netherlands was particularly interesting to us in the U.S. National Health Interview Survey because The Netherlands conducts a national health interview survey that is very similar in important respects to ours. There are also some important similarities and differences in the population characteristics of the two nations that make potential comparisons interesting.

We would like to add other countries to this collaborative effort on health promotion and disease prevention statistics whenever they are available and interested.

Chapter 7
Statistics on health promotion and disease prevention in The Netherlands

by Henk Swinkels, Ph.D., Netherlands Central Bureau of Statistics, Department for Health Statistics

Introduction

Since World War II, the costs of medical care in The Netherlands have increased sharply. The costs of care for different kinds of patients and for the prevention of diseases increased from 1 billion guilders in 1953 to 37 billion guilders in 1987 (table A).

Recent health statistics and epidemiological research have shown that in the last 15–20 years there has been hardly any change in the perceived health status of the population (table B) and that social (table C) and geographic differences still remain.

In 1982, the World Health Organization (WHO) predicted that if the current European development of physical, economic, and social environmental factors continued and people did not behave in a healthier way, there would be a dangerous situation by the year 2000 (1). Health status would decrease absolutely despite the continuing high level of the use of health services. Therefore, Dutch Government policy up to the year 2000 will aim at the promotion of health, given limited provisions. Policy objectives will be expressed as much as possible in terms of the desired improvement in health of the Dutch population. Attention will be drawn to influencing physical, economic, and social environmental factors in order to promote healthier lifestyles. In connection with these objectives, it is necessary to measure relations existing between cultural, social, and other environmental factors, on the one hand, and health, diseases, and the quality of people's lives, on the other.

Health can be seen as a state of balance determined by the circumstances people are in and the power they have, or can get with the aid of others, to defend themselves from disturbances (1, p. 10). An important aspect of this definition of health is its relative meaning with regard to different age groups. Every phase in life has its own threats to health and ways of coping with them. This relative meaning of health is one of the reasons why in The Netherlands a special policy for the elderly exists. Another reason is the increasing number of elderly people. As in many other developed countries, the percentage of elderly people in The Netherlands is increasing rapidly. At the moment the population of The Netherlands amounts to 14.7 million people, among whom there are 1.8 million persons aged 65 years and over (table D). This is 12.4 percent of the total population. Population forecasts of the Netherlands Central Bureau of Statistics predict that persons 65 years and over will constitute about 14 percent in the year 2000 and about 25 percent in the

Table A. Cost of health care as a percent of net national income at market prices: The Netherlands, 1953–87

Year	*Guilders in billions*	*Percent of net national product at market prices*
1953	0.8	3.5
1958	1.4	4.2
1963	2.2	4.7
1968	4.8	5.8
1973	12.3	7.9
1978	23.4	8.7
1983	33.0	9.7
1987	36.8	9.6

SOURCE: Netherlands Central Bureau of Health Statistics. Historical series of The Netherlands, 1899–1989. The Hague. 1989.

Table B. Percent distribution of all adults and elderly adults by perception of general state of health, according to age: The Netherlands, 1970 and 1987

Perception of general state of health and year	*18 years and over*		*65 years and over*	
	Percent	*Standard error*	*Percent*	*Standard error*
Very good				
1970	28.1	1.1	18.9	2.7
1987	27.7	0.6	15.5	1.1
Good				
1970	50.6	1.3	42.4	3.4
1987	52.1	0.6	46.7	1.5
Fair				
1970	12.9	0.8	21.7	2.8
1987	12.1	0.2	22.9	1.3
Not very good				
1970	7.3	0.7	12.9	2.3
1987	5.6	0.3	9.2	0.9
Bad				
1970	1.2	0.3	4.1	1.3
1987	2.5	0.2	5.7	0.7

SOURCES: Swinkels H. Trends in gezondheidsindicatoren, 1970–1984 (Trends of health indicators, 1970–1984). Monthly Bull Health Stat (7):5–15. 1986. (In Dutch with English summary.)

Swinkels H. Trendcyfers Gezondheidsenquite, 1981–1987 (Trend figures, Netherlands Health Interview Survey, 1981–1987). Monthly Bull Health Stat (8–9):14–20. 1988.

Table C. Percent of persons with health status of fair, not very good, and bad, by level of education: The Netherlands, 1983–85

Level of education	*Unadjusted*	*Adjusted for age and sex*	*Standard error*
Primary school	35.2	29.0	0.6
Junior (vocational) training	17.9	20.1	0.5
Secondary (vocational) training	13.9	16.7	0.4
Vocational college	11.9	12.7	0.7
University	12.5	13.2	1.3

SOURCE: Netherlands Central Bureau of Statistics. Netherlands Health Interview Survey, 1981–1985. The Hague. 1988.

Table D. Number and percent distribution of medium variant of population forecast for The Netherlands by age: The Netherlands, 1988, 2000, and 2035

Age	*1988*	*2000*	*2035*
	Number in millions		
All ages	14.7	15.6	14.6
	Percent distribution		
0–19 years	26.9	24.4	20.5
20–64 years	60.7	61.5	54.8
65 years and over	12.4	13.5	24.7

SOURCE: Cruijsen H. Bevolkingsprognose voor Nederland, 1986–2035 (Population forecasts for The Netherlands, 1986–2035). Monthly Bull Popul Stat 2:15–21. 1987. (In Dutch with English summary.)

year 2035. This means that the percentage of persons aged 65 and over is expected to double by the year 2035.

National objectives

In 1984, the Dutch Government accepted the 38 targets developed by WHO (2, p. 5). In The Netherlands these targets are of great importance for national health policy: In fact, they are regarded as identical to health policy. A selection of targets of relevance to the elderly is listed in appendix I. A number of these targets deal with health status, lifestyle, and environmental factors.

The national objectives for health promotion and disease prevention to be presented in this paper and the statistics concerning these objectives are derived mostly from The Netherlands 1988 report, "Health for All by the Year 2000" (2). This report was produced by the Ministry of Welfare, Health and Cultural Affairs in cooperation with the Netherlands Central Bureau of Statistics. The majority of the data in this report are derived from the Netherlands Central Bureau of Statistics and in particular from its Health Interview Survey. The report describes progress toward the targets developed by WHO.

During recent years there has been a shift of emphasis in policy in The Netherlands, which calls for closer observation of the effects of policy on general standards of health (3, p. 132). Increasingly, this is being done in accordance with the methods advocated by WHO. These methods are:

- Setting up health and policy goals.
- Determining indicators against which developments relating to these goals can be measured.
- Monitoring these developments (2, p. 107).

In The Netherlands the Health 2000 memorandum, the national Health for All document, pays close attention to factors outside the bounds of health care, such as physical and social environment and lifestyle. These factors are being taken into account, and the Government has announced its intention to set up preventive measures and intersectional policy. The position of the elderly in Dutch society has been an important area of concern in Government policy for many years now. One of the ways in which this concern is manifested is the Government's interest in the financial problems of those sectors most affected by the aging of the population.

An important topic in health promotion and disease prevention in The Netherlands is the laws, regulations, and programs aimed at protecting the public against the promotion, production, distribution, and use of potentially harmful consumer goods. Dutch policy in this respect is based on the principle that every citizen has the right to health and safety. The Ministry of Welfare, Health and Cultural Affairs has a general responsibility for safety in the home and is specifically responsible for safety with respect to sports and leisure activities, pesticides, and consumer products. In its health policy this Ministry places considerable emphasis on the promotion of healthy, safe lifestyles and on avoiding unnecessary hazards to health.

A second topic dealing with the policy on health promotion and disease prevention is the existence of laws, regulations, and practices integrating representative public participation in bodies responsible for health promotion at all levels. Public involvement in health education and the promotion of healthy living has grown in importance during recent years. Efforts are being made, through supplementary legislation, planning, and funding, to arouse greater public interest in the factors that may positively or adversely affect health, thus enabling the public to make more conscious decisions regarding their health.

A third topic deals with education programs to increase people's knowledge, motivation, and skills to stay healthy. In The Netherlands the following education programs and information campaigns have been initiated:

- The current intensive alcohol information campaign was started in 1987. It is being conducted in the mass media, schools, and health service and constitutes a serious drive to reduce alcohol consumption.
- A multiyear information plan aimed at promoting discussion on tobacco use was completed early in 1988. It focused on preventing young people from starting to smoke, helping smokers to give up smoking, and protecting nonsmokers.

- An important item of the national objectives is the promotion of healthy habits such as maintaining good nutrition, not smoking, getting enough exercise, and coping with stress. With respect to good nutrition, the following should be mentioned: In April 1986 the Nutrition Council issued an advisory report titled "Guidelines on Good Nutrition" (4), which sets out the components of a healthy diet. Over the last few years the Nutrition Council and the Health Council have issued a number of different advisory reports dealing with the link between diet and health, such as "Diet and Cardiovascular Disease" and "Diet and Cancer."

The Nutrition Council recommends that people make efforts to reach an appropriate weight and sums up the following guidelines:

- Make sure your diet is varied.
- Eat fats (particularly saturated ones) in moderation and make sure that you have adequate intake of polyunsaturated fats.
- Eat cholesterol in moderation.
- Make sure that you have an adequate intake of complex carbohydrates and dietary fiber, and avoid eating sugars too frequently and in excessively large quantities.
- Drink alcohol in moderation.
- Use cooking salt in moderation.

As indicated in the Progress Report on Nutrition Policy, which was forwarded to the Parliament in September 1987, these guidelines will serve as a basis for the promotion of sensible eating habits over the next few years.

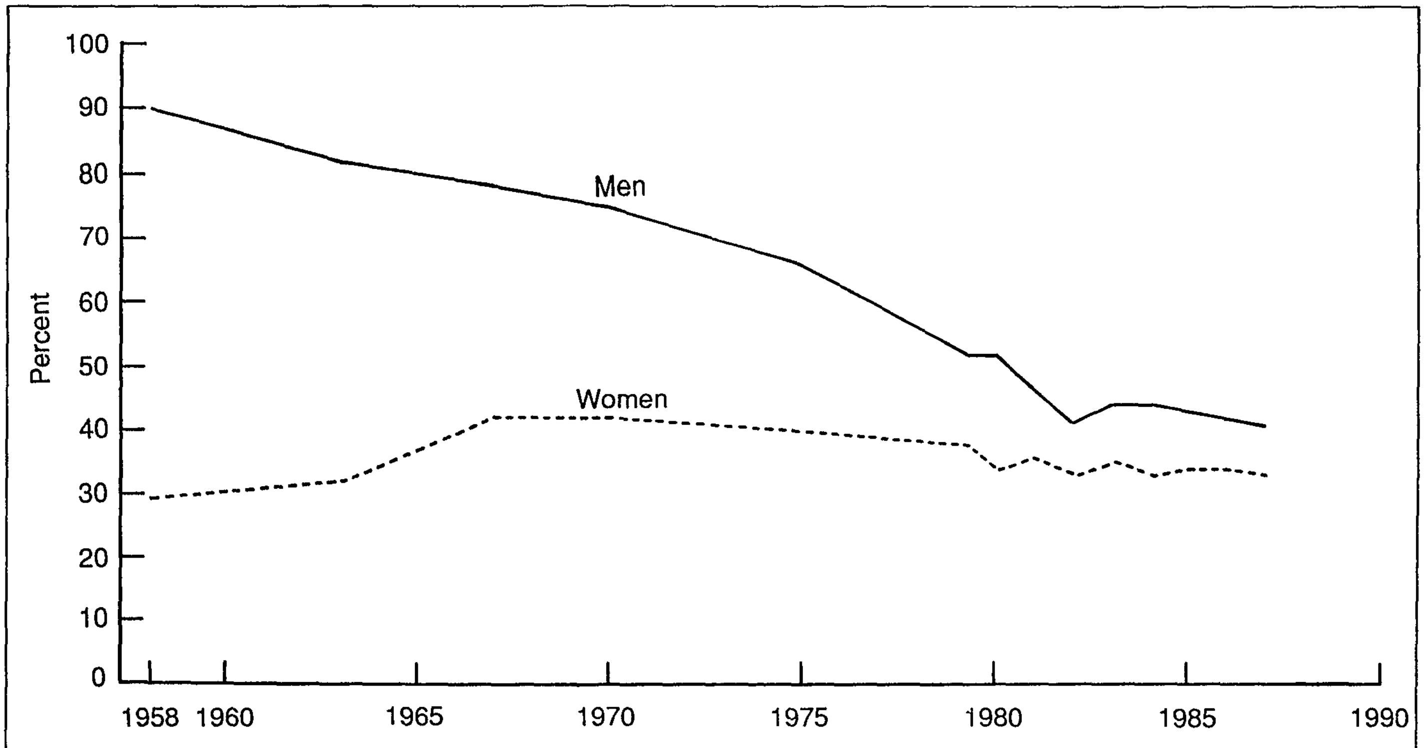
Statistics measuring progress toward national objectives

A joint working group of WHO (Regional Office for Europe) and the Netherlands Central Bureau of Statistics convened in Voorburg on June 21–23, 1988, to discuss common methods and instruments for health interview surveys. The general experience and progress in countries monitoring health in the framework of "Health for All by the Year 2000" by way of health interview surveys was reviewed. Common instruments and methodological issues such as the use, coverage, and precision of indicators were discussed, and special survey topics were submitted. On the last day recommendations and instruments were discussed, and a draft plan for future action was drawn up. Participants came from eight European countries and Japan.

A number of the national objectives data are available now. Some examples follow. According to target 16 of WHO, there should be significant increases by 1995 in positive health behavior, such as nonsmoking, balanced nutrition, appropriate physical activity, and good stress management. "It has been estimated that up to 10 million people in the European Region are at risk of death from illnesses related to smoking between 1980 and the year 2000" (5, p. 66). With respect to nonsmoking, the situation in The Netherlands has already changed positively, as is shown by results of various surveys. Figure 1, based on several surveys in the period 1958–87, shows a decline in the percentage of smokers from 90 to 41 among men but no drastic change among women (6, p. 23).

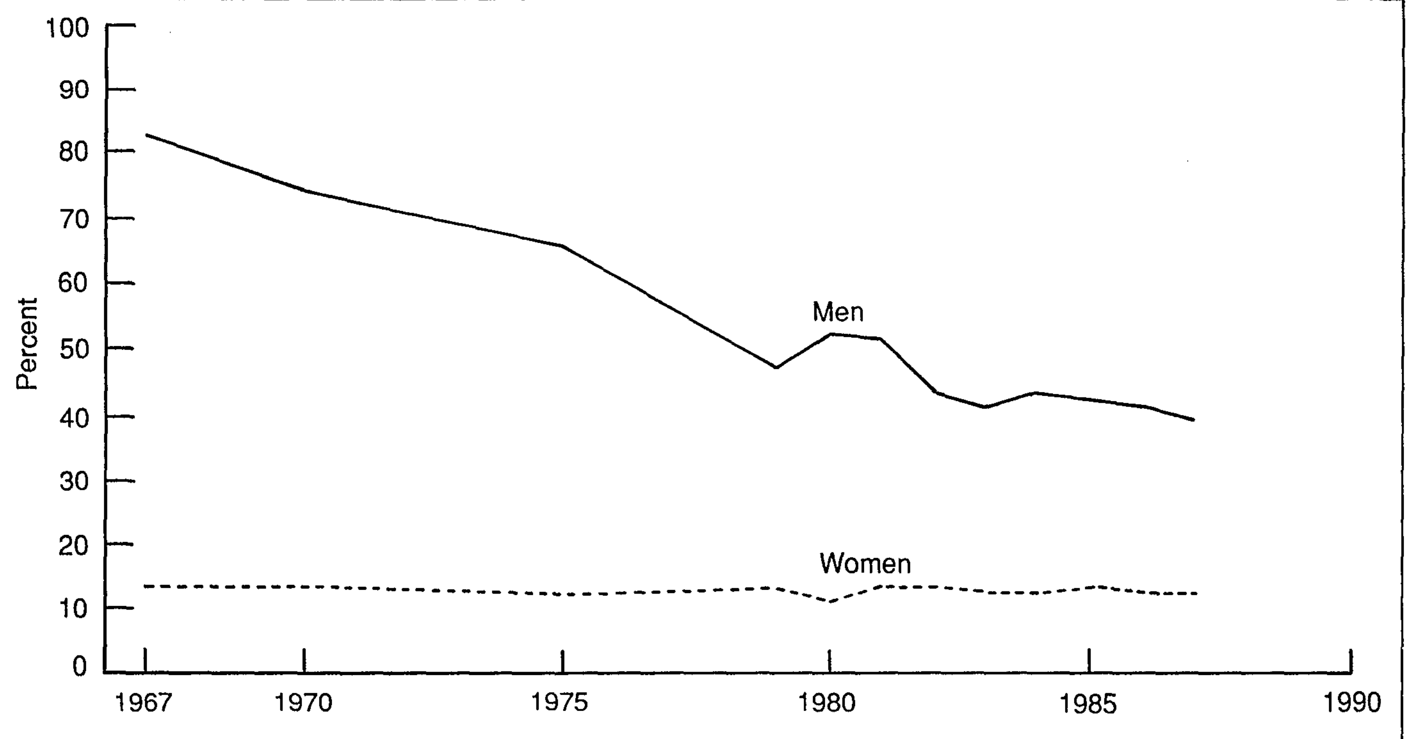
Figure 2 shows the proportion of smokers among persons in the age group 65 years and over from 1967 through 1987. The percentage of smokers in this group declined from 83 to 39 among men and shows a pattern similar to that of the total population. Again, as in the total population, the percentage among elderly women did not change significantly during the period. However, the level of smokers among elderly women is remarkably lower than among the total population of women.

Target 17 of WHO deals with alcohol consumption. The measurement of alcohol consumption by means of population surveys has proven to underestimate consumption levels: A substantial proportion of heavy drinkers are not reached by surveys (nonresponse), and many moderate drinkers seem to underreport their use of alcohol. Nevertheless, it should be realized that population-based surveys are practically the only source on the distribution of alcohol use among the general population. The distribution figures are not perfect, but as a rule are sufficient for many purposes, such as the measurement of trends. Table E shows a decrease in the percentage of nondrinkers from 1983 to 1986, among men from 17 percent to 16 percent and among women from 43



SOURCE: Stichting Volksgezondheid en Roken (Foundation on Smoking and Health). Jaarverslag (Annual report), 1987. The Hague. 1988.

Figure 1. Percent of persons 15 years of age and over who smoke, by sex: The Netherlands, 1958–87



SOURCE: Stichting Volksgezondheid en Roken (Foundation on Smoking and Health). Jaarverslag (Annual report), 1987. The Hague. 1988.

Figure 2. Percent of persons 65 years of age and over who smoke, by sex: The Netherlands, 1967–87

Table E. Percent of persons who are nondrinkers, by sex and age: The Netherlands, 1983 and 1986

	Men		Women	
Age	*1983*	*1986*	*1983*	*1986*
		Percent		
Total	17	16	43	38
18–24 years	16	14	42	33
25–34 years	9	12	27	28
35–44 years	9	11	31	29
45–54 years	14	12	43	34
55–64 years	27	22	56	50
65–74 years	33	25	60	54
75 years and over	42	38	75	63
		Number		
Sample size	1,952	1,982	2,039	2,065

SOURCE: Ministry of Welfare, Health and Public Affairs. Health for all by the year 2000, Rapportage Nederland 1988 (Report of The Netherlands, 1988). Rijswijk. 1988.

Table F. Percent of persons who are overweight, by age: The Netherlands, 1981–87

	18 years and over		65 years and over	
Year	*Percent*	*Standard error*	*Percent*	*Standard error*
1981	15.9	0.4	27.1	1.3
1982	15.1	0.4	23.1	1.3
1983	15.7	0.4	25.5	1.3
1984	16.1	0.4	27.4	1.3
1985	16.0	0.4	26.0	1.3
1986	16.2	0.4	25.3	1.3
1987	16.4	0.4	28.3	1.3

NOTE: Overweight persons are those with a body-mass index ≥ 27.0.

SOURCE: Verweij GCG. Developments in underweight and overweight, 1901–1989. Monthly Bull Health Stat 11:5–10. 1989. (In Dutch with English summary.)

percent to 38 percent. In both groups the decrease is mainly in the elderly population.

Given the present state of Dutch eating habits, high fat consumption is the main problem. The nature and quantity of the fats in the diet and their cholesterol content have been linked with cardiovascular disease. There is also thought to be a correlation between the amount of fat in the diet and cancer, particularly breast cancer and cancer of the large intestine. In The Netherlands, fats account for approximately 40 percent of total energy intake. According to the Nutrition Council's report, fat consumption should be reduced to 30–35 percent of the daily energy intake. This should preferably be achieved by cutting down the intake of saturated fats. In view of this, the emphasis of nutrition policy for the next few years is placed on reducing the consumption of fats, especially saturated fats. A large-scale survey of the dietary habits of the Dutch public was started in 1987. This survey involves a representative sample of 2,000 households. Over a 2-day period, the members of each household note their food and drink intake, including quantities. The data are being collected over a whole year so as to take account of seasonal fluctuations. The dietary intake will be calculated with the help of the Netherlands Nutrients Database. This large-scale diet survey is planned to be repeated in a few years' time, so it will be possible to calculate whether fat consumption has been reduced. Data on overweight are available from the Netherlands Health Interview Survey. These data show no significant changes from 1981 to 1987 (table F).

The Netherlands continuous Health Interview Survey has yielded invaluable data for health management, planning, and evaluation. Hitherto, many new data contributed to government decisions. Existing statistics have been complemented with extra data from the Health Interview Survey, which has increased their usefulness substantially (3, p. 129).

The Netherlands Health Interview Survey contains a supplementary part whose contents vary from year to year. This part is reserved for items that do not require continuous measurement but for which only periodic information is needed. In addition, supplements are also suited to evaluate political decisions within a reasonable timespan. In the 1989 survey, this part will contain a number of questions about smoking, drinking, and eating habits. The integration of the supplementary part into the continuous part makes it possible to relate these questions about smoking, drinking, and eating habits to characteristics from the continuous part of the survey, such as sociodemographic variables, health indicators, and data on medical consumption.

In future Health Interview Surveys, it will be possible to include these (and other) questions again in order to measure trends. Some general information about the Netherlands Health Interview Survey can be found in appendix II.

Acknowledgment

The views expressed in this paper are those of the author and do not necessarily reflect the position or policies of the Netherlands Central Bureau of Statistics.

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Appendix I
Health promotion and disease prevention targets for the elderly

In 1984 the 33 Member States of the European Region accepted the 38 targets for Health for All developed by WHO (2). A tentative selection of these targets of relevance to the elderly with respect to health promotion and disease prevention is listed below.

Target 1. Reduction of the differences—By the year 2000 the actual differences in health status among countries and among groups within countries should be reduced by at least 25 percent by improving the level of health of disadvantaged nations and groups.

Target 13. Healthy public policy—By 1990 national policies in all Member States should ensure that legislative, administrative, and economic mechanisms provide broad intersectoral support and resources for the promotion of healthy lifestyles and effective participation of the people at all levels of such policymaking.

Target 14. Social support systems—By 1990 all Member States should have specific programs that enhance the major roles of the family and other social groups in developing and supporting healthy lifestyles.

Target 15. Knowledge and motivation for healthy behavior—By 1990 educational programs in all Member States should enhance the knowledge, motivation, and skills of people to acquire and maintain health.

Target 16. Positive health behavior—By 1995 in all Member States there should be significant increases in positive health behavior, such as balanced nutrition, nonsmoking, appropriate physical activity, and good stress management.

Target 17. Health-damaging behavior—By 1995 in all Member States there should be significant decreases in health-damaging behavior, such as overuse of alcohol and pharmaceutical products, use of illicit drugs and dangerous chemical substances, and dangerous driving and violent social behavior.

Target 18. Multisectoral policies—By 1990 Member States should have multisectoral policies that effectively protect the environment from health hazards, ensure community awareness and involvement, and support international efforts to curb hazards affecting more than one country.

Target 19. Monitoring and control mechanisms—By 1990 all Member States should have adequate machinery for monitoring, assessing, and controlling environmental hazards that pose a threat to human health, including potentially toxic chemicals, radiation, harmful consumer goods, and biological agents.

Target 20. Control of water pollution—By 1990 all people of the Region should have adequate supplies of safe drinking water, and by the year 1995 pollution of rivers, lakes, and seas should no longer pose a threat to human health.

Target 21. Control of air pollution—By 1995 all people of the Region should be effectively protected against recognized health risks from air pollution.

Target 22. Food safety—By 1990 all Member States should have significantly reduced health risks from food contamination and implemented measures to protect consumers from harmful additives.

Target 23. Control of hazardous wastes—By 1995 all Member States should have eliminated major known health risks associated with the disposal of hazardous wastes.

Target 24. Human settlements and housing—By the year 2000 all people of the Region should have a better opportunity to live in houses and settlements that provide a healthy and safe environment.

Appendix II
The continuous Netherlands Health Interview Survey

Since January 1, 1981, the Netherlands Central Bureau of Statistics (CBS) has been conducting a continuous Health Interview Survey. The aim of the survey is to give a picture of the trends in health and medical consumption of the Dutch population that is as complete as possible. To this end, respondents are interviewed about, among other subjects, their state of health; restricted activity; sick leave; consultations with general practitioners, specialists, and dentists; hospital admittance; and use of medication. At the same time, questions about various personal and background characteristics are also asked.

The survey is conducted among a random sample of residential addresses (excluding homes for aged and institutions). The survey is divided into 26 subsamples evenly spread over the year, i.e., one for each 2-week period. In principle, all residents at the selected addresses are interviewed (except in the case of refusals); since 1983, however, a maximum of four persons are interviewed. If a household consists of more than four persons, the head of the household and (where applicable) his or her partner are interviewed, followed by two other members of the household who are chosen based on whose birthday comes soonest after the date of the interview. The figures are corrected for the underrepresentation resulting from this method.

Nonresponse amounts to about 35 percent. For this reason, the results may be slightly distorted, although it is difficult to establish to what extent. The response group (approximately 10,000 persons a year) corresponds fairly well with the Dutch population. As a rule, a weighting scheme is applied for differences that might arise between the composition of the sample and that of the overall population.

The 1984 version of the Health Interview Survey questionnaire has been translated into English. Questionnaire A is completed for every responding household; questionnaire B, for household members aged 16 years and over. Questionnaire C (for children under 16 years of age) is an abbreviated form of B and has not been printed in English. Finally, D is a self-administered questionnaire for those who already have replied to B. The English versions of the 1984 questionnaires give a good impression of the content of the survey from 1981 until now, although there have been some changes. The major part of questionnaire D was used only in the period 1983–85. During 1986–88, a substantial part of the survey will deal with the measurement of impairment and disability. This part has been developed along the lines of the International Classification of Impairments, Disabilities and Handicaps. In 1989, additional information will be gathered on tobacco use, drinking, and eating habits. The total number of questions amounts to about 50; they have not been translated yet.

The results of the Health Interview Survey are published in the Monthly Bulletin of Health Statistics through quarterly and annual figures on medical consumption and restricted activity as well as articles that examine certain subjects in closer detail. In addition, figures are included in other CBS publications, such as the Compendium of Health Statistics, The CBS Pocket Yearbook, The Statistical Yearbook, and Vademecum of Health Statistics.

Chapter 8
Health promotion among the aged in the United States

by Gerry E. Hendershot, Ph.D., Chief, Illness and Disability Statistics Branch, National Center for Health Statistics

As used in the United States, the term "health promotion and disease prevention" refers to a wide range of programs and activities that elude any simple definition. For purposes of this presentation, however, I mean to include programs that intervene to increase the early use of preventive services in the population, and programs that intervene to improve the health-related habits of individuals in the population.

In 1980 the United States established national objectives for health promotion in this Nation to be achieved by 1990. As the Federal agency responsible for providing health statistics for the Nation, the National Center for Health Statistics (NCHS)—and especially its National Health Interview Survey (NHIS)—has had a major role in tracking progress toward the national objectives. Because the focus of most health promotion activities has been on young and middle-aged persons, the NHIS data have not been especially well suited to describing the status and progress of health promotion among the elderly. The participation of NCHS in this International Collaborative Effort (ICE) is intended to correct that shortcoming by developing better measures of health promotion and disease prevention among the aged.

The purpose of this paper is to review in greater detail the national objectives for health promotion, the use of NHIS for tracking those objectives, the need for objectives and tracking specific to the aged population, some international comparisons already undertaken using NHIS, and the objectives of the ICE on health promotion.

National objectives for health promotion

In 1980 the Surgeon General of the United States published a set of health objectives for the Nation to be achieved by 1990. The objectives were developed by groups of subject matter experts from government and nongovernment organizations. There were 256 specific objectives grouped in 15 priority areas, and each objective specified a goal that could be measured quantitatively. For instance, one objective was to reduce the proportion of adults who smoke to 25 percent. A new set of Objectives for the Year 2000 is being prepared and will be announced in 1990.

By all accounts, the national objectives have had substantial effects on research, policy, and programs. Their existence and authority have provided guidelines for decisions at every level of government—Federal, State, and local—and in the private sector as well.

One aspect of the objectives, and one reason for their success, was a system to track progress toward their achievement. Because the objectives were stated quantitatively, they could be measured by a variety of statistical data systems. Our interest in this report is in using NHIS for tracking progress toward the national objectives.

NHIS represents the civilian noninstitutionalized population of the United States. The survey is based on a multistage, area probability sample of 50,000 households, a population of 125,000 persons. NHIS is cross-sectional in design, although it includes a capability to do followup longitudinal studies as well. The survey is in the field throughout the year, with each week's interviewing assignment constituting a nationally representative sample. The data are collected by means of face-to-face, standardized interviews in the homes of the sample families. The questionnaire has two parts: An unchanging set of basic questions about health status, health care, and demographic characteristics (the core questionnaire); and one or more sets of questionnaires on special health topics that change each year (supplements).

Both core and supplement data from NHIS have been used to track progress toward the 1990 Objectives, but the focus in this paper will be on NHIS supplements used for that purpose. In 1985 NHIS included a special supplement on Health Promotion and Disease Prevention that was designed to measure progress toward many of the 1990 Objectives, including reducing smoking, encouraging exercise, practicing good nutrition, and controlling hypertension. For that survey one adult was randomly selected from each NHIS sample family, for a total of 32,000 completed interviews. (The NHIS sample was only three-fourths of its full size that year because of budget limitations.)

The 1985 survey will be repeated in 1990 using essentially the same questionnaire, with minor modifications to correct problems in the earlier questionnaire. Again, one adult will be randomly selected in each NHIS sample family, for an expected 47,000 completed questionnaires. (The 1990 NHIS sample will be full size.)

To provide baseline data for the new Year 2000 Objectives for the Nation, scheduled for publication in 1990, the 1991 NHIS will include a special questionnaire on health promotion. Plans beyond that are less certain, of course, but it seems probable that the 1991 survey will be repeated at the midpoint and endpoint for the objectives, 1995 and 2000.

These several surveys demonstrate that NHIS has a major and continuing involvement in measuring behaviors related to health promotion and disease prevention in the United States.

Aging and health promotion

In the *Proceedings of the Surgeon General's Workshop on Health Promotion and Aging* (1) the following statement is found:

> The 1990 Objectives did not adequately address this population.... This time we know more about the effectiveness of health promotion for this age group.... One national strategy must be to balance curative medicine with preventing disease and promoting health.... Leading chronic conditions afflicting older people...respond to health promotion interventions such as exercise, healthy diet, and early care.

The statement reflects the growing recognition between the formulation of the 1990 Objectives and the preparation of the Year 2000 Objectives that it is important to consider the older population when setting objectives for health. That growing interest has affected the drafting of the Year 2000 Objectives: One of the 21 priority areas in the draft objectives is to "maintain the health and quality of life of older people." That priority area will include numerous specific, quantitative goals related to the older population. With the elevation of health promotion for the aged to the level of a national priority, it has become imperative that improvements be made in the data systems used to track progress toward this objective.

The need for better data on health promotion among the aged was recognized by a panel of experts convened by the U.S. National Academy of Sciences, whose report (2) included these recommendations:

- That modules of health promotion items be developed that are appropriate for the elderly.
- That these survey modules be tested on the elderly.
- That successful modules be incorporated in surveys such as NHIS.

Implicit in these recommendations (and explicit in the report itself) is that the health promotion modules now in use in NHIS are not fully appropriate to the aged population, nor have they been fully tested on the aged population.

NHIS measures of health promotion variables

While it is not possible in this brief presentation to review the many NHIS measures of health-related behavior, two will be considered here—smoking and physical exercise—to illustrate the kinds of data collected and some problems with these measures for the aged population.

One of the 1990 Objectives was to reduce the prevalence of cigarette smoking. The 1985 NHIS showed that among persons 65–74 years of age, the prevalence of smoking was about 22 percent for men and 18 percent for women; among persons 75 years of age and over, the corresponding rates were 15 and 7 percent. Among persons 65–74 who had ever smoked, 71 percent of men and 57 percent of women had stopped smoking by 1985; the corresponding figures for persons 75 years of age and over were 77 and 72 percent.

While these findings indicate that the prevalence of smoking among older persons is relatively low and large proportions have quit smoking, there are problems with interpreting this as a success in terms of the objectives. For instance, because smoking increases the risk of mortality from several causes, the older persons who survived to be included in NHIS would disproportionately include persons who never smoked and persons who stopped smoking early in life. For an adequate understanding of the risk in the older population from smoking, information about the duration of smoking and duration since quitting is also needed.

Another of the objectives was to increase the proportions of people who get regular exercise. To measure physical activity, the 1985 NHIS asked questions about 22 leisuretime activities, such as jogging, playing volleyball, and playing baseball. If any of the activities were reported to have been engaged in during the 2 weeks before the interview, information was obtained about the frequency, duration, and intensity of the activity. The information was used to estimate the number of kilocalories (kcal) expended per kilogram (kg) of body weight per day, and that measure was used to classify the population in categories of physical activity.

Among persons 65–74 years of age, the percent "very active" (3 kcal/kg/day) was 29 for men and 15 for women; for persons 75 years of age and over, the corresponding percents were 14 and 7. The meaning of these figures in terms of health objectives for older persons is not clear, because many of the questions asked were about activities not often engaged in by elders, and perhaps not even appropriate for them. Conversely, many physical activities that are appropriate for elders were not on the list of questions asked. Furthermore, the standard for "very active" was applied to all age groups, whereas the standard probably should vary across age groups to account for changes in physical condition associated with age.

International comparisons

These problems of measurement in NHIS will be compounded by issues of comparability when efforts are made to make international comparisons, the goal of the ICE. Some comparisons have been made between the 1985 NHIS on health promotion and a health promotion survey done in Canada in the same year. While the comparisons did not focus on the elderly populations of the two nations, they do illustrate some of the opportunities and problems in international comparisons.

Considering two types of health-related behavior, smoking and exercise, comparison of the United States and Canada showed that smoking was equally prevalent among men in the two countries but lower for women in the United States than in Canada. With respect to the important measure used earlier—quitting smoking—no comparison could be made between the two countries because those data were not available in the Canadian survey.

There was no measure of kcal/kg/day in the Canadian survey, but both it and the U.S. survey asked a more general question about the level of physical activity. According to that less precise measure, both men and women in Canada were more likely than their U.S. counterparts to be "regularly active."

These two brief examples of comparisons between two neighboring countries with many cultural similarities underscore the problems likely to be encountered in international comparisons of data from health promotion surveys.

Objectives for the ICE

The U.S. Health Objectives for the Year 2000 probably will make health promotion for the aged population a priority topic. NHIS will be an important data source for setting objectives for the aged and for tracking progress toward them. As pointed out by experts in the aging field, NHIS does not currently use health promotion questions designed for and tested on the aged population. Other nations, such as Canada and The Netherlands, have conducted surveys on health promotion and are facing some of the same data demands and survey problems experienced in NHIS. By sharing the experiences of those nations, it may be possible to improve and standardize some health promotion data items for the elderly, and that will make it possible to make international comparisons.

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Chapter 9
Optimal survey research methods for studying health-related behaviors of older people

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Professor of Medicine, Boston University

I was invited to focus on optimal research methods for studying health-related behaviors of older people in household surveys. Given the well-documented aging of our population and the need for valid and reliable data on which to base sound social policy, the issue of research methods appropriate to older people is becoming increasingly important. Obviously, with limited time and space available, my discussion must be highly selective: In fact, I am going to consider only four issues. First, and by way of background, we shall review some of the social and health characteristics of older people that can influence the success of any field approach. Second, mixed or multimode data gathering and its particular advantages with older populations is discussed. Third, the promise and appropriateness of inhome physical measurement protocols, especially in studies of older people, are reviewed. Finally, the much neglected issue of interviewer and fieldworker training for studies of older people is highlighted. Wherever possible, key points will be illustrated from ongoing field research work with older people being conducted by staff at the New England Research Institute (NERI).

Social characteristics and health status

Field studies of older people living independently in the community present a great challenge to researchers because the social and physical characteristics of older people obviously influence their willingness and/or ability to participate in research studies. Consider, for example, the social situation of the oldest old (persons 75 years of age and over). People in this age group are more likely than younger people to be women (71 percent), to be widowed (72 percent), to live alone (45 percent), and to have little formal education (48 percent have 8 years or less). Such characteristics influence the relative success of different field approaches. For example, the proportion of older people living alone (which is the situation of one of two women 85 years of age and over) may affect the success of in-person interviewing in the community. There are numerous reports from community leaders and media sources that older people living in large cities are fearful for their personal safety and therefore are likely to exhibit reluctance to permit strangers (i.e., research workers) to enter their homes to ask personal questions. In the United States, widespread fear of drug-related violence and mugging, especially among inner-city elderly, probably influences the success of in-person interviewing. Recognizing these risks, many community groups attended by older people advise their members not to answer personal questions on the telephone or to let strangers into their homes.

Having perhaps even greater impact on participation in research are the health and functional status of the oldest old. Without appreciation of the physical limitations and social circumstances of older people and appropriate adjustment of traditional field methods in order to accommodate older people and facilitate participation, both response rates and data quality are compromised.

In the context of these limitations common among older people, the use of proxies is attracting considerable attention: It offers the promise of obtaining at least some (otherwise lost) information on people who are unable to participate in a study (1–3). Several studies reveal that responses by proxies correlate highly with self-reports in areas such as functional and mental health, life satisfaction, and depression (4). But there are limitations: Proxies apparently rate mental health and depression as worse than do respondents themselves. NERI researchers are conducting a study to determine the validity of data obtained from primary informal caregivers and different categories of institutional staff concerning older people in nursing homes (5).

Rather than reflecting an unwillingness to respond, nonresponse may result from an inability to respond to an inappropriate field approach. Table A summarizes some health statistics for the elderly that determine which field approaches are feasible. Among people 75 years of age and over, about 4 out of 10 have hearing impairments, with about 40–60 percent experiencing difficulty even with a hearing aid (6–8). One out of every four people 85 years of age and over reports trouble with vision, with around 50 percent experiencing difficulty seeing even with glasses. Difficulty getting out of bed or a chair (regarded as a good indicator of severe limitation of activity) is a common experience among people 75 years of age and over, with marked differences between men and women. For example, 12 percent of men 85 years and over, compared with 22 percent of women the same age, experience such difficulties. Difficulty grasping small objects (such as a pen) ranges from 8 percent in men 65–74 years to 16 percent among women 85 years and over.

The recognition that some aspects of cognition decline in older age is the source of major concern about survey data quality with older people (9,10). Excellent work, principally by Herzog and her colleagues at Michigan, has been undertaken on the quality of older adults' survey responses, by comparing the responses to external records or by using a multimethod-multitrait approach and then contrasting the validities obtained with those of middle-aged and younger adults. No substantial differences have been detected. Although survey questions often produce errors in response, generally these are little different among older and younger respondents (11–16).

Researchers focusing on older populations must weigh the advantages and disadvantages of the different approaches to obtaining quality data and the appropriateness of these approaches given the physical limitations and social characteristics discussed above. For a long time, the face-to-face, or in-person, interview was thought to be the only way to obtain valid and reliable information; it has become the "gold standard" for field methods in social and epidemiologic research. Even today, there are some who still regard it as the only approach, but that situation seems to be

Table A. Percent of persons 65 years of age and over, by age, sex, physical limitations, and social characteristics: United States, January–June 1984

Respondent characteristic	*Total 65 years and over*	*65–74 years*		*75–84 years*		*85 years and over*	
		Male	*Female*	*Male*	*Female*	*Male*	*Female*
Physical limitation				Percent			
Hearing	27.8	30.0	17.5	39.9	28.2	58.3	44.3
Difficulty even with hearing aid[1]	38.9	40.8	27.2	52.3	40.6	66.1	60.9
Vision	12.8	9.7	9.4	16.7	15.6	25.0	27.5
Difficulty even with glasses[2]	31.1	23.3	25.8	38.0	40.0	45.0	55.9
Difficulty getting out of bed or chair	8.0	4.8	7.0	5.9	11.2	12.7	22.2
Difficulty grasping small objects	10.7	8.1	10.5	9.6	14.1	10.3	16.4
Social characteristic							
Lives alone	31.8	13.6	35.5	19.0	52.9	28.3	52.9
Lacks telephone	3.1	3.9	2.3	4.4	2.5	5.4	3.7
Less than 5 years at current address	17.2	18.3	18.0	13.9	15.9	14.1	20.1

[1] Among individuals who wear hearing aids.
[2] Among individuals who wear glasses.

SOURCE: National Center for Health Statistics. Supplement on Aging, National Health Interview Survey. 1984.

changing for a number of reasons: (a) there has been a temporal decline in response rates in face-to-face surveys; (b) in-person interviewing of large numbers in the community is prohibitively expensive, especially because of the labor costs for fieldworkers; (c) unlike the situation in the 1940's and 1950's, when in-person interviewing became well established, there is public concern about strangers and issues of security (which sometimes make it difficult for fieldworkers to obtain access to respondents' homes); and (d) there appears to be a perceived danger to fieldworkers today, although we have yet to uncover evidence of any harm experienced by workers in the field.

Table B summarizes some of the well-known advantages and limitations of the major field approaches: In-person interviews, telephone interviews, and mail questionnaires. (See also (9,17–24).) Clearly the mail questionnaire has distinct cost advantages over telephone and in-person interviewing, which are the more expensive field approaches. Larger sample sizes can be obtained cost efficiently with mail questionnaires and telephone interviews, while in-person interviews generally permit only a relatively small group to be reached. For the cost of 25 cents, one can mail a questionnaire anywhere in the United States, including Alaska and Hawaii. Telephone interviews are more expensive than mail questionnaires (mainly because of interviewer labor), while in-person interviews, especially across a broad geographic area, are by far the most expensive. Mail questionnaires have well-known disadvantages, however. Their response rates are usually quite low (around 50 percent), questionnaires must be very brief, and only limited and quite superficial information can be obtained.

Table B. Advantages and limitations of 3 major field approaches to surveys

Survey characteristic	*In-person (face-to-face) interview*	*Telephone interview*	*Mail questionnaire*
Cost	I	A	H
Sample size	I	A	H
Geographic dispersion	I	A	H
Response rate	H	A	I
Duration of study	I	H	A
Length of interview	H	A	I
Type of information	H	A	I
Data quality:			
Correct respondent questioned	H	H	I
Questions comprehended	H	H	I
Minimization of item nonresponse	H	H	I

NOTE: H = highly appropriate; A = appropriate; I = inappropriate.

Data quality clearly varies by mode. For the mail questionnaire, for example, one is never sure that the correct respondent completed the instrument or that the questions were comprehended, and nothing can be done about item nonresponse, which can occur at high rates. With in-person and telephone interviews, however, one can check that the correct respondent is being addressed, there can be confidence that the question is comprehended, and when appropriate, prompts and some explanation of the question can be provided. Well-trained interviewers, with appropriate monitoring, can significantly minimize item nonresponse. The subject of interviewer training is addressed again below.

Generally speaking, the telephone interview is the most cost-efficient approach, and it is certainly feasible in many areas of research with older people. (See especially (24,25).) While both the mail questionnaire and the in-person interview have advantages (indicated by A or H in table B), they also have obvious disadvantages (indicated by an I) that are not shared by the telephone interview. In our experience, there is virtually no self-report information that cannot be reliably obtained over the telephone with a well-designed instrument and appropriately trained interviewers. Unless physiologic values are required, the in-person interview appears to constitute a suboptimal approach in studies of older populations and a costly luxury from which researchers must be weaned, especially during these economically stringent times for sociomedical research.

When in-person interviewing became well established in the 1950's, only about 40–50 percent of the American public had telephones, and therefore in-person interviewing was the optimal approach. Today, however, almost all older people have telephones, making this a very attractive mode of data gathering (26). Even for the 20–30 percent of potential respondents who may have unlisted telephone numbers (often older women who are fearful for their safety), random-digit-dialing techniques are well developed and permit easy contact with otherwise unreachable respondents (27).

Mail questionnaires have also become more feasible and attractive as a result of the improved and well-tested techniques developed by, for example, Dillman (28,29). Such work ensures acceptable response rates through use of a well-developed sequence of tested steps and attention to the formatting of questions, the length of the instrument, the weight and color of the paper, the way inserts should be folded, the days on which mailings should occur, and so forth. Additionally, technological improvements in microcomputing and memory typewriting make it possible to implement and monitor larger and more complex field designs. We need a Dillman total design method of mail and telephone surveys developed specifically for use with older populations.

The promise of mixed-mode field approaches

Given the common impairments of the oldest old, choosing an appropriate field approach requires discrimination. From table C it is clear that, even within a single study, what may be appropriate and acceptable to some older respondents may be quite inappropriate and disagreeable to others. For example, it is appropriate to distribute mail questionnaires to people who are hard of hearing, but unrealistic to undertake telephone interviews. It may be possible, depending on the skill of the interviewer, to conduct an in-person interview in this situation. Conversely, the sight impaired can complete in-person and telephone interviews but cannot be expected to complete a mail questionnaire. Homeless people are, of course, also site impaired, so mail questionnaires and telephone interviews are out of the question. People with major speech or language pathology (as a result of stroke, for example) cannot easily undertake a telephone interview but may be able to complete a mail questionnaire and, depending on the skill of the interviewer, may be able to complete an in-person interview. Fear of strangers and concern for personal safety may rule out in-person interviews with some respondents but make mail questionnaires and telephone interviews quite acceptable (if sufficient preparatory work is done with community groups and leaders to establish the legitimacy of the study).

Table C. Advantages and limitations of 3 major field approaches to surveys of persons 75 years of age and over, by respondent characteristics

Respondent characteristic	*In-person (face-to-face) interview*	*Telephone interview*	*Mail questionnaire*
Hard of hearing (deaf)	?	I	A
Sight impaired (blind)	A	A	I
Speech or language pathology	?	I	A
Arthritis, tremors, or paraplegia	A	A	I
Fear of strangers	I	A	A

NOTE: A = appropriate; I = inappropriate; ? = possible.

The need to combine different field approaches in studies of older people is illustrated by experience in the Established Populations for Epidemiologic Studies of the Elderly, supported by the National Institute on Aging. This project at different locations involves a baseline inhome interview survey, followed by annual interviews, conducted mainly by telephone (30). In Iowa, 3,673 subjects aged 65 and over responded at baseline to an inhome interview (response rate: 80 percent). A total of 3,497 were reinterviewed, primarily by telephone, at the first followup. Among the remaining 176, 128 had died, 47 refused a reinterview, and one was not interviewed because he was incorrectly coded as dead. At the first followup, 5.3 percent of the subjects required an inhome interview rather than a telephone interview because of hearing problems. Another 8.2 percent of the interviews were conducted with proxy respondents (telephone or inhome) because subjects were too ill, mentally incompetent, or out working on their farm. In New Haven, Connecticut, 2,811 subjects aged 65 and over responded in person at baseline (response rate: 82 percent). A total of 2,562 were reinterviewed at the first followup. Among the remaining 249, 145 had died, 91 refused a reinterview, and 13 are unaccounted for at present. At the first followup, 11.6 percent of the interviews were done face to face in the subject's home because of hearing problems or language problems. (The subject spoke Italian or Russian, rather than English, fluently.) Another 6.1 percent were done by proxy (telephone or inhome) because the respondent was too ill or was mentally incompetent. Note the substantial variation between locations in the reasons for doing something other than interviewing the chosen subject on the telephone.

Perhaps among the elderly, more than any other demographic category, there is a need for flexibility in research methods and a clear case for mixed or multimode surveys (i.e., studies that attempt to obtain the same information from an identified population through different field approaches). For example, one may start with a mail questionnaire, follow up with attempts to reach nonrespondents by telephone, and, where unsuccessful, approach subjects for an in-person interview. Mixed-mode surveys are usually viewed simply as a means of achieving higher response rates by getting responses from people who otherwise would not respond (31). But mixed-mode surveys may be particularly useful in studies of older people who experience the types of impairments and limitations described. In other words, these types of surveys may be a means of getting responses from people who simply cannot respond. Mixed-mode approaches are not only a desirable method for improving response rates, therefore, but in community-based studies of the oldest old, in particular, the approaches may be essential to obtain reliable data (25).

Most mixed-mode surveys start with either mail questionnaires or telephone interviews (19,20,31,32). Followup of nonrespondents usually involves the other of these two methods, face-to-face interviews, or a combination of approaches. The sequence usually ranges from the less expensive (mail questionnaires) to the more expensive (in-person interviews), enabling resources to be devoted to the subjects who are the hardest to reach. Obviously, it is not cost efficient to employ costly in-person interviewing when the same data and quality can be obtained through a cheaper mode. There are quantum leaps in costs from mail questionnaires to telephone interviews to in-person interviews. While cost is usually the major determinant of mode sequence, other considerations, such as time constraint and study content, can also be important factors.

Generally speaking, which approach is adopted and whether mixed modes are employed are determined by cost considerations. With older populations, the cost efficiency of an approach appears less important than the appropriateness and feasibility of that approach. Clearly, based on the data already described, no one mode is appropriate for all elders. Different modes are appropriate for different groups of older people, depending on different types of physical limitations and social circumstances. In studies of younger groups, one can probably get away with using only one mode. (People do that all the time.) With the elderly, however, one has to be prepared to use two or three different approaches. This has obvious implications for interviewer training and protocol development (instrumentation).

While mixed-mode surveys offer considerable promise, particularly in studies of older populations, not surprisingly, mixed-mode surveys have their disadvantages and limitations. This discussion will focus on three concerns: Cost, missing data, and response validity.

Followup often constitutes work in excess of effort normally expended in single-mode mail or telephone surveys, so mixed-mode surveys are always more expensive than surveys using the initial mode alone but less expensive than using the followup mode alone (19,20).

Aside from a few well-known items (e.g., household income), item nonresponse is most frequent on mail questionnaires (19,33,34). Thus, mixed-mode surveys that include this mode may produce somewhat higher levels of missing data. Apparently, part of the problem is caused by inadvertent respondent error, which can be reduced through careful instrument design. Data missing for other reasons are of greater concern. The propensity for item nonresponse can vary with respondent characteristics, especially on mail questionnaires (34,35). These data clearly are not missing at random and can bias survey results (36). We have found in health-related surveys that item nonresponse is related to health status (34). Unfortunately, estimates of bias are not yet available; more work is needed in this area and is under way.

The issue of validity arises from the frequently observed variation among modes in responses to some items in mixed-mode surveys (21,31,37). Telephone and face-to-face interviews may be more likely than mail questionnaires to suffer from biased recall of, for example, a recent visit with a physician (22), or biased responses to questions that are personally sensitive or have socially desirable answers (38). Mode-dependent response variation can be minimized through sensitive interviewing and careful question design (39). Finally, some of this variation is actually caused by factors that are confounded with mode, such as characteristics of early versus late respondents, rather than by the modes themselves (31). This implies that responses to the initial mode are from a biased sample of the population, rather than indicative of mode-dependent variation in the validity of survey responses.

The development of innovative inhome collection of physiologic measures

In the past, even the oldest old have been requested to attend some central clinic or hospital location whenever physiologic measurements were required. Doing research at the investigator's convenience may be acceptable in studies of younger populations, but with older people (especially the oldest old), studies ought to be done at the respondent's or subject's convenience (usually the home or workplace). For poor health and other reasons unrelated to health, older people are often unlikely or unable to respond to requests to come to a clinic. As the Framingham Heart Study cohort has aged, home visits have been instituted to compensate for the problem of increasing nonresponse—primarily because of ill health among men, but not among women, in that study. Agoraphobia (the fear of public places or new experiences) appears, from some of our ongoing work at NERI, to be an important source of nonresponse among older women. In contrast, nonresponse among older men appears to be primarily caused by illness or functional limitations.

For some health researchers the familiar clinic-based physiologic measurements are being replaced with inhome protocols. Technologic improvements (especially microcircuitry and portable compact equipment) are opening new horizons. Permit a personal aside: I recall in work with Dr. Ian Prior some 30 years ago in New Zealand that electrocardiograms (EKG's) presented a real challenge in field studies of Maoris and Tokelau Islanders. In those days, EKG machines were very delicate and required stable power supplies (not always available in rural areas and on some islands). Today, in order to identify silent myocardial infarctions in the community, NERI field staff are successfully conducting 12-lead EKG's on black persons in their homes in high-risk, violence-ridden, inner-city neighborhoods of Boston. We are using the Burdick EK10, which weighs only 8 pounds and is about the size of a telephone directory. Staff at the Minnesota Heart Program, where our EKG strips are being read, have informed us that they are among the best (cleanest) they have seen. At NERI, easily transportable equipment is being used by specially trained field technicians, with no prior medical training or experience, to measure blood pressure, body-mass index, urine, and saliva (for cotinine); for venipuncture, EKG, and fitness testing; and to assist with a full oral health examination.

Inhome physical examinations are safe, reliable, and (except for blood pressure) equivalent in results to clinic-based protocols that use fixed standard equipment with more costly staff, facilities, and overhead. Based on experience in the Pawtucket Heart Health Program, inhome protocols produce at least a 10-percent increase in response rates, and do so at one-third less cost, mainly labor savings (40). In sum, inhome protocols not only are cost efficient but also produce higher quality data, particularly in terms of response rate.

The inhome approach is especially promising and perhaps even essential when studying the biomedical and physiologic status of older, less mobile populations. There are at least three reasons for this. First, it is the only way to gain the participation of some elders, especially the oldest old. They simply will not come in to (if they are women) or are unable to attend (if they are men) an often strange medical facility (e.g., a clinic, health center, hospital, or laboratory). Usually, the research setting to which they are invited is not the institution providing their ongoing primary care. One NERI study prospectively examining lipids, hormones, and bone density in an aging cohort of women living in the community obtains response rates of around 90 percent when respondents are interviewed at home, where the venipuncture is conducted, but experiences about a 20-percent drop in participation when the same women are requested to attend a hospital to undergo dual-photon absorptiometry to measure bone density.

Second, inhome protocols are often the only way to obtain certain types of information of importance to elders' health. Polypharmacy is recognized as an increasingly important problem for older people (both prescribed and over-the-counter medications). It is difficult to obtain detailed and accurate drug usage data in a clinic or hospital visit. "Black and yellow pills" may be the only information some older people are able to provide concerning their medication. Moreover, the most common medications may be overlooked precisely because they are so much a part of the respondent's everyday world. Asking older people to bring all their medicines with them to a clinic or hospital produces uncertain results. When asked by an NERI fieldworker what pills she took, one respondent replied that her doctor gave her "pills for her memory." In response to a supplementary question concerning how often she took them, the respondent replied, "Only when I remember"!

Endocrine functioning is of increasing interest to gerontology researchers because of the possible relationship of hormones to osteoporosis, coronary heart disease, and depression, among other outcomes. Work in this area presents special challenges. These challenges are illustrated by an NERI study of hormone profiles and sexual functioning across the lifespan (1,700 men aged 40–70 years were examined). An inhome protocol was required because: (a) we wanted to study normal aging in a representative population (not in convenience samples of patients—the usual source); (b) we required a random sample of community residents who lived independently; (c) two blood samples over a short interval were required (to control for pulsatile emissions); (d) these samples had to be obtained within 2 hours of awakening to obtain basal levels and to permit control of diurnal variability; and (e) information was required on medications, blood pressure, nutritional behavior (Willett's food frequency questionnaire), etc.

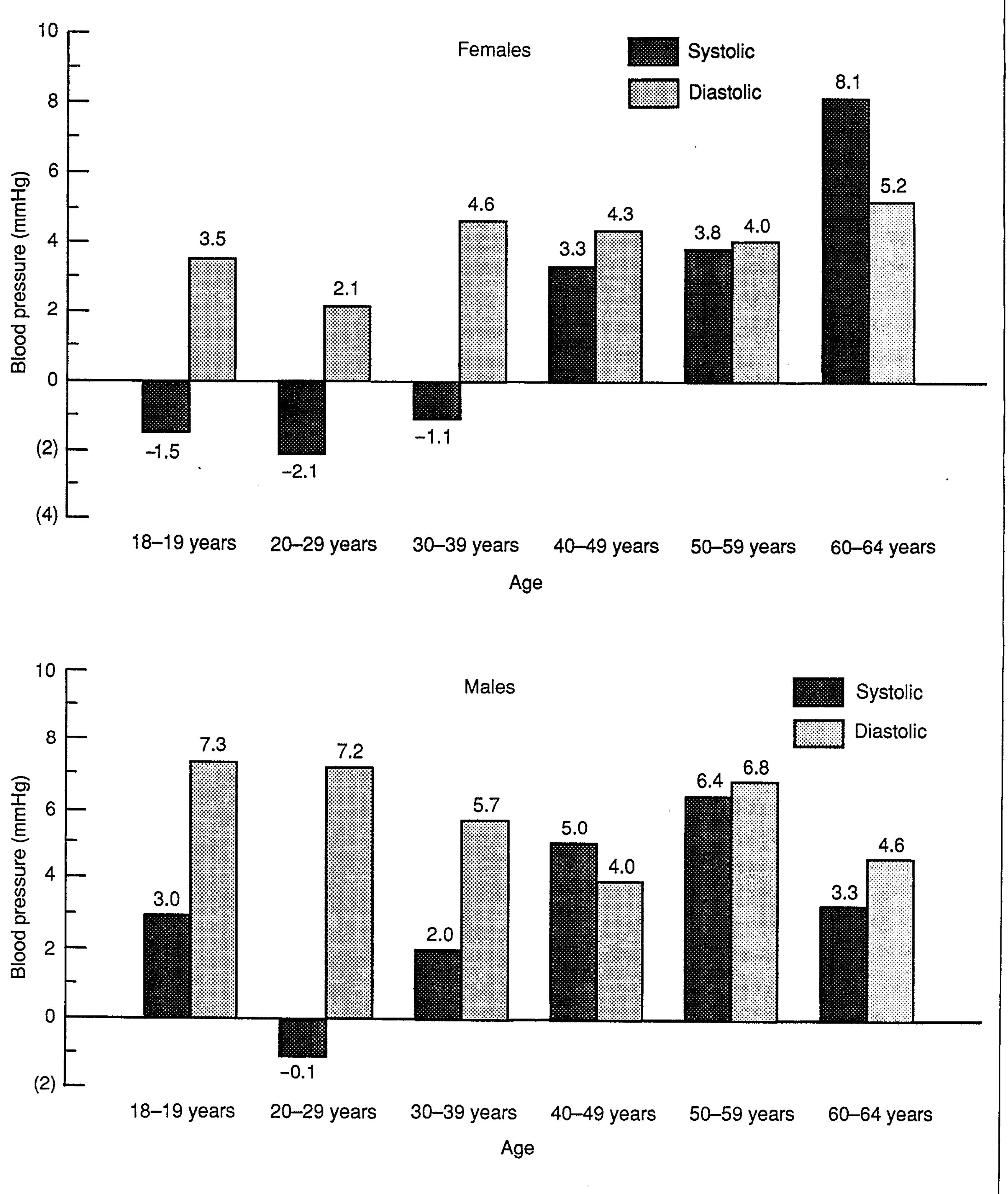
Our recent meta-analysis of the magnitude of research method effects on the age-testosterone relationship provides strong support for an inhome protocol when studying endocrine functioning in older people (41). We found marked differences in results produced by sampling characteristic, target population (whether patients, geriatric residents, or volunteers), and health status (whether people taking prescribed medications were included). We found a significant effect of time of blood sampling on the testosterone-age relation, with groups where no relevant information was given showing steep slopes and groups with afternoon sampling having a nonsignificant positive relation. We also uncovered differences in testosterone between subjects who were supposedly "healthy volunteers" (not the same as a random sample) and those who were selected from patient groups.

Third, and of equal significance, is the fact that there are large differences in some important measurements performed at home compared with a clinic or hospital setting. For example, data from the Pawtucket Heart Health Program show how the difference in blood pressure readings at the two sites increases with age. Figure 1 presents data for systolic and diastolic pressures separately and reveals clear age increases, especially for women (who are the majority of the oldest old).

These data call into question many of our traditional epidemiologic approaches to physiologic measures and suggest that, for example, in any epidemiologic observational study involving blood pressure (e.g., coronary heart disease, diabetes, and stroke) the inhome protocol is the preferred approach. With an inhome protocol you not only get a higher response rate at a lower cost, but you can get more accurate measurements (e.g., for cortisol, prolactin, personality trait, and stress) under natural circumstances.

The matter of interviewer training

Fowler and Mangione (17) observe that consideration of interviewers and quality of interviewing in a survey, although crucial to any study's success, is typically ignored. Groves and Kahn (23) have shown that one-fourth to one-third of survey items are subject to significant interviewer effects (42,43). Interviewers



SOURCE: Unpublished data from the Pawtucket Heart Health Program, The Memorial Hospital, Pawtucket, Rhode Island.

Figure 1. Mean differences in systolic and diastolic blood pressure (clinic minus inhome) for 553 subjects ages 18–64 years completing both protocols, by age and sex

can affect quality in two principal ways. First, if interviewers are not consistently standardized, survey-based estimates are less precise, thereby increasing the amount of random error around the survey estimates and decreasing the extent to which the differences among respondents are detectable in the answers. Second, interviewers can systematically bias data and render them invalid. In a recent study at NERI of middle-aged women, around 30 percent of the variation in some key outcome variables (e.g., social support networks and symptom reporting) was explained by interviewer differences!

The pace at which an interview is conducted, the kind of respondent behaviors interviewers elicit and reinforce, and the goals interviewers communicate to respondents have been shown to relate to data accuracy (44,45). Fowler and Mangione examined the potential of various training and supervisory programs to affect the performance of health survey interviewers and the quality of data they collect (17). Interviewers receiving less than 1 day of basic training generally displayed inadequate interviewing skills. A program of tape recordings, as part of the supervision of household interviewers, was associated with more precise and less biased data if interviewers were more than minimally trained. Training and supervision were found to be related to data quality. Attention to aspects of interviewer management—training and supervision, design of questions to reduce the need for probing, procedures to be used, and the size of assignments—is a cost-effective way to improve the quality of survey-based estimates. I concur with Fowler and Mangione (17), who suggest that standards for the way interviewers are trained and managed have been too long absent, despite a history of research showing that interviewers matter.

Field research with older populations requires special training for interviewers (46–50). It is not sufficient to expose potential interviewers to the usual brief, canned training course that is often provided by inexperienced research organizations and university-based researchers not routinely conducting surveys of older people. Two issues illustrate this need for additional training for fieldwork with older populations.

First, many older respondents have difficulty processing and giving clear responses to apparently straightforward questions. For example, it may take up to 5 minutes to establish whether a respondent has arthritis—a seemingly straightforward question. With older populations, such a question will often elicit prolonged descriptions of disabilities, medications, and utilization behavior associated with the condition of interest. This has important implications for the cost of fieldwork. Interviewers must be trained to sensitively keep the respondent focused and to elicit clear responses in an economical fashion.

Second, in studies of older populations, particular attention must be devoted to concluding an interview. In our experience, respondents frequently enjoy discussing their problems and lives with the interviewer. Often the challenge is not respondent fatigue but interviewer fatigue. A telephone call from an interviewer may be the only call the respondents have received in some time. Respondents often perceive the interviewer as someone who is interested in their situation and circumstances. A problem frequently encountered is how to sensitively and respectfully, but not abruptly, terminate interviews with obviously interested, talkative older respondents. Prolonging the interview after the required data have been obtained has obvious cost implications. As in all types of research, one wants to close the interview as gently as possible, so that the next researcher who calls will encounter an interested respondent and one who will be inclined to participate again.

The issue of staff burnout is particularly important for in-person and telephone interviews of older people because the interviewer may need to almost shout (requiring separate rooms, not corrals), frequently repeat questions, and listen with great concentration. With older populations, fieldwork can, without exaggeration, be physically and emotionally demanding. Herzog and Rodgers (4) observe that interviewers find interviews with older people taxing because of the requirement for greater attention to procedures and because of the often distressing personal situations of many elderly respondents. On average, interviews with older adults take about 10 percent longer than interviews with other adult age groups. NERI has instituted regular office-wide meetings of interviewing staff to respond to the emotional burden and personal drain associated with regular interviewing of older people.

There are many other issues concerning research methods and data gathering with older populations that could be the subject of lengthy discussion. The four highlighted in this paper are only a beginning and emerge as a result of recent NERI experience with field studies of older populations.

With the widely discussed aging of Western populations, particularly the increase in the oldest old, there is an urgent need for valid and reliable data with which to inform health and social policy concerning this demographic category. Researchers are not well prepared to meet the challenges. Research methods derived from and useful in studies of younger populations or convenience samples may be inappropriate and require modification for use with older people whose health status and social circumstances preclude their use.

It is not my intention to argue for one ideal way of conducting social research with older populations. Rather, the essential message in this paper is that there is a need for flexibility. While all field approaches are useful, some appear to be more useful than others, depending on the topic and objective of the study and characteristics of the population under investigation. Mixed-mode surveys are viewed as particularly promising with older populations, although their limitations are well recognized. Certainly, in-person interviews can no longer be considered the "gold standard" and may indeed be a luxury from which social researchers must be weaned, especially during economically stringent times for sociomedical research. Based on recent successful experience with several different observational and experimental studies of older people in the northeastern United States, some suggestions are offered, which I hope will assist other researchers embarking on studies of older people.

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Part IV

Functional disability

Introduction

by Mary Grace Kovar, Dr.P.H., Special Assistant for Data Policy and Analysis, National Center for Health Statistics

The ultimate goal of measuring functional disability is to contribute to the prevention and postponement of functional disability. Reducing the prevalence of disability would improve the quality of life of older people, which is a worthwhile goal in itself. The reduction may also be critical to society. The projected increase in the size of the older population will require a tremendous number of people to provide care if current disability rates prevail. Reducing the number of disabled people would in turn lead to a reduction in the burden of providing care.

Chapter 10
Functional ability and the need for care: Issues for measurement research

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I would like to begin by giving you a scenario of what could happen in the United States. In the mid-1980's, about 12 percent of the population of the United States (28.6 million people) was age 65 and over.

There were 1.5 million residents of nursing homes (1). The proportion of the people who were in nursing homes was higher at older than at younger ages and higher for women than for men. Most of the residents were functionally disabled. Nine out of 10 required assistance in bathing; three-quarters required assistance in dressing; half had difficulty with bowel or bladder control.

However, the vast majority of older people were not in nursing homes. There were more people receiving help with one or more of six activities of daily living (ADL's) in the community (2.5 million people) than there were residents of nursing homes. Again, the prevalence was much higher among people 85 years of age and over than among people ages 65–74 years or 75–84 years (table A).

The very high prevalence of institutionalization and functional disability in old age is critically important. The proportion of the population 85 years of age and over has grown, and it is projected to continue growing rapidly. According to population projections made by the U.S. Bureau of the Census, what was still a population pyramid in 1990 will essentially be a lopsided rectangle by 2025 (figures 1 and 2). The Census midlevel projection is that there will be 58.8 million people 65 years of age and over by 2025—20 percent of the population of the United States (2). Projections, based on the prevalence rates of the 1980's and the Census Bureau population projections, show what an increasingly large older population, especially an increasingly large population of the oldest old, could be like.

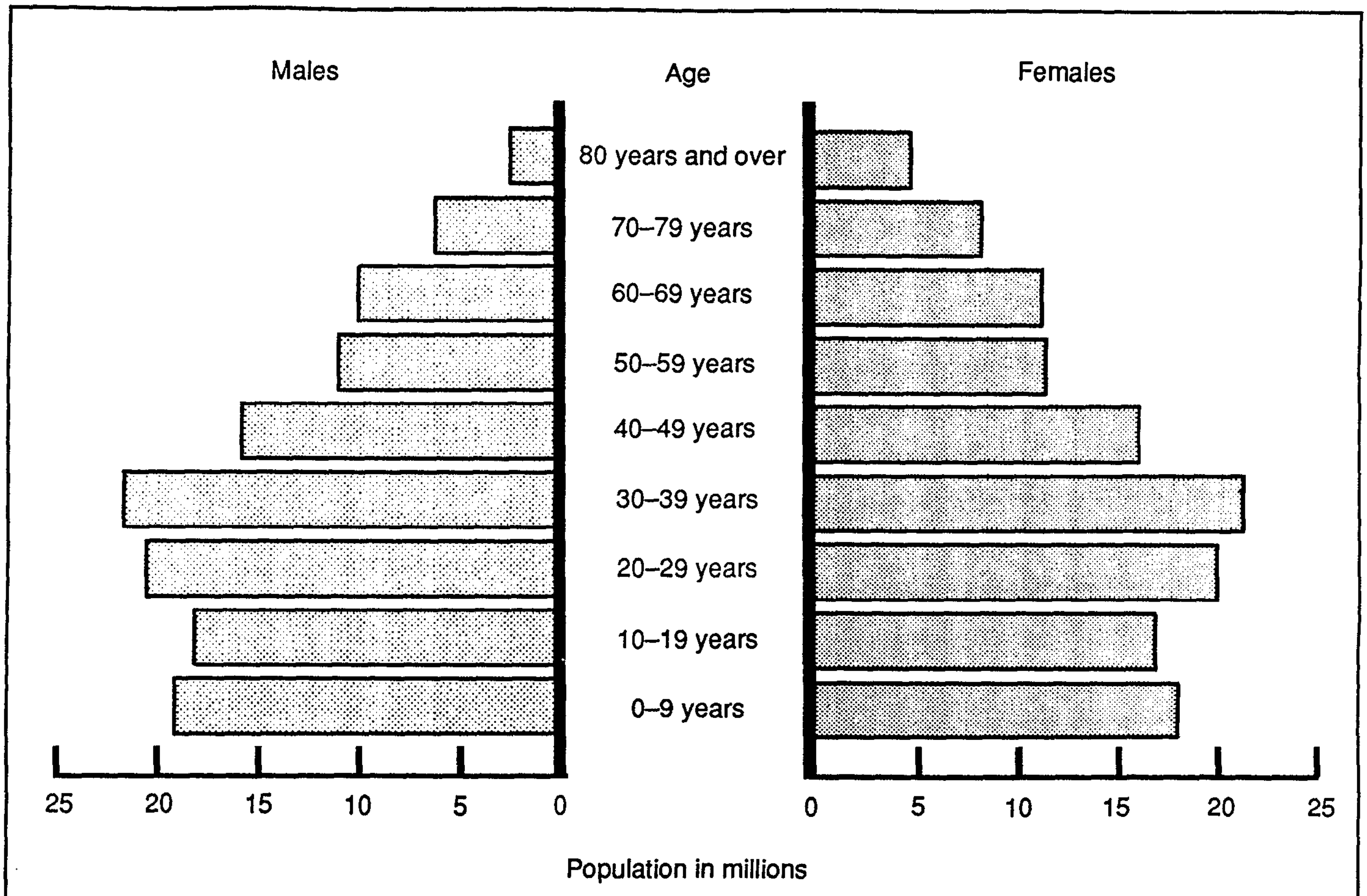
If there is no change in the current age-specific disability rates, postponing mortality will increase the burden of providing care to older people because of the great increase in the number of people in nursing homes or living in the community with functional

Table A. Number and percent of persons 65 years of age and over living in the community, by help received with activities of daily living or instrumental activities of daily living and age: United States, 1984

Age	Population in thousands	Help with ADL's[1] Number in thousands	Help with ADL's[1] Percent	Help with IADL's[2] Number in thousands	Help with IADL's[2] Percent
All ages 65 years and over	26,433	2,549	9.6	3,710	14.0
65–74 years	16,288	973	6.0	1,822	11.2
75–84 years	8,249	986	12.0	1,437	17.4
85 years and over	1,897	589	31.1	451	23.8

[1] Activities of daily living.
[2] Instrumental activities of daily living.

SOURCE: National Center for Health Statistics. Supplement on Aging, National Health Interview Survey. 1984.



SOURCE: U.S. Bureau of the Census. Projections of the population of States by age, sex, and race. Population estimates and projections. Current population reports; series P–25, no 1018. Washington: U.S. Department of Commerce. 1989.

Figure 1. U.S. population, by age: 1990

disability. Assuming that there is no change in the age-sex specific rates:

- There will be 3.1 million residents of nursing homes in 2025. There will be fewer if mortality rates are higher than projected and more if they are lower.
- There will be 6.5 million people receiving help with one or more ADL's in 2025. Again, if death rates are higher, there will be fewer; if death rates are lower, there will be more.

Conversely, postponing disability greatly decreases the burden of providing care to older people even if mortality rates decline and the expectation of life increases.

If disability can be prevented or postponed so that the prevalence of people receiving help declines at the relatively slow rate of 1 percent per year, there will be 2.1 million fewer people receiving help with an ADL in 2025 than there would be if a constant rate continued. Even if mortality is lower than projected, there will be 1.5 million fewer people receiving care than there would be with the midlevel projection and no reduction in the prevalence of disabled people receiving help.

The prevention and postponement of disability is an effective policy for reducing the burden of disability to both individuals and society. This is a goal worth aiming for.

The projected worldwide increase in the population of older people is from 286 million in 1985 to 410 million in the year 2000 (3). The number of older people is expected to continue growing rapidly far into the 21st century. As a consequence, the number of people with disabilities, the number needing help, and the number needing long-term care can be expected to

SOURCE: U.S. Bureau of the Census. Projections of the population of States by age, sex, and race. Population estimates and projections. Current population reports; series P–25, no 1018. Washington: U.S. Department of Commerce. 1989.

Figure 2. U.S. population, by age: 2025

increase unless we can prevent or postpone disability and decrease the age-specific rates.

Measurement issues

It is difficult to forecast the future for even one country. It is far more difficult to forecast the future for the world when we know little about the prevalence of disability in many countries and even less about differences among populations.

The first step is to develop conceptually similar questions on functional disability and the need for care that can be used in cross-cultural and cross-national population studies.

There is an approach to measurement based on a functional ability model (4–6) used to assess the health of older people primarily in terms of functional adequacy. This approach is based on a social definition of health, and it views health as a state of optimum capacity to perform the roles and tasks for which a person has been socialized. The functional adequacy model acknowledges the relationship between level of expectation and health status. The focus is on the complex pattern of interaction between individuals and their ecological and cultural contexts.

This approach recognizes the importance of behavioral capability and the personal and social nature of disability. Using this model, disability is a function of the culture and the expectations for people in that culture. Disability is a condition or state that results in partial or complete limitation of one's "normal" activities.

There are further distinctions between disability and impairment (a physical or psychological abnormality that does not interfere with normal activities) and between disability and handicap (a socially, environmentally, and/or personally specified limitation) (7). Those distinctions are important for measurement. Although it is critical to measure the entire range of functioning—from fully functional to completely dependent, including impairments and handicaps as well as disabilities—disability is distinguished by including the context in which an individual lives.

Given the complexity of the concept, measurement is difficult. Differences in prevalence estimates may be due to differences in the measurement instrument instead of differences in the true prevalence. They may also be due to differences in perception or the cultural context. The fact that functional disability, at least in its less extreme forms, is so intertwined with the cultural and physical environment makes the measurement problem more difficult to solve.

Measuring need for care, unless the need is extreme and obvious, is just as complex, although less has been written about it for population studies. In this context, care is usually defined as care by another person. The need may be modified by characteristics of the housing and the outside environment; availability of aids, such as canes and walkers; availability of community services, whether formal or informal; the perception of the older person or the perception of others; the ability to pay for care, including health insurance; and the mode of providing care. Again, differences in prevalence estimates may be due to differences in the questions used for measurement. The variation in questions about the need for care is enormous.

Some understanding of the etiology of disability is also needed to reduce the risks of disability, to interfere with its progression, and to assess the need for care. The path to functional disability is usually through disease, although it may be through injury. Much is known about the risk of some diseases but less about the risk of others. Little is known about the risk of disability given the presence of disease, and little is known about the progression of disability. It is possible that there are many paths depending on the nature of the underlying disease and the disability itself. International studies with comparable measures will help disentangle the influence of culture, disease, and genetics.

People who are in academic Western environments must also recognize that the vast majority of people in this world do not live in the same social, cultural, or even physical world that they do. They must be careful not to measure disability according to Western standards. Where there is no perception of a need for the ability, there can be no perception of disability. In fact, if in real life there is no need for that particular ability, there is no disability if one is unable to perform it.

Even in one country, perceptions differ. The Supplement on Aging (SOA) to the 1984 National Health Interview Survey included questions on both ADL's and instrumental activities of daily living (IADL's) (8). Responses to the questions show that in the United States there is no perception of need for some of the activities. Some older men report no difficulty in preparing meals; they say that they do not cook. In the same way, some older women report no difficulty managing money; they say that they do not do it.

Some measures are extremely dependent on culture. The SOA included a question on whether the individual had difficulty dressing. Some people volunteered that they had no difficulty dressing because they wore clothes without zippers in the back and without small buttons. The introduction of Velcro, which has simplified fastening clothing and eliminated tying shoes, probably means that data from that question are not comparable over time even in one country. Data from that question would certainly not be comparable over cultures. In Southeast Asia and in parts of Africa, many people do not wear shoes that tie, and many women wear saris or other wraparound clothing that does not require the wearer to have the same abilities as needed for clothing worn in the United States and Europe.

Nevertheless, a question on dressing could still have meaning—the person who cannot dress appropriately for the culture will still be unable to participate without help in the activities usual for the culture. However, responses to the question should not be interpreted as an ability to perform a specific activity—using small hand motions to fasten buttons, reaching around to zip a zipper, bending down to tie shoes—because the activities involved in dressing would be different.

The differences are important to understand, to appreciate, and to use. If the purpose is to determine how well an older individual can function within his or her own cultural environment, it is possible to develop questions that can be used internationally. If the purpose is to develop measures that ascertain how well an individual can perform certain physical motions, it is also possible to develop questions that can be used internationally, but they will be different questions. It is important to realize that the means of postponing or preventing the disability will probably not be the same. The means of reducing the impact will differ, as will the kind of care needed.

Inability to function in one's environment may be due to mental or emotional disease, to lack of cognitive ability, or to physical disease or impairment. Functional disabilities that appear to be similar may have very different etiologies. The means of preventing disability from depression are not the same as the means for preventing disability from heart disease. The care needed by an Alzheimer patient is different from the care needed by a person who cannot walk because of arthritis.

Survey estimates of the prevalence of people with functional disability are important because they are used to form local and national health policy. However, the prevalence estimates can differ greatly according to the way in which the questions are worded and the way in which the answers are tabulated. Estimates can also differ according to who is permitted to respond to the questions. Study design, measurement, and tabulation have an enormous influence on the estimates.

If the SOA had relied only on self-respondents or if the questions had been asked differently, the prevalence of functional disability could have been vastly different. Even controlling for study design and wording of the questions, tabulations can yield different estimates.

On the SOA, people (or proxies) were asked whether they had difficulty with each ADL and IADL. For each activity people had any difficulty doing, they or their proxy were asked the degree of difficulty and whether they received help. Most of the people responded for themselves. People who were 85 years of age and over and people with difficulty or receiving help with ADL's were less likely than others to respond for themselves (8).

If proxy respondents had been declared out of scope and only people who answered for themselves had been the basis for national estimates, the estimated number of people receiving help with two or more ADL's would have been 600,000 people lower than it was. Since the data from this study are being used by the U.S. Congress to design legislation for long-term care, that would have been a dangerous underestimate.

People may ask, "Where is the truth? Isn't it possible that self-respondents denied disability and that proxy respondents overemphasized it?" It is possible, but death is an objective measure, and 29 percent of the people with proxy respondents died within 2 years, in contrast to 9.5 percent of those who responded for themselves (9).

The most prevalent ADL reported on the SOA was difficulty walking. It is worth examining that estimate in more detail to show how the data could be tabulated in different ways. Among people 65–74 years of age (the example is restricted to one age group to avoid confounding), the prevalence of difficulty walking is higher among women than among men, but the proportions of men and women receiving help are virtually identical (table B). That is, women with difficulty walking are less likely to receive help than men.

Table B. Number and percent of persons 65–74 years of age living in the community who have difficulty walking, by sex and amount of difficulty: United States, 1984

Difficulty walking	*Both sexes*	*Men*	*Women*
	Number in thousands		
Total	16,288	7,075	9,213
	Percent		
Any difficulty			
Total	14.2	12.9	15.1
With help	2.9	2.8	2.9
Amount of difficulty			
Some	7.8	6.7	8.7
A lot	4.7	4.7	4.6
Unable to walk	1.6	1.4	1.8

SOURCE: National Center for Health Statistics. Supplement on Aging, National Health Interview Survey. 1984.

However, the data also show that the difference in the prevalence of difficulty is almost entirely due to the higher percentage of women with some difficulty. Women appear to report difficulty with less severe manifestations than do men; the percentages with a lot of difficulty or unable to walk are virtually identical. As one might expect, people with more difficulty are more likely to receive help, which explains why the percentage of women receiving help is about the same as the percentage of men.

Using different combinations of these data, it is possible to make many different estimates of the prevalence of difficulty walking and the need for help (table C). The prevalence could be the 19 percent with any difficulty or the 9 percent who either have a lot of difficulty or are unable to walk. The prevalence of need could be that same 9 percent or the 6.5 percent with a lot of difficulty or the 5 percent currently receiving help.

Those examples are an illustration of the possibility of different respondents, questions, or tabulations leading to different estimates. They illustrate the possibilities for misinterpretation of the data. However, the examples should not be interpreted to mean that the data are not useful. They are, and they are being widely used, but using them well requires knowledge of the study design, the wording of questions, and the items selected for tabulation.

Table C. Number and percent of persons 65 years of age and over living in the community, by amount of difficulty walking: United States, 1984

Amount of difficulty walking	Number in thousands	Percent
Total (with and without difficulty)	26,433	100.0
With and without help		
Any difficulty walking	4,947	18.7
Some difficulty walking	2,534	9.6
A lot of difficulty or unable to walk	2,385	9.0
A lot of difficulty walking	1,717	6.5
Unable to walk	668	2.5
With help		
Any difficulty walking	1,228	4.6
Some difficulty walking	362	1.4
A lot of difficulty or unable to walk	863	3.3
A lot of difficulty walking	495	1.9
Unable to walk	368	1.4

SOURCE: National Center for Health Statistics. Supplement on Aging, National Health Interview Survey. 1984.

Longitudinal studies

Until recently there have been very few longitudinal studies of older men and women. There is a need for more such studies, for they yield information that cannot be obtained from cross-sectional, even repeated cross-sectional, surveys.

In the United States, there are now several such studies. One, the prospective Longitudinal Study of Aging (LSOA), which is based on the SOA, is beginning to yield information about transitions that older people make as they grow older. This study is designed to assess change in functional ability and in living arrangements.

Receiving help with an ADL is highly predictive of death or institutionalization within 2 years (10). Those people who were receiving help with an IADL only or who had difficulty but were not receiving help were at less risk. People without difficulty were least likely to die or enter nursing homes. Even among these people, who were all age 70 and over when they entered the study, there was some reversal. Some people who had been receiving help with one or more ADL's in 1984 reported no difficulty 2 years later.

Other analyses have investigated correlates of "successful aging" (11). While these analyses may be of less importance to issues of functional disability, they do demonstrate the importance of longitudinal data.

Data from the LSOA also show that living alone was not highly predictive of either entering a nursing home or dying. One reason is that relatively few people living alone were receiving help. The numbers are small and the period of followup is short, but if the analysis is restricted to people receiving help with one or more ADL's, people living alone were more likely to become institutionalized than people who were living with others, but they were not more likely to die within 2 years.

The remarkable thing is the stability of the population. Most of the people were in much the same condition and living in the same households 2 years after they were first interviewed.

Summary

Measuring the prevalence of functional disability among older people is extremely important. The number of older people is projected to increase in both the developed and the developing countries. The incidence and prevalence of functional disability are high among older people, and they are higher at older ages. Many countries plan to care for their impaired older populations. They need good information to plan for their care.

The available data are soft. They are often fragmentary and based on research done 20 or 30 years ago when conditions were different. Data may not take into account the differences among people living in widely varying cultures.

Nevertheless, the available data, including data from longitudinal studies, have started to yield useful information. Cross-national studies can only increase the value of the information that many people have devoted enormous resources to obtain.

People should devote their time to cross-national comparisons, with the respect for the careful study of survey design, question wording, and tabulation that has been addressed in this paper. Researchers should also devote time to considering whether questions appropriate in one culture are equally appropriate in another. Investigating such issues is one of the purposes of this conference.

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Chapter 11
Surveys of the situation of the elderly in Hungary

by András Klinger, Ph.D., Chief, Population Statistics Department, Hungarian Central Statistical Office

The aging of the population and the increase in the proportion of the elderly have provided more and more grounds for studying the situation of the elderly in Hungary.

For a very long time, members of the elderly population were not investigated separately. The only exception was a very specific group that we called the "very old." This group initially included all persons 99 years of age and over, but later its scope was extended to include all those 90 years of age and over and, in other cases in the later 1970's and 1980's, 95 years of age and over.

The methodology used for the investigation of the very old varied from time to time, but the investigation was always based on the population census reports. We visited the households of the very old and asked them specific questions. Before the 1990 population census, the last such investigation was carried out in 1987.

In the 1980's the Hungarian Central Statistical Office carried out a number of surveys that increased the knowledge of the situation of the elderly. Many surveys were carried out with the express intention of getting better acquainted with the life and health conditions of elderly Hungarians and gaining insight into the circumstances of only one group of them—the most aged.

1984 microcensus

The first general investigation of the elderly population was performed in 1984, when a so-called microcensus (a term we use for a sample census) was organized by the Hungarian Central Statistical Office. The sample included 2 percent of the total population of Hungary—elderly and nonelderly—i.e., more than 200,000 persons. The microcensus included general questions about the population, such as number of persons, housing, and family situations. At the same time, however, it was a specific investigation into the lives of elderly persons.

By the definition used in the 1984 microcensus—one of the most important sources of data of this period—the elderly are persons who have reached pensionable age (males 60 years of age and over or females 55 years and over), irrespective of their economic activity. The term also includes persons younger than the legal pensionable age who receive, by their own right, a pension (on the grounds of age exemption) or a disability pension.

The primary difference between the grouping applied in the microcensus and that used in other surveys is that the former also covers younger persons. The basis for the inclusion of different groups was the nearly identical way of life and the relatively uniform source of subsistence. This made it possible to perform a comprehensive study of the housing, life, and health conditions of a population corresponding to the applied system of criteria.

The grouping of the elderly as defined above, although it differs from the categories used in domestic and international practice (which in turn generally also differ from one another), makes it possible—by also taking into consideration other grouping criteria—to compare the results of the microcensus with the findings from other surveys.

The persons who fit into this grouping first answered a basic questionnaire regarding their housing conditions (39 questions), family-household relations (4 questions), and personal characteristics (36 questions). They also filled out an additional 4-page questionnaire containing 29 questions divided into 3 sections. The first section consisted of 10 questions regarding general personal characteristics. The section had questions about the elderly person's marriage history, cohabiting partnership, and number of children. In the case of active earners it contained questions about the expected date of retirement and whether the person had plans to undertake work after retirement. Pensioners had to answer questions regarding the date when they started receiving pensions, whether they had since undertaken work, and whether they had plans to work in the future.

Data on occupational history are available about the dependent elderly and those elderly who were receiving pensions by the "widowed's right." (The widowed have the right to a certain proportion of the pension their deceased spouses would have received; the size of the pension depends on the living spouse's age and occupational status.) Finally—also within the first section—the number of days of work performed in the household and auxiliary (farming) plots was reported.

The second section contained health-related questions regarding diseases of more than 3 months' duration, handicaps, use of spectacles or dental prostheses, and accidents that had occurred during the year preceding the survey. This section also included a question regarding the person who took care of the ataxic elderly person. The last three questions, asked only about persons 70 years of age and over, concerned their motility.

The third section served to render the study of the housing and life conditions more profound and to make it more complete by bringing in new points of view. With respect to housing conditions, questions were asked about the elderly person's title to the housing (the basic questionnaire concerned the title of the whole household) and the number of places used by the elderly exclusively, as well as the characteristics of the place where they slept.

With respect to life conditions, the questionnaire asked about contracting for "support for life," relationships with kin, eating habits, and other circumstances. (In Hungary, "support for life" entails a contract between an elderly person and someone who moves into the older person's apartment and provides care. If the death of the older person occurs after completion of the contract, the caretaker legally becomes an occupant of the apartment. This institution was necessitated by the grave housing shortage in Hungary.)

The questionnaire also included questions regarding the form of social support (from friends or family) as well as the use of day care centers. Finally, 14 subquestions were aimed at eliciting information about elderly persons' habits of amusing themselves and leisure activities.

The microcensus covered 2 percent of the population and of the total available housing, and the survey included 52,055 elderly persons. Nearly 90 percent of the latter, 46,724 persons, were of pensionable age (males and females 60 years of age and over and 55 years of age and over, respectively). Of the population 60 years of age and over, 39,240 persons were included in the 2-percent sample of the microcensus (table A).

1987 survey

The next investigation, the survey of the most aged in 1987, was not a sample survey but one which tried to be full scope. Earlier surveys pursuing similar aims had been carried out on the basis of addresses used for the population censuses, usually in the year following the population censuses. The first such survey took place in 1935 and was repeated in 1943, 1960, and 1970. Addresses for the 1987 survey were provided by the State Population Registration Office. On the basis of the data in the population register, a list of names of persons born in 1887 and earlier was prepared.

Table A. Number of the elderly surveyed in the microcensus, by sex and age group: Hungary, 1984

Age group	*Both sexes*	*Male*	*Female*
Total	52,055	19,815	32,240
1–54 years	3,470	1,806	1,664
55–59 years	9,345	1,861	7,484
60 years and over	39,240	16,148	23,092
Pensioners under pensionable age	5,331	3,667	1,664
Persons of pensionable age	46,724	16,148	30,576

The population register had the names of 275 persons born in 1887 and earlier. The survey had to be carried out in two steps. First, the data in the population register had to be checked, and the statistical questionnaire had to be filled out; in the second step, the elderly subjects were examined by a medico-gerontological team.

Of the 275 persons, 7 were younger than 99 years; 10 were not known at the indicated addresses; 20 had died in 1986 or earlier, and 10 had died in 1987; 10 refused to answer questions or were in a state in which it was impossible to receive answers from them. Statistical questionnaires were filled out for 218 persons.

The 10 sections of the statistical questionnaire included 80 questions. Among questions regarding general characteristics, one concerned documents certifying the date of birth. The same section included questions about the present and earlier residences of the person surveyed.

The aim of the questions regarding grandparents, parents, brothers, and sisters was to discover whether there had been other family members who reached an equally high age, and from what diseases and at what age the grandparents, parents, brothers, and sisters had died.

The third section concerned the marriage history, spouses, and descendants of persons born in 1887 and earlier. This section included a question regarding keeping up relationships with relatives, which had also been asked in the microcensus.

The scope of inquiry regarding educational attainment and occupational history was completed by questions about the financial situation—the type and sum of pensions, the form of social support. (The latter question had also been used in the additional questionnaire of the microcensus, while questions regarding educational attainment and the type of pension were included in the basic questionnaire of the microcensus. Further, the sum of the pension was also known, as the microcensus was based on data from the National Pensions Office.)

The questions regarding households, housing, and life conditions were somewhat broader in scope than the questions in the microcensus had been. However, this is because the basic unit of sampling in the microcensus—and consequently also in the survey—had been the dwelling, so separate questionnaires were filled out about the dwelling and about each individual living there. This survey included only the population 99 years of age and over.

The scope of inquiry regarding the state of health also included questions formerly asked in the microcensus (for example, subjective judgment about the state of health, bodily deficiency, motility). Also asked were questions regarding those states of health that gain in importance as age increases.

The scope of inquiry regarding daily eating habits was completed by questions regarding food consumed for breakfast and supper, as well as by questions regarding dietary habits as a child, an adult, and at present. To establish the level of nourishment and indicators of body proportions, the lowest and the highest adult-age body weights, as well as the height in adulthood, also figured among the questions. As for health-damaging practices, questions regarding the consumption of alcoholic beverages and kinds of tobacco concerned habits both as an adult and at present. The scope of questions regarding amusement and pastime activities was narrower than it had been in the microcensus, which is in accordance with age-specific characteristics.

There were four questions regarding the impact of changes in the economic-political situation on the life of the persons surveyed. Those surveyed had the opportunity to answer two questions regarding their opinion about the secret of longevity and what they would still like to achieve in life. Finally, the surveyor could register a personal opinion about the intellectual agility of the person surveyed and about the way the person was being taken care of.

The survey of the most aged covered 218 persons. Naturally, their number is decreasing rapidly with advancing age. Of them, those 99 years of age were the greatest number (96). The oldest two citizens were both females 107 years of age. The sex ratio is characterized by an overwhelming female predominance: Less than a quarter of those surveyed were males (50 persons) (table B).

The study of the situation of the elderly in the 1980's in Hungary is rendered possible by these two surveys and by the data of surveys carried out with other aims.

Table B. Number of persons 99 years of age and over, by sex, year of birth, and age: Hungary, 1987

Year of birth and age	Both sexes	Male	Female
Total	218	50	168
1887 (99 years)	96	24	72
1886 (100 years)	61	8	53
1885 (101 years)	33	11	22
1884 (102 years)	11	3	8
1883 (103 years)	8	2	6
1882 (104 years)	3	1	2
1881 (105 years)	4	1	3
1879 (107 years)	2	-	2

Comprehensive analyses and data collections have already been published on the basis of these and other surveys. The volume containing the data from the surveys of the elderly that appeared in the series of microcensus publications includes, besides a relatively narrow analysis, significant tabular material. For the purpose of analyzing the results, besides the tables published in the volume, other issues can be examined through computer processing of the raw data. By combining the information stored on various magnetic tapes, further statistical tables can also be prepared. In the future, it will be possible to look for a way to expand the stored information about the elderly, possibly by data about these same people to be collected in future surveys.

One extraordinarily interesting aspect of the analyses in the population census programs from the beginning of this century until 1949 is the study of the handicapped. The 1949 census was the first conducted after the Second World War. The Government was greatly interested in knowing which kinds of handicaps were caused by the war and which were not.

Of the 52,055 elderly surveyed in the 1984 microcensus, 7,198 (14 percent) suffered from at least one handicap. The number of handicaps was 7,908, i.e., on the average there was 1.1 handicap for 1 handicapped person.

Of the handicaps, the most frequently encountered were those of the sensory organs (62 percent of the handicaps belonged to this group). In accordance with age-specific characteristics, the proportions of the elderly with impaired hearing (the sample included 2,024 elderly with impaired hearing, and impaired hearing accounted for 41 percent of the sensory organ handicaps) and with poor eyesight (1,909 persons, 39 percent) were the highest. The proportion of those elderly with damaged motility was 3 percent; one-fifth of the handicaps and 22 percent of handicapped persons belonged in this group (table C).

The proportion of the handicapped within the age-grouped data on the elderly—with the exception of those 54 years of age and under receiving pensions in their own right—gradually increased with age. Consequently, the handicaps of the elderly are primarily due to age, to natural wear and tear. This was also indicated by the especially high proportions of those with impaired hearing and poor eyesight.

Among males, the proportion of the handicapped was higher: 16 percent versus 12 percent among females. This higher proportion was found everywhere except among the group ages 75–79 years. Because the proportion of males constantly decreases as age progresses, the difference between the two sexes becomes more and more striking (table D).

The 1987 survey of the most aged registered significantly fewer handicapped among the population 99 years of age than would have been expected on the basis of the rising proportion of the handicapped as age progresses.

Table C. Number of handicaps among the elderly and number of elderly persons with handicaps, by sex and type and number of handicaps: Hungary, 1984

Type and number of handicaps	Both sexes	Male	Female
Type	Number of handicaps		
Total	7,908	3,496	4,412
Physical handicap	538	325	213
Damaged motility	1,594	745	849
Mental handicap	571	228	343
Sense organ handicap	4,883	2,018	2,865
Other	322	180	142
Number	Number of handicapped persons		
Total	7,198	3,198	4,000
1 handicap	6,543	2,920	3,623
2 handicaps	600	258	342
3 or more handicaps	55	20	35

Table D. Percent of the handicapped elderly, by sex and age group: Hungary, 1984

Age group	*Both sexes*	*Male*	*Female*
Total	13.8	16.1	12.4
1–54 years	24.5	28.5	20.2
55–59 years	8.0	15.4	6.2
60–64 years	8.5	10.1	7.3
65–69 years	10.9	11.8	10.3
70–74 years	14.1	14.9	13.6
75–79 years	20.0	19.5	20.3
80–84 years	24.7	26.1	24.0
85–89 years	32.4	37.7	30.1
90 years and over	44.4	50.5	41.5

Naturally, this is due to the fact that the increase in the proportion of the handicapped as age progresses does not originate from any increased survival chances of the handicapped but is the result of their increasing tendency to develop handicaps owing to the natural wear and tear of aging. We must look at other reasons to explain such a conspicuous difference between the proportion of the handicapped at the time of the two surveys.

It would be erroneous to conclude that only a person without a physical, mental, or sensory organ handicap has the chance to reach the age of 100 years. Of the 218 most aged persons, 38 had some handicap, and one of them was handicapped (deaf and mute) since birth. (According to the survey, she had been dropped on her head as an infant and is thought to have become deaf and mute as a consequence.) The majority became handicapped after the age of 80 years; 8, at the age of 80–89 years; and 22, at the age of 90 years and over.

Among the most aged, one handicap was characteristic. Of the 38 handicapped, 5 had 2 handicaps. Three or more handicaps together were not found. The deficiency of the deaf and mute person described above was regarded as one handicap.

Among the persons 99 years of age and over, blindness in one or both eyes was encountered most often (table E). Fifteen persons (39 percent of the handicapped) were completely blind, and four of them, besides being blind, were also deaf. In each case, blindness developed after the age of 80 years. Twelve of them went blind after the age of 90. Fourteen persons were blind in one eye. Other handicaps were encountered less frequently. It is characteristic that the other handicaps—with the exception of the case of the deaf and mute person—began to develop at adult age, mainly at old age.

A sex-specific analysis was prevented by the fact that three-quarters of the most aged were females. The sex ratio of the 38 handicapped was 29 females and 9 males. The most frequently encountered handicap—

Table E. Number of handicaps among the most aged and number with handicaps, by age became handicapped and type and number of handicaps: Hungary, 1987

Type and number of handicaps	*All ages*	*Age became handicapped*					
		Birth	*49 years and under*	*50–69 years*	*70–79 years*	*80–89 years*	*90 years and over*
Type				Number of handicaps			
Total	43	1	3	2	3	10	24
Blind in both eyes	15	-	-	-	-	3	12
Blind in one eye	14	-	2	-	3	3	6
Deaf and mute	1	1	-	-	-	-	-
Completely deaf	6	-	-	-	-	1	5
Lame, amputated hand	1	-	-	-	-	1	-
Lame, amputated foot	3	-	-	2	-	1	-
Other	3	-	1	-	-	1	1
Number				Number of handicapped persons			
Total	38	1	2	2	3	8	22
1 handicap	33	1	1	2	3	7	19
2 handicaps	5	-	1	-	-	1	3

blindness—was characteristic of females: Of the 15 blind, there was only one male.

It was not always possible to form a judgment as to whether a handicap existed. There were some cases in which the physical and mental condition of the person surveyed made it impossible to fill out the questionnaire completely. Establishing the existence of handicaps was rendered more difficult by the need to treat a significant portion of the physiological symptoms originating from old age as natural conditions that characterize the age. Thus, poor eyesight does not figure among the handicaps. However, it is to be mentioned that the eyesight of 111 persons was—in their opinion or that of others in their environment—poor. While 15 were blind according to the answers to the question about handicaps, based on the answers to the question regarding eyesight, 16 persons were completely incapable of seeing. With two people it was impossible to establish whether they could see. Similar problems also arose in connection with hearing. One hundred twenty-five persons had impaired hearing, and seven could not hear at all. (The number of completely deaf persons and deaf and mute persons being the same, the results of the two questions coincided in this respect.) However, in the case of one person it was impossible to establish whether she could hear.

Among the handicapped, one could also mention the 47 persons who, as a consequence of old-age mental decline, were capable of only reduced mental activity or who were mentally deficient. Taking all the above into account, it can be established that the contradiction between the results of the survey of the elderly in the microcensus, on the one hand, and the results regarding the handicapped within the survey of the most aged, on the other, only seem to exist, originating from the differences in categorization between the two surveys.

Surveying the handicapped also will figure in the survey program of the 1990 population census. An additional questionnaire to be addressed to 20 percent of the total population includes five questions regarding bodily, mental, or sensory defects: "What kind of defect do you have?", "What is the cause of your defect?", "When did it begin?", "Do you have any limitation in working?", "If you do not work, do you intend to work?" Taking into consideration both the age group and the combination of age group and kind of economic activity, it will be possible to compare the data on handicaps from the 1984 microcensus, the 1987 survey of the most aged, and the 1990 population census.

Among the most aged, active support and care by the residential community is needed not only by the handicapped but also by those 180 persons who, according to the survey, had not developed handicaps. Increased care by persons in the immediate environment is also needed by those whose limited motility is not a handicap in the sense used here but the consequence of a natural condition. A question regarding motility was included both in the program of the microcensus and in that of the survey of the most aged. The data from the microcensus concerned the population born in 1914 and earlier, i.e., 70 years of age and over at the time of the survey.

In the case of both surveys, three questions concerned motility: The frequency of leaving the dwelling; the difficulties in walking upstairs and downstairs; and walking within the dwelling. Comparison of the data seems to be appropriate in connection with the last problem, walking within the dwelling.

Of the 19,583 persons 70 years of age and over surveyed, 469 (2 percent) could not walk within their dwellings. An additional 342 persons could walk within the dwelling only with the help of another person. Thus, 4 percent of the population 70 years of age and over had problems walking within their own dwellings.

Within their dwellings, 24 of the most aged could not walk at all and 19 could walk only with the help of another person. In spite of their advanced age, a relatively high number could walk independently at least within their dwellings. Of them, 105 could walk leaning on something (a stick or a walking frame) or holding on to pieces of furniture, while 68 could walk without any assistance (table F).

Naturally, the possibilities of analyzing the data on the elderly and the most aged have not been exhausted. The distribution by types of settlement, housing conditions, household-family relations, income situation, health status, and type and number of chronic diseases are all viewpoints that—when studied with the already published analyses—present the situation of the population from different aspects and call the attention of society to what needs to be done.

Table F. Number and percent distribution of the elderly population by manner of walking within a flat dwelling, according to age: Hungary, 1984 and 1987

Manner of walking within a flat dwelling	70 years of age and over[1]		99 years of age and over[2]	
	Number	Percent distribution	Number	Percent distribution
Total	19,583	100.0	218	100.0
Without any difficulty	14,209	72.6	39	17.9
Cautiously but without assistance	-	-	29	13.2
Holding on to pieces of furniture	1,990	10.2	37	17.0
Leaning on a stick	2,256	11.5	66	30.3
Using a walking frame or some other device	162	0.8	2	0.9
With the assistance of another person	342	1.7	19	8.7
Cannot walk at all	469	2.4	24	11.0
Cannot be established, no answer	155	0.8	2	0.9

[1] Data from the 1984 microcensus.
[2] Data from the 1987 survey of the most aged.

NOTE: A flat dwelling is one without stairs.

Chapter 12

A comparison of demographic, health, and housing variables in studies of elderly populations in Canada and the United States

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Introduction

With the aging of the population, scientists and policymakers are constantly searching for current valid data. However, the collection of population data can be both expensive and time consuming. As a result, policy decisions may be made on the basis of outdated or limited data. One possible solution to overcome this difficulty is to employ recent and valid data collected in similar jurisdictions. Questions then arise as to whether data collected in the United States can be generalized to Canada, or to parts of Canada such as Ontario; or whether data collected from New York or Ohio can be generalized to Ontario, or data from Oregon or Washington to British Columbia. Given the political, economic, and cultural differences between Canada and the United States, most investigators would argue that the use of data collected in one jurisdiction for policy decisions in another jurisdiction would have limited validity and usefulness.

To consider a specific example, in recent years a number of data sets describing the elderly population in the United States and Canada have become available, and it is of interest to compare the results obtained from these data. If similar measures are used and if the results are found to be similar, this would enhance the credibility of the results' reliability for interpretive or policy use in other jurisdictions. This conclusion would also suggest that, with respect to some factors, the two populations are essentially similar, implying that inferences derived from U.S. data could be assumed to be generally valid for Canada. However, if the results differ appreciably, this would suggest that for cultural and methodological reasons the data should not be used in other jurisdictions. Regional differences within Canada are also of interest because they may indicate greater similarities to some regions of the United States because of economic and/or cultural factors, in particular if the data for the largest province, Ontario, are compared with data for the rest of Canada. In addition, if longitudinal data are available in some areas, interpretations might be made across a period of time involving a greater part of the adult years.

Methodology

Description of the surveys used

The Canadian General Social Survey (GSS) was designed to monitor social trends and to obtain information on specific policy issues of current interest (1). The first cycle of this annual survey, conducted in the fall of 1985, includes variables concerning health and well-being, with an additional focus on social support for those 55 years of age and over. The target population was noninstitutionalized residents of Canada 15 years of age and over, excluding residents of the Yukon and Northwest Territories. The elderly respondents (65 years of age and over) were selected from households that had recently rotated out of the Labor Force Survey, and they were interviewed in person. The resulting sample size for persons 65 years of age and over was 3,130. The data presented in this paper have been weighted to adjust for sampling variation and response bias.

The data for the United States (2) were derived from the Supplement on Aging (SOA) to the 1984 National Health Interview Survey (NHIS) (3). The NHIS is an ongoing weekly survey that also examines health and well-being, and in 1984 the supplement focused on issues associated with aging. The target population for this survey is the civilian noninstitutionalized population of the United States. The SOA sample of respondents 65 years of age and over included all eligible people in the surveyed households, each interviewed in person. This sample of elderly persons (65 years of age and over) totaled 5,982 (2).

The Ontario Long-Term Study of Aging (Ontario LSA), 1959–78, was a longitudinal survey conducted to examine the process of aging, particularly during the preretirement period. A stratified quota sample of 2,000 men 45 years of age in the labor force in 1959 was selected to be interviewed annually over a period of 20 years. With attrition, 1,039 participants completed the study in 1978. (For details of the Ontario LSA, see (4).) The Ontario LSA data permit some comparisons to be made with the GSS; for example, the percentage of Ontario males ages 65–74 years in 1985 who report 0–8 years of education afforded similar values for the two studies, 32.4 percent and 32.6 percent, thus supporting the validity of both studies.

Measurement

Unfortunately, the various survey data are based on different questions, as is often the case. For this reason it was not possible to produce comparable Canadian measures for all of the U.S. data (2). Specific variables from the SOA that were not available from the Canadian data sets included race; the interval since last doctor contact; place of residence (urban or rural); and the questions, "How good a job do you feel you are doing in taking care of your health?", "How much control do you think you have over your future health?", "During the past year, has your overall health caused you a great deal of worry, some worry, hardly any worry, or no worry at all?", "Compared to your own level of physical activity 1 year ago, would you say you are now more active, less active, or about the same as you were then?", and "How often do you walk a mile or more at a time without resting?" In addition, some questions—such as, "Do you feel that you get as much exercise as you need or less than you need?"—were asked in a different way in Canada. The question concerning bed days in a year was estimated for only the last 14 days in Canada, and the question in Canada concerning hospitalization during the year asked about the number of nights spent in a hospital. Further, the question on regular exercise routine was not asked explicitly in Canada, where the question concerned only how regularly specific activities were carried out. Also, in a few instances the responses to similar questions were grouped differently in the two studies, for example, the time since last residential move and the number of activity limitations.

However, a number of questions are identical or almost identical in the surveys carried out in the two countries, and it is therefore possible to compare the responses to these questions. The variables described below, which were selected for this comparison, are based on similar questions.

Marital status in the Canadian GSS was collected as part of the household chart, which listed the basic demographic characteristics of all household members and their relationships to the respondent. In the NHIS SOA, marital status was asked as part of the interview, as it was for the Ontario LSA surveys.

Family size is computed from the household charts for both the Canadian GSS and the NHIS.

The questions concerning the education of the respondent are worded differently in the three surveys. However, the differences are minor and are unlikely to affect the conclusions. The GSS has the most complex series of questions. Respondents were asked, "How many years of elementary/secondary education have you completed?", followed by, "Have you graduated from secondary school?" and "What is the highest level?" To make Ontario grade 13 graduates comparable to graduates in the other Provinces and the United States, they were considered to have 12 years of secondary schooling. Those with college, university, or other postsecondary education were coded in the category 13 years or more, while those who did not complete high school but had some other further education had 1 year added to their total.

In the NHIS the respondents were asked, "What is the highest grade or year of regular school ______ has ever attended?" This was coded as the number of years at the highest level of education: Elementary, high school, and college. Similarly, the Ontario LSA asked "What is your education?" and coded the number of years at each level.

Housing was also measured differently in the various surveys. The GSS asked the respondent, "In what type of dwelling are you now living?", whereas the NHIS instructed the interviewer to classify the living quarters. Again, this different manner of asking the question is unlikely to affect the conclusions concerning the influence of type of housing.

The measurement of major daily activity of the respondents was also slightly different in the three studies. The GSS survey asked, "During those 2 weeks, was your main activity working, going to school, keeping house, or something else?", plus a series of questions designed to assess the labor force status of the respondents. The NHIS questionnaire, on the other hand, asked, "What was ______ doing most of the past 12 months: Working at a job or business, keeping house, going to school, or something else?" In an attempt to make the two surveys comparable, the GSS-derived labor force status was used as the main indicator of usual activity, using the question quoted above to separate respondents not in the labor force into those keeping house and those going to school.

The questions concerning perceived health status are fairly similar, except that the GSS asked the respondents to compare themselves to people of their own age. This could lead to a possible positive bias when compared with the other surveys. In addition, because of coding differences it was necessary to combine the "good" to "excellent" categories.

The last variable chosen for comparison was the number of doctor contacts in a year. In the GSS, the two relevant questions were: "During the last 12 months, how many times did you see or talk to a general practitioner about your health?" and "During the last 12 months, how many times did you see or talk to a medical specialist about your health?" The results of these two questions were summed to arrive at a total number of doctor contacts.

In the NHIS, respondents were asked, "During the past 12 months, about how many times did ______ see or talk to a medical doctor or assistant (about ______)? (Do not count doctors seen while an overnight patient in a hospital.)" The exclusion of contacts while in the hospital may cause a negative bias in the number of contacts when compared with the other studies, especially for those with frequent contact who are more likely to have been hospitalized.

Two measures in the Ontario LSA concerning doctor contacts were used, one from the initial 1959 survey, which is similar to that in the GSS, and a later one based on two questions asked in 1975: "Have you visited or been examined by an M.D. since last interview?" and "If yes, number of visits." Since the latter does not explicitly include talking to a doctor without a visit, this may also lead to slightly lower values for the Ontario LSA when comparing these results with those of the other two studies.

Data presentation

The data are presented for the population 65 years and over, subdivided for the population ages 65–74 years and for the population 75 years of age and over, given as percentages. Because the numbers surveyed are relatively large, most of the differences, both between different jurisdictions and between males and females, are significant at the $p < 0.05$ level. Specifically, all the standard errors were less than 0.075 percent, hence a difference of 0.5 percent is highly significant. This shows that the differences are not due to the expected difference that would arise if another similar sample were selected. However, a significant difference may not indicate a real difference, since the wording of the questions was not always identical. Also, differences in responses to many of the questions, such as those pertaining to perceived health status, might arise because of a different perception of what a different health status signifies; for example, a more positive outlook on life might give rise to a relatively larger proportion of individuals reporting their health as excellent.

Results

The results comparing Canada and the United States are shown in table A.

Table A. Percent distribution of persons 65 years and over by selected characteristics, according to age: United States and Canada

			65–74 years						*75 years and over*					
	65 years and over		*Both sexes*		*Men*		*Women*		*Both sexes*		*Men*		*Women*	
Characteristic	*Canada*	*United States*	*Canada*	*United States*	*Canada*	*United States*	*Canada*	*United States*	*Canada*	*United States*	*Canada*	*United States*	*Canada*	*United States*
	Percent distribution													
Marital status														
Married	57.1	54.7	64.0	63.3	80.4	80.3	50.0	50.3	45.1	40.9	67.1	70.4	31.5	23.8
Widowed	31.4	34.1	24.1	25.0	8.5	8.3	37.3	37.8	44.2	48.8	23.2	21.6	57.2	64.5
Divorced or separated	3.9	6.3	4.1	6.9	3.3	6.2	4.8	7.4	3.7	5.4	4.6	4.4	3.2	6.0
Never married	7.5	4.4	7.8	4.4	7.8	4.8	7.9	4.0	7.0	4.4	5.1	3.1	8.2	5.2
Family size														
1 person	31.0	32.2	26.1	26.4	15.7	13.9	34.9	36.0	39.7	41.4	23.5	21.3	49.7	53.1
Alone	28.2	30.5	23.6	24.8	14.8	12.3	31.1	34.4	36.2	39.7	20.7	20.6	45.8	50.7
With a nonrelative	2.8	1.7	2.5	1.6	0.9	1.7	3.8	1.6	3.5	1.8	2.8	0.7	3.9	2.4
2 persons	52.0	53.0	55.3	58.1	62.1	67.0	49.4	51.2	46.2	44.9	62.3	65.9	36.3	32.9
Spouse	45.1	46.0	49.5	52.2	59.8	63.8	40.9	43.3	37.3	35.8	54.3	62.0	26.8	20.8
Other relative	6.9	7.1	5.7	5.8	2.4	3.2	8.6	7.8	8.9	9.1	8.0	3.9	9.5	12.1
3 or more persons	17.0	14.8	18.6	15.5	22.1	19.1	15.7	12.8	14.1	13.6	14.2	12.9	14.0	14.1
3 persons	9.8	8.9	11.3	9.6	13.4	12.1	9.5	7.6	7.3	7.7	8.7	8.4	6.4	7.3
4 or more persons	7.1	5.9	7.3	6.0	8.7	6.9	6.2	5.2	6.8	5.9	5.4	4.4	7.6	6.8
Education														
0–8 years	46.9	34.6	41.7	29.7	43.8	32.1	39.8	27.9	56.1	42.5	62.8	45.1	52.0	41.0
9–11 years	22.4	16.8	24.1	17.6	21.9	16.8	25.9	18.2	19.6	15.6	16.6	15.5	21.5	15.7
12 years[1]	9.9	28.1	11.1	31.7	10.0	26.9	12.1	35.4	7.7	22.4	7.0	19.7	8.1	23.9
13 years or more	19.5	18.6	21.9	19.6	23.0	22.8	21.0	17.2	15.4	17.0	12.8	17.3	17.0	16.9
Housing														
House or apartment	95.5	93.5	95.9	93.5	95.9	94.5	94.3	92.8	96.3	93.3	96.5	92.3	96.2	94.0
Other	3.3	6.5	3.4	6.5	2.8	5.4	3.9	7.3	3.2	6.7	2.4	7.7	3.8	6.1
Usual activity														
Working	9.0	10.7	12.7	14.8	19.6	20.8	6.8	10.2	2.6	3.9	5.6	6.8	0.8	2.3
Keeping house	53.0	42.8	50.8	42.1	15.3	4.0	80.9	71.4	56.8	43.9	17.0	5.2	81.4	66.2
Other	35.4	46.6	34.1	43.1	61.9	75.2	10.6	18.4	37.5	52.2	71.3	88.0	16.6	31.5
Perceived health status														
Good to excellent	62.0	66.7	66.9	67.6	66.9	66.7	63.3	68.3	56.9	65.2	60.3	64.2	54.8	65.6
Fair	28.9	21.4	27.4	21.4	24.7	20.6	29.7	22.1	31.5	21.3	29.2	21.3	32.9	21.2
Poor	8.9	11.5	7.4	10.6	8.1	12.5	6.8	9.2	11.6	13.0	10.5	13.8	12.3	12.5

Number of doctor contacts in year														
0 contacts	11.7	18.6	12.8	19.7	14.4	21.2	11.5	18.5	9.7	17.0	12.9	17.7	7.7	16.5
1–2 contacts	27.5	27.8	30.7	28.9	32.4	28.8	29.2	29.0	21.9	26.1	25.5	28.7	19.7	24.6
3–6 contacts	30.1	31.7	29.1	30.3	28.8	30.2	29.3	30.4	31.8	34.0	30.4	33.6	32.6	34.3
7–12 contacts	16.9	13.2	16.2	13.0	14.1	12.7	17.9	13.3	18.2	13.4	16.3	11.8	19.4	14.4
13–24 contacts	9.5	4.9	7.8	4.9	6.7	4.3	8.8	5.3	12.4	4.8	9.4	3.4	14.3	5.6
25 contacts or more	2.9	3.3	2.4	2.9	2.8	2.6	2.1	3.2	3.8	3.8	3.7	4.2	3.9	3.6
	Number													
Estimated population in thousands	2,472	26,299	1,573	16,227	722	7,048	851	9,178	900	10,063	344	3,685	556	6,378
Sample size	3,130	5,982	1,898	3,731	953	1,625	954	2,106	1,232	2,251	511	822	721	1,429

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[1] Includes grade 13; see text.

NOTE: Figures may not add to 100.0 because of missing data.

Marital status

More individuals in Canada than in the United States reported their marital status as never married (7.5 percent versus 4.4 percent). This difference is observed in both age groups and for both sexes in the two samples. This consistency suggests that being never married is indeed more common in Canada than in the United States for the population 65 years of age and over. The reason for this difference is not known, but it may have occurred because of higher Canadian death rates during World War I or because of differences in immigration policies. At the same time, there are appreciable variations within Canada, with percentages ranging from 3.5 percent to 13.2 percent (data not shown). For example, in Ontario the percentage of never-married persons is 4.8 percent, close to the U.S. figure (table B). Ontario is more prosperous than the rest of Canada, as can be seen from table C; this suggests that a low never-married proportion is related to prosperity. In this connection, it may be noted that there is a reasonably strong correlation in Canada between annual marriages per million population (1926–55) and the gross national product (GNP) per capita in 1985 dollars ($r = 0.658$; $p < 0.01$) and income per capita in 1985 ($r = 0.621$; $p < 0.01$). At the same time, prosperity is not the complete explanation because cultural or religious factors, which may affect practices, beliefs, or attitudes (particularly of women toward careers) also play a role, as illustrated by the relatively high never-married rate for the Quebec region (13.2 percent). It should also be noted that the relatively high correlation coefficients arise because groups are considered; the correlations might be lower if individuals were considered (the ecological fallacy).

With respect to the elderly who report their status as divorced or separated, the percentage is higher in the United States than in Canada, except for males in the age group 75 years and over (table A). One reason for this finding may be that, until recently, it was easier to divorce in the United States than in Canada. However, within the Canadian regions, again there are pronounced differences, and these percentages range from 0.5 percent to 10.0 percent. It may be that a greater percentage of never-married persons is inversely related to a greater percentage of divorced

Table B. Percent of persons reporting never-married status, by age: United States, Canada, and Ontario

Age	United States	Canada	Ontario: Cross-sectional	Ontario: Longitudinal[1]	Rest of Canada
			Percent		
65 years and over	4.4	7.5	4.8	---	9.1
75 years and over					
Total	4.4	7.0	3.4	---	9.3
Men	3.1	5.1	1.4	---	7.3
Women	5.2	8.2	4.6	---	10.6
65–74 years					
Total	4.4	7.8	5.7	---	9.0
Men	4.8	7.8	6.6	---	8.4
Women	4.0	7.9	5.0	---	9.5
Men aged 65 years	---	---	---	1.9	---
Men aged 45 years	---	---	---	4.4	---

[1] The percentages for the Ontario Long-Term Study of Aging (LSA) are relatively low compared with the relevant Canadian General Social Survey (GSS) data (6.6 percent for Ontario males ages 65–74 years). Presumably never-married males participate infrequently in longitudinal studies. They also drop out from a long-term study more frequently for all reasons, including death. (See Forbes WF, McPherson BD, Shadbolt-Forbes MA. The validation of longitudinal studies: The case of the Ontario Longitudinal Study of Aging. Can J Aging 8(1):51–67. 1989.) This suggestion is supported by examining the data for the men in the Ontario LSA at age 45; if only men who completed the study are considered, this percentage is 2.9 percent, considerably lower than the value of 4.4 percent for males at the beginning of the Ontario LSA.

Table C. Income per capita, gross national product per capita, and number of marriages per million population: Canada, Ontario, and United States, selected years 1926–85

	Income per capita			*Gross national product*		*Marriages per million population*	
Year	*Canada*	*Ontario*	*United States*	*Canada*	*United States*	*Canada*	*Ontario*
	1985 dollars[1]					Number	
1926	$2,935	$3,359	---	$3,730	---	588	622
1930	2,965	3,669	$3,983	3,870	$4,762	585	630
1935	2,714	3,442	3,686	3,449	4,430	592	626
1940	3,454	4,339	4,546	4,683	5,841	904	917
1945	5,331	6,446	7,341	6,788	9,122	747	711
1950	5,249	6,364	6,679	6,627	8,384	760	815
1955	6,045	7,223	---	7,711	9,649	680	706
1985	15,708	17,186	13,902	17,891	16,757	---	---

[1] Monetary statistics are reported in the currency of the relevant country adjusted by the respective consumer price index; the average rate of exchange for the U.S. dollar in Canada in 1985 was 1.366.

SOURCES: Department of Finance. Annual reference tables. Quarterly economic review. Ottawa: Ministry of Supply and Services Canada. 1987.

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or separated persons, because a larger proportion of married persons may lead to more divorces or separations. In fact, if data for the Canadian Provinces are compared, a relatively high negative correlation is observed for the age group 60–64 years (r = -0.72). However, this correlation is much less for the other age groups, possibly because of the greater mortality of the never-married or because both these groups may tend to migrate to other regions in Canada.

A major difference between the sexes is observed in widowhood; for example, in the age group 65–74 years, the percentage of widowed women in the United States is 37.8 percent, while the percentage of widowed men is 8.3 percent; for Canada the corresponding percentages are 37.3 percent for women and 8.5 percent for men (table A). These sex differences presumably occur mainly because of the higher death rate of widowed males than widowed females. Similar differences have been noted in other countries. For example, for Australia the percentage of widowed males in the age group 70 years and over for 1981 has been reported as 20.8 percent, whereas for females it was 60.2 percent (5). These data confirm the importance of subdividing data on marital status by both age and sex, since both variables affect marital status.

Family size and living arrangement

It appears to be slightly more common in the United States than in Canada for elderly persons to live alone; however, again there are appreciable differences within regions in Canada (data not shown), and the differences are not consistent for all age-sex groups (table A). In both countries, as is well known, women live alone more often than men, and these differences are pronounced and consistent. A relatively small number of elderly women live with a nonrelative, and this figure is generally slightly higher for Canada than for the United States (table A).

Considering two-person families, specifically the elderly living with a spouse, there do not appear to be pronounced differences between Canada and the United States (table A) except in the age group 75 years and over. There are substantial differences between the sexes, particularly at the higher ages. The percentage of men in Canada who live with their spouse is 54.3 percent, whereas for women it is only 26.8 percent. In the United States, the corresponding figures are 62.0 percent and 20.8 percent. These sex differences presumably arise because of the higher male mortality in both countries.

The percentage of elderly who live in a household of four or more related people is consistently greater in Canada than in the United States (table A), perhaps because of smaller families in the United States. Consistent with this explanation, the figures for Ontario are slightly smaller than figures for the rest of Canada (6.8 percent and 7.1 percent, respectively). The role of prosperity is also indicated by considering the Atlantic region in Canada, a poorer region with more outward migration, where the percentage is 11.2 percent. If the proportion of households of four or more people is plotted against gross domestic product per capita in 1985 or against personal income per capita in 1985 for the 10 Canadian provinces, correlation coefficients of -0.63 ($p < 0.03$) and -0.71 ($p < 0.01$), respectively, are obtained. Again, this suggests an association between lack of prosperity and relatively large families.

Education

There are appreciable differences between Canada and the United States in levels of educational attainment. Specifically, a larger percentage of individuals in Canada than in the United States report 0–8 years of education (table D). The percentage for Ontario is 42.4 percent, somewhat closer to the U.S. percentage. In the British Columbia region, the percentage (31.4 percent) is lower than the U.S. figure, but in the Atlantic region it is 49.5 percent and in the Quebec region it is as high as 60.2 percent. This difference between Canada and the United States appears to be similar for the age groups 65–74 years and 75 years and over. A cohort effect is evident in both countries because the percentages are consistently higher at the older ages. Incidentally, the Ontario LSA percentages for 45-year-old males who were about 70 years old in 1985, the time of the GSS Survey (32.4 percent), are similar to the GSS percentages for Ontario for the age group 65–74 years (32.6 percent; table D). Reasons for the differences between the United States and most parts of Canada may include the smaller number of colleges and universities in Canada at the time these cohorts were of high school age and/or the more rural values prevalent in Canada at that time.

Somewhat surprisingly, since these cohorts of Canadians appear more often to have little formal education, the proportion of individuals reporting 13

Table D. Percent of persons reporting 0–8 years of education, by age: United States, Canada, and Ontario

			Ontario		
Age	*United States*	*Canada*	*Cross-sectional*	*Longitudinal*	*Rest of Canada*
			Percent		
65 years and over	34.6	46.9	42.4	---	49.6
75 years and over					
Total	42.5	56.1	56.7	---	55.8
Men	45.1	62.8	68.5	---	59.5
Women	41.0	52.0	50.1	---	53.3
65–74 years					
Total	29.7	41.7	33.5	---	46.2
Men	32.1	43.8	32.6	---	50.3
Women	27.9	39.8	34.3	---	42.8
Men aged 45 years	---	---	---	[1]32.4	---

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[1] The percentage for males who completed the Ontario Long-Term Study of Aging is 30.5 percent.

years or more of education is similar for Canada and the United States (table A). The largest difference between the two countries appears to be for individuals reporting 12 years of education (9.9 percent for Canada versus 28.1 percent for the United States; table A); the value for Ontario (11.1 percent) is again slightly closer to the value for the United States (data not shown). However, the questions were worded slightly differently (see the section on measurement). Also, there are relatively large differences between the Canadian provinces (data not shown). Again, the differences may be related, at least in part, to greater prosperity in the United States or to cultural norms pertaining to the pursuit of higher education, as well as the greater availability of institutions of higher education in the United States.

With respect to sex differences, more males than females report 0–8 years of education in both Canada and the United States, and this effect is noted in both age groups (table A). At the same time, there are also more males than females reporting 13 years or more of education for the age group 65–74 years; for the age group 75 years and over, the male and female values for the United States are 17.3 percent versus 16.9 percent, respectively, but for Canada the reverse effect is observed (12.8 percent for men versus 17.0 percent for women). This latter figure is surprising; possibly upper class older women were overrepresented in the sample.

Table E. Percent of persons reporting living in a house or apartment, by age: United States, Canada, and Ontario

Age	*United States*	*Canada*	*Ontario*	*Rest of Canada*
	Percent			
65 years and over ...	93.5	95.5	97.7	94.2
75 years and over				
Total ...	93.3	96.3	98.6	94.9
Men ...	92.3	96.5	97.4	96.0
Women ...	94.0	96.2	99.3	94.1
65–74 years				
Total ...	93.5	95.0	97.1	93.8
Men ...	94.5	95.9	96.8	95.4
Women ...	92.8	94.3	97.4	92.5

Type of housing

The percentage of individuals who report living in a house or apartment is slightly higher in Canada than in the United States (table A), although in the Quebec region the percentage (91.9 percent) is lower than in the United States (data not shown). For Ontario, the percentage is even higher (table E). This suggests that prosperity is one of the factors influencing type of housing selected early and late in life. Incidentally, for the 10 Canadian Provinces the correlation between the 1985 unemployment rate and the proportion living in a house or apartment is negative ($r = -0.32$), but it is not significant. Another reason for the difference between Canada and the United States may be that Canada represents a more stable, or less mobile, population. That is, Canadians may be slightly more likely to live in a house or apartment. Another possibility is that the difference may be related to climate, with the harsher Canadian climate making temporary accommodation, such as trailers, less suitable.

Major daily activity

The percentage of elderly persons who report they are working is slightly higher in the United States than for all of Canada (table A), but the range of values within the Canadian regions is relatively large and includes the value for the United States (data not shown). Reasons for the differences may include variations in climate and in the amount and availability of public and private pension plans. The difference between Canada and the United States is consistent across the two age groups and for both males and females (table A). As expected, the percentage who work is appreciably lower in the higher age groups (table A). Also, as expected, the percentage who report that keeping house is the major activity is considerably larger for females than for males. Elderly Canadian males also seem more often to be keeping house than their U.S. counterparts.

Perceived health status

The percentage of elderly persons who report their health as being good to excellent is slightly higher in the United States than in Canada. Similar differences are observed in both age groups (tables A and F). At the same time, the proportion reporting poor health is consistently greater in the United States (table A).

This is one of the few examples in which all five regions of Canada (4.5 percent to 11 percent) fall below the U.S. value (11.5 percent). One reason for this greater rate of individuals reporting poor health in the United States may be the greater rate of institutionalization in Canada; both samples included only the noninstitutionalized populations. Another reason may be the slightly different wording of the question (see the section on measurement). With age, as expected, the percentage reporting good or excellent health decreases; the data for Ontario, both cross-sectional and longitudinal, also show this trend (table F).

Number of doctor contacts

Another estimate of health status is provided by the reported number of doctor contacts during 1 year. The percentage of individuals who reported no doctor contacts is larger in the United States than in Canada (table G). This is another example in which the range within the five Canadian regions (10.3 percent to 15.1 percent) does not include the U.S. percentage. Presumably these differences are, at least in part, related to the more ready access to health services and the lower personal costs for each visit, for most individuals, in Canada than the United States. The Ontario figures tend to be relatively low, except for males 75 years of age and over (table G). However, for one to six doctor contacts, the Ontario percentages are lower than those for the other four Canadian regions (data not shown). The Ontario LSA data are somewhat higher (table G), but this may be because of a selection bias whereby Ontario LSA subjects were relatively healthier.

The percentage of individuals reporting 25 or more doctor contacts is also greater in the United States than in Canada (3.3 percent versus 2.9 percent), and is even higher in Ontario (table H). The percentages from the longitudinal data are relatively low, possibly because only visits to doctors were recorded; calls were excluded (see the section on measurement). Also, when the Ontario LSA subjects were 45 years of age, access to health services in Ontario may have been more limited since the Ontario health insurance plan was not then in force. Although some individuals who report this number of contacts probably have health problems that require them to visit a physician on a regular basis, this percentage would be expected to be similar in the three jurisdictions, unless survival or institutionalization of frail persons varies appreciably. Incidentally, the percentage of individuals who report 13–24 contacts is consistently greater in Canada than in the United States (table A).

Concluding remarks

In spite of numerous difficulties that arise when comparing the various characteristics of elderly

Table F. Percent of persons reporting good to excellent health status, by age: United States, Canada, and Ontario

Age	United States	Canada	Ontario		Rest of Canada
			Cross-sectional	Longitudinal	
65 years and over	66.7	62.0	63.7	---	61.0
75 years and over					
Total	65.2	56.9	52.2	---	59.9
Men	64.2	60.3	57.5	---	61.9
Women	65.6	54.8	49.2	---	58.5
65–74 years					
Total	67.6	64.9	70.8	---	61.6
Men	66.7	66.9	72.4	---	63.8
Women	68.3	63.3	69.5	---	59.9
Men aged 62 years	---	---	---	[1]69.8	---
Men aged 45 years	---	---	---	[1]85.1	---

[1] The percentages for individuals who completed the Ontario Long-Term Study of Aging are slightly higher: 86.1 percent for men 45 years of age and 72.4 percent for men 62 years of age.

Table G. Percent of persons reporting no doctor contacts during 1 year, by age: United States, Canada, and Ontario

Age	United States	Canada	Ontario: Cross-sectional	Ontario: Longitudinal	Rest of Canada
			Percent		
65 years and over	18.6	11.7	10.4	---	12.4
75 years and over					
Total	17.0	9.7	9.4	---	9.9
Men	17.7	12.9	18.4	---	9.6
Women	16.5	7.7	4.3	---	10.1
65–74 years					
Total	19.7	12.8	11.1	---	13.8
Men	21.2	14.4	14.0	---	14.6
Women	18.5	11.5	8.5	---	13.1
Men aged 62 years	---	---	---	[1]24.6	---
Men aged 45 years	---	---	---	[1]35.0	---

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[1] The percentages for males who completed the Ontario Long-Term Study of Aging were 25.2 percent at 62 years of age and 34.3 percent at 45 years of age.

Table H. Percent of persons reporting 25 doctor contacts or more during 1 year, by age: United States, Canada, and Ontario

Age	United States	Canada	Ontario: Cross-sectional	Ontario: Longitudinal	Rest of Canada
			Percent		
65 years and over	3.3	2.9	3.5	---	2.6
75 years and over					
Total	3.8	3.8	4.8	---	3.2
Men	4.2	3.7	6.5	---	2.0
Women	3.6	3.9	3.9	---	4.0
65–74 years					
Total	2.9	2.4	2.6	---	2.3
Men	2.6	2.8	3.6	---	2.3
Women	3.2	2.1	1.8	---	2.3
Men aged 62 years	---	---	---	[1]2.2	---
Men aged 45 years	---	---	---	[1]0.6	---

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[1] The percentages for males who completed the Ontario Long-Term Study of Aging were 1.7 percent at 62 years of age and 0.9 percent at 45 years of age.

populations in Canada and the United States, some comparisons are possible. For example, never-married status is more common among the elderly in Canada than it is in the United States. Also, being divorced or separated appears to be more common in the United States than in Canada. In addition, it seems slightly more common for elderly persons to live alone in the United States than in Canada, and less common for a family to be comprised of four or more people in the United States.

With respect to education, it appears that, compared with elderly persons in the United States, a greater percentage of elderly persons in Canada report 0–8 years of education. On the other hand, the proportion of elderly reporting 13 years or more of education is similar. The largest differences are for individuals reporting 12 years of education; this proportion is considerably greater in the United States.

There are only slight differences with respect to type of housing. Specifically, more elderly people in Canada than in the United States report living in a house or an apartment. There are also only slight differences in the percentage of elderly persons who report being employed, which again is slightly higher in the United States than in Canada.

With respect to health status, the questions asked were not identical, but it seems that the percentage of elderly persons who report their health as being good to excellent is slightly higher in the United States than in Canada. A greater percentage of the elderly in the United States than in Canada report having no doctor contacts. At the same time, the percentage of individuals reporting 25 or more doctor contacts is also greater in the United States than in Canada.

It should be noted that the variations within the Canadian regions are generally larger than the differences between the United States and Canada. Two exceptions were the differences between Canada and the United States in the proportion of individuals who report poor health and the proportion of individuals who report having no doctor contacts. It is tempting to ascribe these differences to variations in the two health care systems.

In summary, it is difficult to answer the questions posed at the beginning of this paper. If the questions are worded in an identical manner, one's confidence in the similarities and differences noted increases. For example, the observed differences in education were relatively large, suggesting that this variable should be statistically controlled if data from the United States are to be generalized to Canada. It should also be noted that many of the variables are related, and this may account for some of the observed differences. For example, the level of education might well be related to a number of variables, including health and housing variables, and it is therefore not clear which of these variables account for the observed differences unless education is controlled in the analyses.

Acknowledgment

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Chapter 13

Function in old age: Measurement, comparability, and service planning

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In the interest of time, I will skip my theoretical introduction, except to say that while we would really like to measure health, we know how to measure only disease. At least we think we know but we are not sure, so we must measure several aspects—of morbidity, of mortality, of health behavior, and so on—to obtain a rounded picture. The titles of the different sessions of this conference come from these aspects of disease. In this session, we are looking at functional disability.

Assessment of function, according to the recent World Health Organization (WHO) Expert Committee on the Health of the Elderly, should include the following seven areas, of which the first four items are intrinsic and the last three are extrinsic:

- Activities of daily living (ADL's).
- Mental health functioning.
- Psychosocial functioning.
- Physical health functioning.
- Social resources.
- Economic resources.
- Environmental resources.

The ADL scales include mobility, instrumental ADL's, and physical ADL's. The mental health section includes psychiatric symptomatology as well as cognitive function, while the psychosocial functioning is the personal assessment of well-being. Physical health functioning includes a range of measures, from self-perceived health status through symptoms, diagnosed conditions, utilization of health services, and activity levels and measures of incapacity such as bed days.

Now the expression of these functional abilities and thus the results of surveys are of course greatly modified, as Dr. Kovar reminded us, by the availability of family, friends, and neighborhood resources; the adequacy of income; and the quality of housing and availability of transportation, shopping, and public services, listed here under the general rubric of environmental resources.

Multiphasic assessment, comprising all these variables, is necessary for the treatment and support of the individual and for the rational planning of services for the community. But how nice it would be to have a single simple question to measure health status, and I will come back to that in a minute.

Cross-national studies

Information on extrinsic factors in aging and the effects of different patterns of social support and health care can come from comparative and cross-national studies (table A). As we have already heard, the methodological pitfalls are considerable: There are many problems of measurement that have to be resolved on the road to such studies.

Table A. Percent of respondents 70–74 years of age who rate their health as worse than that of others their own age, by sex: Selected communities, 1980–81

Community sampled	*Men*	*Women*
	Percent	
Upper Normandy	13	16
Florence	18	12
Belgrade	20	22
Bucharest	24	30
Bialystok	26	34
Kiev	22	33

SOURCE: World Health Organization surveys, 1980–81.

To return to our simple question and to generalize a point made by Dr. Forbes, the WHO survey of the elderly in 11 countries used the same questionnaire, suitably translated, in 16 different populations ages 60–100 years. The response to a general question on a self-appraisal of health showed wide variations in different populations, with urban-rural, sex, and East-West differences.

The more sophisticated version of this question, "If you compare your health with that of other persons you know of your own age, is your health better, about the same, worse, don't know?", gives the results illustrated in table A for the age group 70–74 years, for which the numbers were adequate and the response rates relatively high. The same East-West trend is seen in each 5-year age and sex group.

Are these differences real? Are these answers culturally driven? Or are there explanations perhaps linked to faults in the survey methodology? We really do not have all the answers.

In most surveys, assessment of health and disability is on firmer ground; many multiphasic survey instruments have been proposed, and not a few have been evaluated. Nearly all of them, however, are limited in that they are based on responses to questions asked by an interviewer under conditions open to a number of confounding factors.

A major confounding factor is education. In one national study in Israel in 1984, three-quarters of persons 75 years of age and over with little or no schooling rated their health as poor or bad. Of persons the same age who had had 9 years or more of schooling, less than half gave that answer. Was this due to education alone? Or the differences in socioeconomic level or ethnicity of those with higher and lower education? Or a combination of these and other factors?

These are differences that are obviously affected by the methodology and need to be teased out. Several studies, including our own, have shown that the uneducated do poorly on cognitive function screening tests, and the universal validity of these tests has been questioned, specifically in the United States.

In the course of development of a new screening test for our own heterogeneous and often uneducated population, we tested a second instrument in parallel—with questions on health, ADL's, and instrumental ADL's—on a small subset of 200 individuals. Performances in the cognitive screening test and in the ADL's were significantly correlated.

Elderly subjects who reported one or more deficiencies in the Katz ADL scale showed a significantly higher score on the Brookdale Cognitive Screening Test—that is, increased disability—as did those with two or more instrumental ADL deficiencies. These associations were stronger at higher levels of education, and similar results were reported last month (November 1988) in the *American Journal of Epidemiology* (1) on a far larger sample from East Boston.

Even aside from the confounding effects of education, however, do some people perform badly on all questionnaires or are there more subtle relationships between mental and physical disabilities?

Subjective and objective health

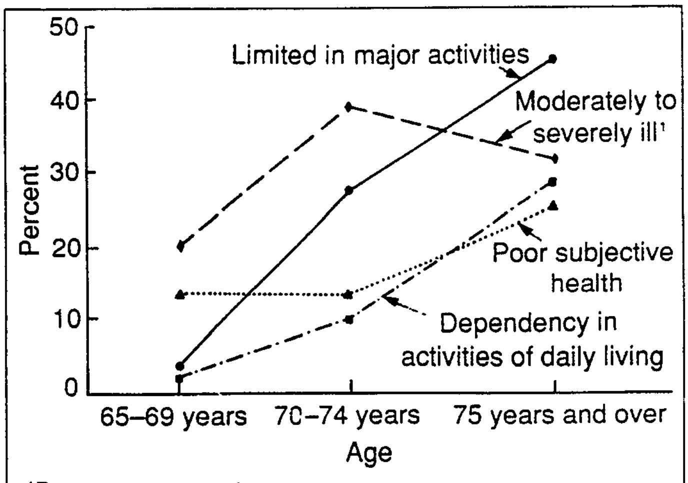
Our basic problem is that we do not have objective definitions, let alone objective measures, of health in old age. We need more progress in geriatric clinical assessment to differentiate between the decrements of old age and disease pathology. The correlations between defined diseases and limitations of mobility to be reported by Harris and Kovar are an important advance in this direction.

Svanborg reported from the Swedish Gothenburg Study that half of those 70 years of age who were being treated for heart failure were, in fact, showing a mild dyspnea on exertion, some cardiac enlargement, and a little swelling of the ankles, which could be considered physiologically normal at their age. Of course, the other half of the group did indeed have heart failure.

Difficulty in climbing stairs could be due to arthritis of the knees in one person, emphysema of the lungs in another, and cardiac failure in a third. The outcome on a disability scale might be similar, as Dr. Cohen reminded us, but the possibilities for prevention and amelioration by treatment are quite different. A full medical evaluation of a disabled person is always necessary, and an estimate of prognosis is important in formulating care plans.

There is not necessarily a correlation between ADL dependency and the number of conditions or diseases reported. Figure 1 illustrates the results of a survey of all the elderly in one Israeli community (2). There was a direct correlation between the number of conditions reported and the feeling of ill health, but not, as you see, between number of conditions and ADL dependency.

It is well known that there is, in fact, little or no correlation between measures of different aspects of health and disability that have been designed in various questionnaires. Figure 2 illustrates data derived from a sample of elderly people in a neighborhood of Jerusalem as reported by Dr. Rosa Gofin (3). I gave the title to this figure some 6 years ago when I believed that "objective" assessments had been made in population studies. Today I would call them "doctors' guesses" and suggest that we actually compare two subjective assessments of health, one by the subject herself or himself and one by the professional observer.



¹Doctor assessment.

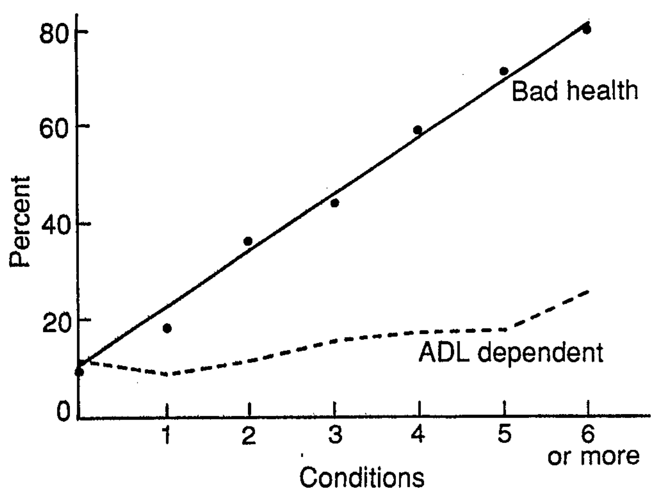
NOTE: 217 men were assessed.

SOURCE: Gofin R. The health status of elderly men: A community study. J Public Health 96:345–54. 1982.

Figure 2. Indexes of subjective and objective health in men 65 years of age and over: Jerusalem, 1969–71

Proxy reporting

The last methodological point that I would like to make adumbrates a point, made by Dr. Kovar and particularly by Dr. Forbes, on the effect of type of respondent on the answer to questions. We know that many disabled elderly persons could be kept in the community if appropriate social and health support were available. In a study by Factor and colleagues in Israel (figure 3), elderly persons on waiting lists for admission to the different types of long-term care institutions were reassessed (4). Forty-three percent of the elderly who were moderately disabled in performing ADL's said that they could remain in the community, given adequate support. The informal caregivers were conservative. They thought only 37 percent could remain. But the multidisciplinary assessment team of public health nurse and social worker felt that 82 percent could remain in the community. The influence of experience, beliefs, availability of services, and attitudes of assessor on such a decision are critical.

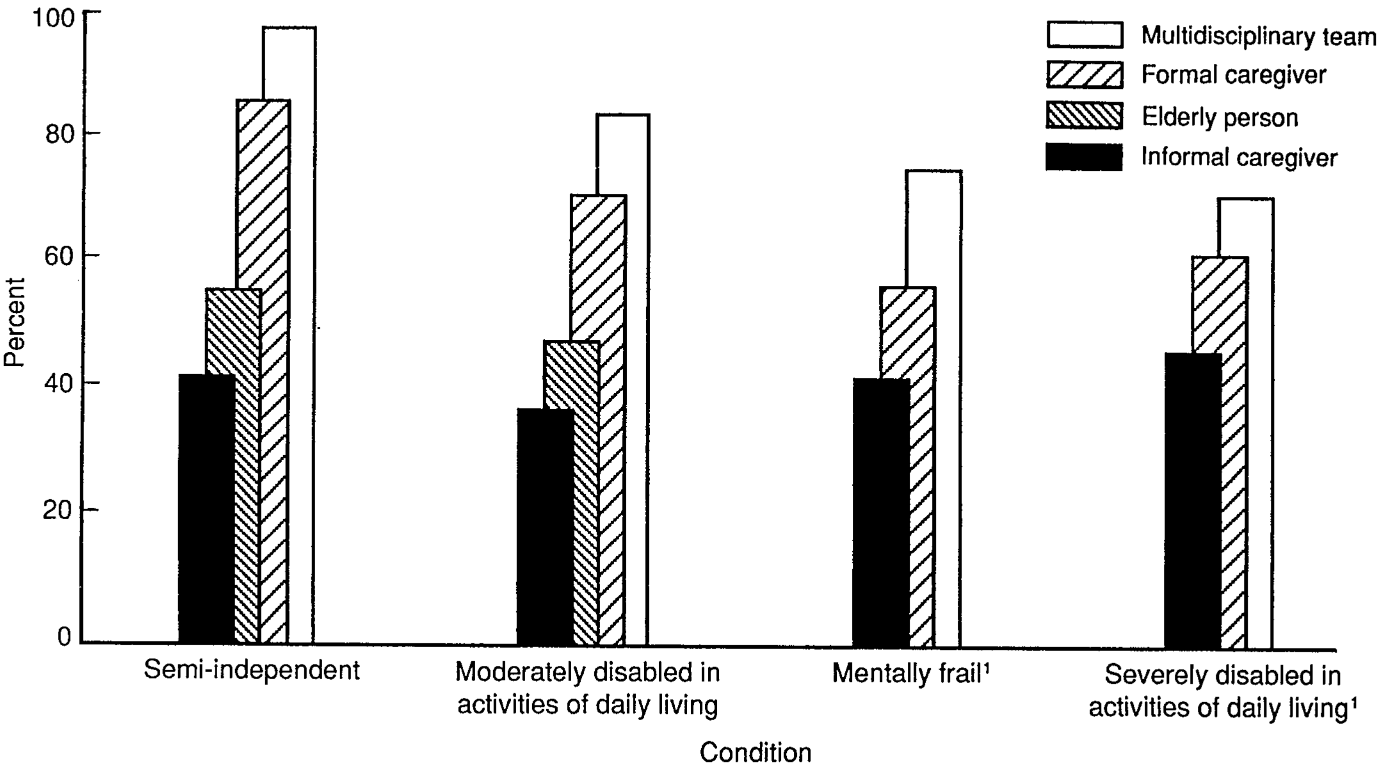


SOURCE: Barell V, Kaplan G. Reported health of the elderly: The Kiryat Ono census. Isr J Med Sci 21:254–9. 1985.

Figure 1. Percent of elderly persons, by prevalent conditions reported, bad health, and dependency in activities of daily living (ADL's): Kiryat Ono, Israel, 1984

Unfortunately, such soft data are all that we have. When age-specific disability rates of those requiring admission to long-term care institutions are applied to future population predictions, we derive forecasts of future needs for long-term care. It will be necessary to refine our measurement techniques considerably before we can put confidence limits on those estimates.

As Dr. Kovar said in the introduction, the goal of measuring functional disability is to contribute to its postponement or prevention. I would add that the goal should also be to contribute to its amelioration. We shall need adequate, cost-effective services to do so.



[1] Elder's opinion not presented as many could not be interviewed.

SOURCE: Factor H. Brookdale Institute for Gerontology, Jerusalem. Personal communication. 1987.

Figure 3. Percent of elderly on approved waiting lists for institutionalization who could remain in the community, by condition of elderly and type of informant: Israel, 1987

Conclusions

It is a characteristic of epidemiologists that they rarely provide final answers to questions but usually produce a new hypothesis for test in yet further studies that some agency will fund. Therefore, the moral of these arguments really is *festina lente* or, in a free translation, "Let us progress systematically." For collaborative studies in disability and indeed, as we have heard, for studies in one country, we need a research program that will include at least the following four elements. I offer these as topics for discussion in the workshop.

1. We will need checks of the validity of each survey instrument in each population tested and the consistency of the findings in repeat interviews.
2. We will need to develop more longitudinal studies to provide data on the incidence of defined disability and the changes in prevalence, i.e., how many people improve in time, even if only a little.
3. We will have to combine the hitherto separate approaches of epidemiology, social survey, and clinical medicine and relate dysfunction to pathology and disease.
4. Finally, repeating a suggestion of Dr. Forbes, we must undertake clinical trials to establish the effects of changing risk factors and the value of different regimes of intervention.

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Chapter 14
Functional disability issues

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Dr. Davies has laid out our work better than I can and, with his usual farsightedness, has seen to it that we shall all be busy well into the next century. The proposed international collaborative effort is only one of many that will be needed if we are to reach the ultimate goal.

We have to take the first small steps now. We need to plan collaborative research that can be carried out during the next few years. I hope that the research is designed to begin the development of a manageable set of questions that can be used in interview surveys to measure the prevalence of functional disability and the need for care from another person. If possible, the measures will include duration and frequency of both disability and need.

I think that we agree that dissimilar questions can measure similar concepts and that similar questions can measure dissimilar concepts. Therefore, we need to develop conceptually similar questions on functional disability and the need for care that can be used in cross-cultural and cross-national population studies. Doing so will take the kind of research that Dr. Davies has outlined.

Some of this research should be done in conjunction with other projects. In particular, since the path to disability is usually through disease, the research projects should be coordinated with those on chronic disease morbidity. That is especially important if our goal is to prevent or postpone disability.

While that is going on, we can use the data that we have and design tabulations to make comparisons that we can trust across cultures and nations. I think that Dr. Forbes has shown the way, and we are ready to begin.

Part V

International health care research

Introduction

by Jacob J. Feldman, Ph.D., Associate Director for Analysis and Epidemiology, National Center for Health Statistics

Dr. Feinleib, yesterday morning, indicated that the major focus of this conference is essentially methodological: The primary reason that we are interested in these current comparative analyses is that the National Center for Health Statistics intends to apply what we learn through these projects to the improvement of our measurement methods.

We hope the same thing will also happen in all of your countries, and perhaps at that point comparative analysis for more substantive purposes may be possible. Certainly, the current major goal is for each of us to be able to improve the way in which we measure the various health variables that are being discussed here.

However, it is clear that in order to improve measurements, you have to know why you are trying to measure what you are trying to measure. A writer, presumably an ecclesiastical writer, once indicated that we measure but we know not what we measure. To the extent to which that is the case, of course, it is very difficult to arrive at protocols for these projects.

I do want to commend to you a volume by the Committee on National Statistics. The Center and other parts of the Public Health Service and the Department of Health and Human Services in general formed a committee for the purpose of exploring the issues of statistical needs in the future. The volume that came out of that project is *The Aging Population in the 21st Century: Statistics for Health Policy* (1). This volume attempts to deal with the uses of statistics. In other words, it is set up in a framework of deciding (a) what the policy issues would be at that time and then (b) what statistics might be needed in order to inform those policy discussions. Therefore, as background to the activity we are currently undertaking, I would recommend that you review the data needs that are explicated in that volume.

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Chapter 15
Cross-national research in health care

by Gary Robert Andrews, M.B., Director,
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Introduction

In 1983 the United Nations (U.N.) called a World Assembly on Aging, which drew attention to the dramatic phenomenon of the graying of the world (1). The scale on which population aging is now occurring worldwide is beyond ordinary human conception. Further, the experience of population aging on such a scale is an entirely new event: The world has faced nothing like it in times past.

In 1980 the global population could be characterized as "young": Thirty-five percent of all persons were ages 0–14, and 8.5 percent were 60 years of age and over, according to U.N. estimates (2). At that time, significant aging in population terms was already evident in the more developed regions, with some 15 percent of their population in the age group 60 years and over. The less developed regions were by contrast exceedingly youthful, with 39 percent of their aggregate population in the age group 0–14 years, and only 6 percent in the age group 60 years and over.

This pattern of relative youthfulness reflects past high fertility and reduction of mortality, particularly among infants and young children. As a result, policymakers have tended to focus attention on such issues as birth control and provision of health care, education, and other services to growing cohorts of the young. Relatively little attention has been given to the longer term consequences of successful birth control programs and improved life expectancy at birth, which result in an increasing relative weight of the elderly in the population and growing numbers of persons surviving to old age.

The profile of the world's population will change dramatically, however, during the next four decades. Mainly as a result of current and anticipated changes in fertility, the world will become markedly older. U.N. projections forecast that by 2025 only 25 percent of the world's population will be in the age group 0–14 years, and nearly 14 percent will be in the age group 60 years and over. There will be a significant shift toward aging in developing countries. By the year 2000, roughly two out of three of the world's 600 million people 60 years of age and over will be living in developing countries, compared with 50 percent in 1980. The growth of the elderly population will be particularly marked in Asia, owing primarily to the growth expected in the number of aged in China and India. Between now and the year 2020, the population 60 years of age and over will increase in China and India by over 100 million, and in Indonesia by more than 20 million. In the developing world overall, while the total population will increase by 95 percent from 1980 to 2000, the population 60 years of age and over will rise by almost 240 percent (3).

The impact of aging of the population will be felt in many key policy areas, including economic, social, and health arenas. Decisionmakers must be persuaded to anticipate aging and its influence upon needs and priorities for government policies and services. This is especially true for health services, given the association between morbidity and aging and the associated increase in needs for health care.

China, with over 90 million people 60 years of age and over, now has the world's largest population of older persons. In the 21st century, as a result of the implementation of the official policy of one child per married couple, it could be the most rapidly aging of all of the world's countries. The successful nationwide implementation of the policy according to current projections would result in 40 percent of the total population being 65 years of age and over by the middle of the next century (4).

There is an urgent need for relevant, sound, and timely information on the health impacts of aging in all of the countries and regions of the world. Much of the work that has previously been done in this area relates to the situation in Western developed countries. In Asia and other developing regions of the world, the geophysical, socioeconomic, and cultural settings are very different from those of Europe or North America, and it is essential to undertake research now to provide data that will underpin policy directions and programs aimed at maintaining and restoring health of the elderly in the future in these settings. The different historical, current, and projected demographic experience of various parts of the world provides an extraordinary potential range of natural experiments. In these diverse settings there are significant variations in terms of the trajectories of demographic and epidemiologic transitions and the consequent social, economic, and health impacts.

Cross-national comparative research—the challenge

The idea of cross-national comparisons of health and well-being clearly implies an ability to measure health and well-being and to define accurately the presence or absence of disability among individuals and populations. Further, it suggests that this can be done reliably and validly across nations and between cultures. There are, however, several factors that lead us to raise questions about the quality of much of the efforts to go beyond the reporting of results of individual studies in this critical area of human inquiry.

Thus, in terms of international comparative effort, we can ask the following questions:

- Are our conceptual ideas of health and disability sufficiently refined that it is possible to effectively operationalize them in very different settings with some confidence?
- Are the definitions that might then be applied to these concepts of health and disability in practice precise enough to be used as a basis for developing cross-national research tools designed to quantify health and disability at individual and population levels?
- Are measures available (or likely to be developed) that may be applied cross-culturally or cross-nationally to the assessment of health status in the field with efficiency, reliability, and validity?
- Do existing and proposed national data collections provide coverage of health and functioning of the population in such a way that it will be possible to derive valid, internationally comparable measures of specific changes in population health status in terms of frequency (incidence and/or prevalence), distribution, and consequences?
- Do existing methods of data analysis provide appropriate derived measures that are capable of interpreting existing patterns as well as projecting future trends of population health status and aging in a form that is internationally relevant to health and social policy and planning considerations?

Each of these questions is capable of generating a whole symposium in its own right, so I plan to focus specifically on the questions related to study design and methodology and to explore the impact of variations in method and in the application of similar methods in different circumstances.

Lawrence Branch (5) noted at the National Institute on Aging (NIA) 1977 Second Conference on the Epidemiology of Aging that the concept of "functional abilities" is amorphous, and to a considerable extent the functional abilities of the elderly will reflect those aspects that are measured in a particular study. Disabilities or functional limitations, he went on to note, could usefully be viewed as a continuum from minimal or zero limitation to high or severe, and most measures deal with only one part of the spectrum. The need for and value of a composite measure of functional limitation was argued.

The desirability of such a composite measure is clearly evident, but the difficulty in deriving a satisfactory tool in practice illustrates the complexity of the issues with which we are grappling. We still lack a universally accepted composite measure, and international research remains plagued by a myriad of variations in such basic measurement arenas as activities of daily living, cognitive functioning, general activities scales, physical performance measures, and general health status. This situation attests to the fundamental barriers to achieving what appear to be relatively modest objectives in this essential exercise.

Part of the explanation for this situation, I think, lies in the general approach that has been taken to research on aging over the last couple of decades. Increasing attention has been paid to the scientific examination of aging and age-related phenomena at every level from basic biological, social, behavioral, economic, biomedical, and demographic perspectives. All of this has progressed our understanding of aging in individual and societal terms very substantially. We now know a great deal more about older individuals in various circumstances and locations than we knew some decades ago. The vast majority of these new insights are, however, based upon simple descriptive data. For instance, with regard to any specific older age group living in a particular location in the developed world at present, we could with a fair degree of confidence estimate their physiologic, health, mental, and functional status; their rates of utilization of health services and social services; economic circumstances; and so on. We would, however, have a great deal of trouble explaining the dynamics behind these categorical descriptions of the population: Why some are demented and others not; of those who show signs of dementia, why some are in institutions and some are not; etc. We also strike some significant difficulties when we attempt to compare detailed findings between different locations, across nations, between cultures, or between developed and developing countries.

Our problems are thus multifold; we are largely confined to using simple descriptions of point prevalence of states, and such measures as we have to assess these are rarely standardized across populations. If any effective attempt is to be made in applying available data to international geographic comparisons, then we have to develop either highly standardized measures or a means of calculating the effects of variations in study design and methods applied in different settings.

Problems associated with research design and sampling

Sampling

It is evident from the literature on population studies and aging that often different approaches are taken to sampling in most studies. National representative sampling is costly, technically difficult, and rare. However, the design effects of sampling methods used to reduce costs, such as stratification and clustering, can be taken into account in analysis. Sampling frames, sample generation method, and sample size calculation should be clearly defined. Any systematic bias should be identified at the outset and controlled for in subsequent analysis. In practice it is often not so simple. Enumeration of the older population is often inadequate in many of the standard sampling frames used, such as electoral rolls, social security beneficiary lists, health service registers, and community registers of various kinds. If true nationally representative probability sampling is not possible (and it usually is not), then at least precise definition of the chosen sampling frame and method and identification of variation in composition from national demographic, socioeconomic, ethnic, and other characteristics should be the minimum requirements. This at least allows for appropriate weighting in analysis.

Nonsampling errors including response rates

There are in any data collection and survey efforts a variety of potential major sources of error. Some of the more common problems are the following.

- *Observer bias*—Reflecting variations in interpretation of responses by different observers.
- *Assumption bias*—Faulty logic or mistaken belief of the investigator.
- *Recall bias*—Particularly important in the elderly.
- *Questionnaire failure*—Ambiguous or misleading items.

Other errors can occur as a function of time, data processing, or interpretation. It is clear that all these issues are particularly relevant to cross-national research and call for close attention to be paid to interviewer training (and retraining), precise definition and instructions, along with stringent quality control measures.

Response (or nonresponse) rates are often not systematically reported by researchers. In our experience, response rates have generally been higher in developing country studies, perhaps reflecting cultural differences or less previous exposure to social or health survey research. The basic characteristics of nonrespondents should always be investigated by whatever means are available so at least potential bias introduced by their exclusion can be assessed. In our experience, generally there has been little difference noted in the characteristics of respondents and nonrespondents. We do have the impression that there are some cultural variations; for example, in some societies disabled individuals may be underrepresented if disability is considered a social stigma.

Proxy respondents

If one is concerned about including information on the severely disabled and particularly those with severe mental disability, then provision for proxy responses to factual questions is very important. The choice of proxy, the precise definition of what is acceptable as proxy information, and the specification of proxy responses in analysis are all important. A consistent approach to proxy responses when information is collected sequentially is essential, and data should be collected from the same proxy over time whenever possible. Although there are reservations about surrogate interviewing, it is clearly preferable to receiving no information at all. Recent studies have suggested that in many situations proxy interviews have been successfully used (6).

Institutional populations

A majority of studies of aging populations exclude those who are resident in institutions and deal only with the so-called "community-based" or "noninstitutionalized" elderly. While such an approach is acceptable for many purposes, it does result in samples that cannot be said to be representative of the whole population. Usually rates of institutionalization increase with age so that, apart from geographic variations, different proportions of various age groups will be available for inclusion in studies of the community-based elderly. Institutions for the elderly are now found everywhere in both developed and developing countries; differing administrative definitions of institutions themselves, variation in admission policies, differing levels of care classifications, and so forth, mean that comparisons of institutional populations can be difficult. Separately collected data on institutional populations can be usefully taken into account, but such data need to be defined precisely, as methods of information collection will vary widely. In general population studies, the institutionalized account for only a small proportion of the total study group; therefore it is necessary, if information on them is specifically required, to either oversample or to study those in institutions separately.

Modes of data collection

McKinlay and others (7) have reviewed various methods for field data collection of sociomedical information among the elderly, including face-to-face, telephone, and self-administered formats. They concluded that "all field approaches are useful, some appear more useful than others depending on the topic and objective of the study and the characteristics of the population under investigation." There appears to be a good case for mixed-mode approaches. The main difficulties arise in trying to compare data that have been collected using different modes. In the view of McKinlay et al., in-person interviews can no longer be considered the "gold standard," and they may increasingly be a luxury from which researchers need to be weaned, especially in situations of financial stringency. In our experience, a combined approach is often useful so that the benefits of particular methods in specific areas can be achieved.

Performance-based measures of physical function

In the search for more objective measures of physical functioning, the U.S. Established Populations for Epidemiologic Study of the Elderly (EPESE) studies have begun using a series of simple physical performance tests that can be administered in an elderly subject's own home by a tester with minimal training (8). This approach has also been employed in the Third U.S. National Health and Nutrition Examination Survey as well as in a number of smaller surveys, and we are trying the method in our Southeast Asian studies. The method is simple and appears to be highly reliable. The tests, which primarily evaluate gait, strength, and balance, relate primarily to the lower limb and trunk and do not give any indication of upper extremity function. In some countries, legal difficulties arise in conducting physical tests without the direct supervision of a medical practitioner. Nevertheless, the approach shows considerable promise and deserves wide application and further evaluation as a potentially culture-free means of quantification of certain aspects of disability. One of the criticisms of the use of objective performance-based tests is that they are actually assessing impairment, which is defined in the World Health Organization (WHO) International Classification of Impairment, Disability and Handicap as being a loss of physiologic or anatomic function, rather than disability, which is a restriction in an individual's functional performance as a result of impairment (9).

Timeframes

Different studies are conducted according to differing timeframes for data collection, with consequent variations in seasonal influences and potential significant cohort effects. Compensating for variations in timeframes or projection periods can be a complex exercise, and data collected and projected on the same or similar schedules are preferred.

Clinical assessment

The place of clinical assessment in both community and institution studies is often a vexing issue. Full clinical examination is a costly process; clinical methods and records are very hard to standardize. Some basic clinical information, at least in such terms as diagnosis and procedures conducted, can usually be obtained by interrogating primary care and/or institutional records. Such records are not always easily accessible or able to be linked with survey data.

When resources allow them, some basic standardized clinical assessments can provide valuable data. These include, for instance, anthropometric measures, blood pressure recording, and tests of vision and hearing. More sophisticated clinical measurements can be performed using reliable instrumentation for testing respiratory and cardiac function, bone density, etc. In addition, clinical laboratory investigation may be undertaken to provide biochemical, hematological, immunological, hormonal, and other basic physiologic data with minimum distress to subjects. The conduct of these procedures is generally justified only when there are specific hypothesis-driven questions under investigation. It is worth noting that in many areas self-reported information yields comparable results to objective testing, e.g., in assessment of vision and hearing.

Institution-based, population-based, and administrative data linkages

With rare exceptions, record linkage arrangements that are able to provide sets of data on individuals across a range of sources are not available. There are also major problems in linking aggregate data from these sources due to great variation in definitions, methods of collection, timeframes, coverage, etc. This is especially so in less developed countries. A prospective approach may be feasible, with the long-term goal of developing population information systems that can link various sources of aggregated data through use of some common identifier such as a health insurance or social security number. One of the barriers to this development is the growing concern over privacy and confidentiality within many communities.

Other issues

In general, it must be said that the absolute standardization of study designs, sampling rules, definitions, measurement procedures, etc., in cross-national studies is no simple task. Even the most straightforward effort can be confounded by cultural, language, custom, religious, legal, and other considerations. Anecdotes abound: In our studies, we have come across people who had never held a writing implement in their lives, so that a simple test requiring the copying of a drawing did not work; people who had no conception of and no need to know the current date; people who never used beds; people who never used chairs; people who lived below the ground rather than in upper level housing; others who ate routinely with their hands and used no utensils; others who identified a "spirit presence," which by Western standards would be enough to classify them as paranoid; and so on. The application of many otherwise highly standardized measures of function in these individuals would invariably give misleading results, as would the simple comparison of findings from studies of populations with differing characteristics in these and many other respects (10).

Measurement of mental function is particularly difficult in cross-cultural studies, and in spite of vigorous attempts, especially over the past decade, there are still considerable problems in assessing mental health. The lack of a wholly internationally portable instrument available suggests that there is a need to define mental health and cognitive function in culture-specific terms and to develop instruments that measure the same mental functions but use different culturally appropriate items. For this to be an effective way around the problem, there is clear need for indepth validation studies linking assessment and outcome in different cultural settings.

Cross-national comparison may be complicated by the diverse health care "environments" in which studies are conducted. Health care systems show considerable regional and national variation, including differing funding arrangements, disparate forms of health legislation, varying administrative structures, diverse categorization of health workers, and different health care practices. In this latter instance, attention needs to be paid to the relative importance of traditional health practices in developing country settings.

In addition, there is some question about the meaning of "healthy" in different settings. David Curb, formerly of NIA, has raised elsewhere the issue of whether the idea of "healthy aging," "successful aging," or "disability-free aging" may in a sense discriminate against those who show little or no significant disability (or handicap) broadly defined, but who nevertheless have significant defined chronic morbidity and are apparently remarkably well adapted to their situation. Adaptation of this sort may well have some very culturally specific features, reflecting different expectations, requirements, and environments. The finding in the Boston EPESE study that only 15.3 percent of the population 65 years of age and over exhibited neither disability nor chronic disease does seem to suggest some broader criterion is needed, at least for successful aging (11).

Political considerations can intrude in the conduct of cross-national and cross-cultural research. The way in which data are interpreted may have politically sensitive overtones, and there may be pressure on investigators in some circumstances to present and report their data in certain ways that are not scientifically valid but are acceptable politically. It is important to be aware of this potentially embarrassing possibility and to have the ground rules laid down at the outset in order to avoid such conflicts and to ensure scientific rigor in the reporting of cross-national findings.

Time-series (longitudinal) data

There are good arguments for moving toward longitudinal rather than cross-sectional data collections on aging and function for both national and international purposes. There is already a considerable amount of data available from longitudinal studies conducted in a number of countries, and further initiatives in this area are currently being planned. The problems outlined above are further magnified, however, in the conduct of longitudinal research. Those studies already completed and under way show great variation in design, sampling, coverage, timeframes, and methods, making comparability very difficult. Newer studies, such as The Australian Longitudinal Study of Aging and the Determinants of Healthy Aging project of WHO, present an excellent opportunity for a more collaborative international approach (12). The WHO project, which is planned as a multicountry effort involving both developed and developing countries at the outset, is particularly well placed to foster the idea of the development and use of internationally accepted standardized design and instrumentation. While international collaborative longitudinal studies are a welcome prospect, even greater attention will need to be given to design and measurement issues, quality control, analysis, and interpretation.

Technical considerations

Apart from the scientific and methodological issues discussed above, there are a number of potential pitfalls in conducting cross-national research that I have labeled "technical problems." They are all easily resolved but can constitute major barriers to good cross-national endeavors if they are not effectively addressed at the outset.

- Communication is a critical issue. A good communication network is essential, supported by whatever means available and, if possible, utilizing international electronic mail systems such as BITNET.

- Standardization of procedures, not just the research tools, is necessary. Investigators need to know precisely what is expected of them in terms of records, reporting, and administrative procedures.
- A clear set of agreements covering data recording, entry, transfer, processing, and analysis is essential. We generally argue for a highly centralized approach to ensure project objectives are achieved, to maintain quality control, and to achieve maximum efficiency in this phase of the work. It is, however, very important that the data be turned around quickly and that national investigators be able to get their own data back on disk or tape, in addition to whatever preliminary analysis is available, as early as possible.
- Finally, agreed-upon guidelines regarding reporting and publication of results should also be established at the beginning in order to avoid potential conflict and misunderstanding in this often sensitive area. In my view, it is highly desirable that the data from significant cross-national studies be made available in the public domain within a reasonable time, say after 12 months, and this needs to be planned for and understood by all involved at the commencement of the project.

Conclusion

There exists a substantial body of argument in favor of cross-national and cross-cultural research on aging. Much is to be gained by analyses of cross-national variance and the critical examination of differing experience of population aging and its consequences.

There are, however, a number of conceptual and practical barriers to effective cross-national comparative research. These barriers need to be systematically addressed. Considerable effort needs to be applied to definitional, methodological, and analytic issues associated with cross-national research to ensure that the rich opportunities for valid comparative analyses can be effectively exploited.

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Part VI

Comparative analysis of health statistics for selected diseases common in older persons in the United States

Introduction

by Tamara Harris, M.D., Medical Officer,
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The objectives of this project are threefold. The first goal, which complements the project proposed by Dr. Rosenberg in Part II (Chapter 5), is to understand methodologic constraints in cross-national comparisons, both constraints generic to cross-national comparisons for any age group and constraints particular to older populations. The second goal includes identification of methodologies to validate the statistics for the disease that will be selected for cross-national comparison as part of this project. The third goal is to collect data and to attempt to contrast rates of selected diseases, taking into consideration the methodologic constraints identified earlier in the project. From these comparisons, it would be possible to develop hypotheses regarding geographic differences of observed prevalence rates in selected diseases common in older persons.

Chapter 16

Opportunities for international collaboration: Comparisons of morbidity and mortality for chronic diseases in older persons

by Jacob A. Brody, M.D., Dean, School of Public Health, The University of Illinois at Chicago

Population data are improving and becoming more available (1), while data on morbidity and functional abilities are more difficult to ascertain and, therefore, more difficult to use and compare. Thus, the goals for utilization of data on nonfatal events for the International Collaborative Effort on Aging must be realistic and perhaps humble.

The world is experiencing a unique historical occurrence. At the same time that more people are dying at older ages, the elderly themselves are experiencing an increase in life expectancy at a rate faster than that of the rest of the population. Two general pathways toward longevity have emerged. One, representing developed countries, is exemplified by the Swedish experience, and the other by that of Japan. Sweden and perhaps a few other small nations are approximately 10–30 years ahead of the other developed countries of the world. At present 17 percent of the Swedish population is 65 years of age and over. Low birth rates this century coupled with very low mortality rates produced a pattern in which about 80 percent of all deaths occur after age 65. Very low mortality at younger ages is a phenomenon being experienced increasingly throughout the world and will continue and become the norm for humankind, barring the introduction of major new diseases or extreme social disruption. Sweden has achieved most of what could be termed the Phase I increase in survival. Only major scientific breakthroughs can greatly increase Swedish longevity. All developed countries are rapidly approaching the Swedish standard, and within about 30 years most will have approximately 20 percent of their populations 65 years of age and over. Higher birth rates could alter this, as could gains in premature mortality (deaths under age 65). Medical and social progress should reduce premature mortality by 25–50 percent in the foreseeable future, but because in Sweden this represents only 20 percent of all deaths, the gains in longevity are limited.

The Japanese experience represents the apogee of what is possible in the developing world. Obviously, no other country is likely to have the material wealth of Japan that has caused so rapid a decline in premature deaths. It is also likely that few developing nations will have as low birth rates as have occurred in Japan since its postwar Baby Boom. The lesson to be learned is how rapidly and massively the change in the age structure of the population can be effectuated. Japan actually is doubling its population 65 years of age and over within the span of 26 years—an event that was accomplished in 45 years in the United Kingdom, 66 years in the United States, 85 years in Sweden, and 115 years in France (1). Life expectancy in Japan is now greater than 77 years—the longest in the world. The inevitability of rapid increase in life expectancy within developing nations is already clearly visible and frequently is occurring in the face of poverty, social instability, and relatively higher birth rates. These phenomena give the lie to Alexander Pope's poetic plea, "The proper study of Mankind is Man" ("Know Then Thyself"). The proper study is now Old Men or, more properly, Old Women.

Life expectancy at age 65 is an increasingly useful statistic in view of the decline of premature deaths. By knowing how long half our elderly population will survive, we can recognize the diseases and conditions that our societies must address. Among 17 of the most developed Western nations, life expectancy has risen steadily since 1950, and with the exception of the astonishing leap forward by Japan, the relative position of these nations has changed little.

The United States has had one of the longer life expectancies at age 65, although life expectancy at birth is in the lower grouping. It appears that increased life expectancy among the elderly will be occurring worldwide even without major medical or social intervention. In all developed countries, at least 65–70 percent of total deaths occur after age 65, and of these deaths, 80 percent are from heart disease, stroke, and cancer, while only 20 percent are from all other causes. It is likely, therefore, that medical intervention in terms of prevention and postponement of disease, medical and technological advances, and social policy and attitude may affect longevity and will affect the quality of this increased life expectancy.

Recommendations

Age-specific onset of indicator diseases and conditions

As we increase life expectancy, most data suggest that we are accomplishing this by providing a few additional years of active life expectancy at the expense of many years of compromised health and well-being. We must develop a protocol that will yield data about the age-specific onset of diseases, conditions, and other measurable events. We should identify sources that are currently available, or with affordable input, we could successfully address this subject prospectively. Without age-specific data, we cannot determine if we are extending or indeed "compressing" morbidity.

Age at menopause is important and can be studied. In developed countries, women have added 20–30 years of life this century. Has a concomitant change occurred in age at menopause, or is this important hormonal landmark a fixed event for the species? Considerable information could be gained from the various studies already published. For the most part, these studies reveal no change in the age at menopause. A surrogate approach would be to review records in countries with excellent birth certificate records since the turn of the century. The item to be studied is the maximum age for the oldest 100 or 1,000 mothers per year since about 1900. The figures will surely be much less dramatic than the change in age at death, but if no trend for older ages at final parity is encountered it makes more expensive and complex studies less attractive.

Hip fracture

Data on the age-specific, sex-specific, race-specific onset of hip fracture over time may be available in several developed countries or specific areawide populations. Current data suggest an increase in age-specific hip fracture incidence in Northern Europe; this has been reported in North America as a preliminary observation by the National Center for Health Statistics during this meeting. Hip fracture is an age-dependent condition (2,3) and is a surrogate for measuring many other aging parameters. Data will thus be useful in terms of physiologic aging, medical and social needs, and perhaps in determining causal factors.

Sensory diseases and conditions

The eyes and ears are remarkably complex structures that seem to be maintained in the vast majority of people for 40 or more years with only limited deterioration. Thereafter, an array of deleterious events occur to the eyes and ears progressively with age. Because the very high age-dependent increase has a most unhappy impact, knowledge leading to a better social adjustment for what is now considered inevitable and new hope for understanding of mechanisms that can postpone or prevent these conditions is of great importance.

We must also learn if the age-specific onset of the various forms of deafness and blindness has been stable over time or has changed with increasing longevity. Various opportunities probably exist in which vision and hearing were tested in given populations over time. There may also be opportunities to determine age-specific onset of cataracts or the more dramatic onset of macular degeneration in the elderly.

Terminal decline

The medical literature frequently refers to an event or phenomenon called the terminal decline, which refers to a clinical state in which the patient deteriorates regardless of intervention. Does the terminal decline exist? If so, in what percent of deaths does it occur? How long is a person in terminal decline, and how can we recognize it clinically? If it is indeed a frequent and important event, we must learn to identify it and address it. It would tell us a great deal about the physiology involved in dying, as well as provide us with a discernible clinical event in which the need for medical intervention is radically altered. There are considerable ethical and financial implications if we can succeed in defining and recognizing the terminal decline. Mortality followback studies may be of some use, but most useful would be population-based studies that follow clinical course to fatal outcome.

Alzheimer's disease and related dementias

This constellation of diseases is being widely studied. We must continue our attempts to achieve specific diagnoses and the natural history of these diseases. We must develop methods to determine the age-specific onset of dementias and document whether the onset can be postponed or prevented and whether curative measures are a realistic expectation.

Prevalence of the dementias rises to about 20 percent by age 80. In the next 30 years in the developed world, and in perhaps 50 years in most of the world, about half of all deaths will be occurring after age 80. Life expectancy at age 65 is already greater than 80 years throughout the world. Unless the age-specific incidence of the dementias is postponed by 5–10 years, we are facing a prospect that will greatly alter my enthusiasm and ethical perspective concerning increased longevity.

Functional status

This topic is also addressed in other portions of the report. My impression is that better conceptualization and experimentation are needed before we attempt comparisons of age-specific changes in functional status over time in different countries. Problems relate to how to measure functional status and why. The methods of measurement are becoming better but certainly have not achieved the status of a robust predictor of subsequent life events. Functional status is frequently used as a surrogate measure of composite disease impact, but the correlations between diseases and functional status are not well defined. Functional status is also used to determine need. In various parameters it does this well. It is disturbing, however, that in the United States, three of four current legislative proposals to provide long-term care are based on the activities of daily living, only one of the many approaches to evaluating functional status. This illustrates the risk of promoting a single approach, since we run the risk now of having achieved our goal of influencing policymakers, but with a faulty tool that will not effectively pick up some of the most prevalent age-dependent disabilities, such as Alzheimer's disease. Therefore, I suggest collaborative research and evaluation studies to evolve criteria for functional assessment in terms of their intended use.

Concluding remarks

By 2020 the developed countries and some of the developing countries will have achieved a population profile resembling that currently observed in Sweden. Fully 80 percent of deaths will occur after age 65. With small variations, 80 percent of these deaths will be caused by cardiovascular and cerebrovascular disease and cancer. About 20 percent of the entire population will be over age 65.

Gains in preventing premature mortality (deaths under age 65) will be made, but since only 20 percent of all deaths will be premature, the impact on life expectancy will not be great. The gains we shall see will result from continuing increased life expectancy after age 65. Currently, life expectancy at age 65 is 15–20 years and rising.

As death is postponed, are we also postponing the age-specific onset of the age-dependent nonfatal diseases and conditions that increase inexorably with age? These include failing vision and hearing, arthritis, and the dementias. Data concerning hip fracture suggest that the reverse is actually occurring, with an increase in age-specific incidence. We have no real data on trends in age-specific onset in other age-dependent, nonfatal conditions that consume life's quality and override and confound many of our functional measurements. Menopause has not been postponed appreciably in populations in which women have added 20–30 years of life expectancy this century.

Data available throughout the world must be analyzed retrospectively and ultimately prospectively to determine the age-specific onset of the nonfatal age-dependent conditions. Unless we learn how to measure trends in age-specific onset and ultimately how to postpone their onset at a faster rate than we postpone mortality, the net result will be an increase in morbidity and disability rather than the hoped-for compression of morbidity.

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Chapter 17
Epidemiology of aging in Hong Kong: Health status of the Hong Kong Chinese elderly

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Introduction

Demographic trends and population projections have indicated a rapid increase in the world's elderly population, expected to reach 410 million by the year 2000. Of this population, 59 percent will be living in the less developed countries (1, p. 22). These demographic changes call for close examination of the implications of aging and formulation of national policies to cater to the emerging issues related to aging populations.

Hong Kong is a city-state located in the southern tip of Mainland China. It has gone through tremendous industrialization and population growth in the past 40 years. The life expectancy at birth in Hong Kong in 1986 was 74 years of age for men and 79.8 years of age for women, which compares favorably with that in the United States (men, 72 years of age, and women, 79.3 years of age) and Japan (men, 75.1 years of age, and women, 80.8 years of age). The longer life expectancy, together with the dramatic decline in the birth rate, has resulted in a fast-aging population in Hong Kong. The population 60 years of age and over has increased from 150,000 (4.8 percent of the total population in 1961) to 653,200 (11.5 percent of the total population in 1986) and is expected to reach 12.6 percent in 1991. The older old population (85 years of age and over) will also increase from 1986 to 2006, from 4,900 to 31,000 for men and from 18,600 to 61,000 for women (2,3).

The changes in economic situations, traditional values, and family structure in Hong Kong are also affecting the care and well-being of the fast-growing elderly population. Because the developed countries have gone through an earlier phase of aging and the problems associated with an aging population will be increasingly faced by many developing countries, cross-national comparisons among different countries will provide the necessary groundwork for future planning and development of strategies toward this common concern.

This paper presents the available health statistics for the Hong Kong elderly, together with a description of the health status of the population 70 years of age and over, based on the cross-sectional baseline data from a longitudinal study, which aims to investigate the determinants of health in a Hong Kong elderly cohort.

Methods

The mortality and cancer incidence data for the population 65 years of age and over are extracted from the departmental reports of the Director of Medical and Health Services of Hong Kong. The health status of the Hong Kong elderly cohort is based on cross-sectional baseline data from a longitudinal study that began in 1985. The sampling method has been described in previous reports (4–6).

Briefly, a cohort of subjects 70 years of age and over—including both persons living in the community and those living in homes for the elderly—was recruited into the longitudinal study from Shatin New Town (the major town in the New Territories of Hong Kong, where the Chinese University of Hong Kong is located). Of the community cohort, 711 were sampled from subjects who enrolled in the non-means-tested

Old Age Allowance Scheme (which has as its only criteria for eligibility an age of 70 years and over and residence in Hong Kong for at least 5 years) and the social centers for the elderly. Another 321 subjects were residents of the homes for the elderly in Shatin. These homes mainly provide accommodation, and the subjects were independent with regard to their activities of daily living (ADL's) on admission to the homes.

The main objectives of the study are:

- To test the hypothesis that social support parameters are related to mortality.
- To study the factors related to mortality and morbidity and to construct the predictors of mortality and determinants of healthy aging among the Chinese elderly.

However, the baseline cross-sectional data alone are useful to describe the characteristics and health status of the Hong Kong Chinese elderly.

The subjects were personally interviewed upon first contact at their place of residence, and information was collected with the use of standard questionnaires. The interview schedule was largely based on the World Health Organization (WHO) Eleven Countries Study (7) and on some existing instruments that had established validity and reliability overseas and/or in other surveys carried out in Hong Kong. The instruments were modified to suit local conditions and the elderly sample. The questionnaire was translated into the local dialect and pretested. Data on more than 35 social, health, behavioral, and biological variables were recorded at the baseline interview. The following is a description of the relevant variables presented in this report.

Self-reported symptoms and diseases or conditions

In addition to sociodemographic data, a checklist of 24 symptoms experienced in the preceding 2 weeks and a separate checklist of 25 diseases or conditions experienced in the previous 12 months were administered. Both checklists were based on the WHO Eleven Countries Study (7). The former included symptoms such as headache, lack of appetite, tiredness, and feelings of faintness, and the latter included diseases or conditions such as arthritis, high blood pressure, heart problems, stroke, tuberculosis, and chronic bronchitis. Their capacity in coping with ADL's was obtained from the subjects' response to 14 questions based on the WHO Study. The questions ranged from whether they had difficulties with basic self-care, such as eating or dressing, to more high-level activities, such as carrying heavy weights and doing heavy housework.

Mental health

The VIRO Orientation Scale (8), modified to suit the local situation, was used to assess each subject's cognitive functioning with regard to intactness and orientation in time, person, and place. The level of psychosomatic ill health was measured by an index derived from 17 symptoms possibly experienced during the past 2 weeks; the items used were also adopted from the WHO Eleven Countries Study.

Health behavior

Health behavior variables included smoking (smoked regularly every day for at least 1 year), drinking, physical exercise, and sleeping pattern. The subjects were classified into ever, ex-, or never smokers. The average number of hours of sleep per day was also obtained.

Results

Health statistics

Table A shows the mortality pattern of the Hong Kong elderly population 65 years of age and over. In 1986, cancer, heart disease, and cerebrovascular diseases accounted for approximately one-half of all deaths. There has been some decline in mortality from cerebrovascular diseases in the past 25 years, while the mortality rate due to heart and hypertensive heart disease fluctuates around 8–10 per 1,000. Cancer has now overtaken heart disease as the leading cause of death, having increased from 5 to 9.7 per 1,000 in the population 65 years of age and over. Injury and poisoning (including suicide), respiratory problems such as chronic bronchitis and asthma, and tuberculosis are also among the 10 leading causes of death in elderly persons (9).

There has been a notable decline in deaths from infectious and parasitic diseases. Tuberculosis was

Table A. Rate and percent distribution of causes of death for the population 65 years of age and over, by cause of death: Hong Kong, 1961, 1976, and 1986

Cause of death	*1961*	*1976*	*1986*
	Rate per 1,000 persons		
All causes .... (001–999)	45.2	46.4	38.1
Malignant neoplasms...... (140–208)	5.0	8.3	9.7
Heart diseases, including hypertensive heart disease .... (390–429)	8.2	10.1	7.6
Cerebrovascular disease .... (430–438)	7.5	6.5	5.2
Pneumonia, all forms.......... (480–486)	4.4	5.5	3.1
Nephritis, nephrotic syndrome, and nephrosis ... (580–589)	0.9	0.6	1.6
All other causes	19.3	15.4	10.9
	Percent distribution		
All causes .... (001–999)	100.0	100.0	100.0
Malignant neoplasms...... (140–208)	11.1	17.9	25.6
Heart diseases, including hypertensive heart disease .... (390–429)	18.1	21.8	19.9
Cerebrovascular disease .... (430–438)	16.5	14.1	13.7
Pneumonia, all forms.......... (480–486)	9.6	11.9	8.1
Nephritis, nephrotic syndrome, and nephrosis ... (580–589)	1.9	1.2	4.1
All other causes	42.8	33.1	28.7

NOTE: Numbers in parentheses indicate the detailed list number from the 9th Revision International Classification of Diseases for 1976 and 1986. Figures may not add to totals because of rounding.

Table B. Rate of cancer mortality for the population 65 years of age and over, by sex and type of cancer: Hong Kong, 1986

Type of cancer	*Men*	*Women*
	Rate per 1,000 persons	
Trachea, bronchus, and lung .... (162)	4.53	2.22
Liver and intrahepatic bile ducts .... (155)	1.56	1.30
Stomach .... (151)	1.01	0.53
Esophagus .... (150)	0.84	0.18
Colon............. (153)	0.79	0.51
Bladder .... (188)	0.49	0.17
Rectum .... (154)	0.47	0.25
Pancreas......... (157)	0.37	0.29
Nasopharynx...... (147)	0.37	0.15
Female breast ..... (107)	...	0.44
Cervix uteri .... (180)	...	0.24
Prostate.......... (185)	0.31	...

NOTE: Numbers in parentheses are from the 9th Revision International Classification of Diseases for 1976 and 1986.

among the five leading causes of death in Hong Kong in the early 1960's, but the death rate has dropped from 60.2 per 100,000 in 1961 to 7.4 in 1986. At present, mortality from tuberculosis is largely confined to the older age group, with 64 percent of all tuberculosis deaths in 1987 occurring to those 65 years of age and over (8). The average age of death from tuberculosis was 43 in 1961, as compared to 69 in 1987.

Table B shows the major categories of cancer mortality in the elderly group. In 1986, lung cancer was the major cause of cancer deaths for both men and women. Death rates from lung cancer among Hong Kong women are among the highest in the world. Cancers of the gastrointestinal system form the next major cause of cancer deaths. Liver cancer is of considerable significance, causing 1.6 deaths per 1,000 in elderly men and 1.3 deaths per 1,000 women. For women, breast cancer ranks as the fourth major cause of cancer deaths, after liver, stomach, and colon cancers (9,10).

Table C shows the incidence of cancer in 1983. Bronchial cancer has the highest incidence in both sexes. Although there has been a slight decrease in the

Table C. Rate of incidence of cancer for the population 65 years of age and over, by sex and type of cancer: Hong Kong, 1983

Type of cancer	*Men*	*Women*
	Rate per 10,000 persons	
Trachea, bronchus, and lung .... (162)	46.8	18.2
Stomach .... (151)	14.3	7.4
Liver and intrahepatic bile ducts .... (155)	13.7	5.2
Bladder .... (188)	12.6	4.6
Colon............. (153)	11.6	10.2
Esophagus .... (150)	10.6	2.7
Rectum .... (154)	8.9	6.7
Nasopharynx...... (147)	4.7	1.8
Female breast ..... (107)	...	12.4
Cervix uteri .... (180)	...	4.8
Prostate.......... (185)	7.4	...

NOTE: Numbers in parentheses are from the 9th Revision International Classification of Diseases.

incidence of nasopharyngeal cancer in recent years, it is still high in Hong Kong. Its rate peaks in the younger age groups, and it therefore occupies a lower rank in cancer incidence rates in the aged population. Breast cancer has the second highest incidence rate in women, and its incidence is increasing in Hong Kong. On the other hand, the incidence of cancer of the cervix has been declining over the years.

Results of survey

Sociodemographic characteristics

Some of the social characteristics of the subjects at baseline have been described in a previous report (5). As shown in table D, the majority of the subjects originally came from southern China (Guangdong) and had been residing in Hong Kong for long periods of time. Thirty-one percent of the subjects were residents of the old age homes and hostels, and the subjects were mainly older widowed women. In the community, the subjects were younger, with about one-third being men. The characteristics of the community cohort were compared to the overall Hong Kong elderly population using the 1986 by-census data (11). (A by-census is a sample census held midway between full-scale censuses, which are conducted every 10 years.) The distribution of sexes was quite similar. There was a higher proportion of married subjects in the Hong Kong general population, probably because the by-census data encompass those 65 years of age and over, while our study population was restricted to those 70 years of age and over. As with the Hong Kong elderly, the community subjects were of a fairly low educational level. While 55 percent had no formal education, the proportions varied between women (76 percent) and men (21 percent).

Only 7 percent of the community subjects were still engaged in some form of work. The main occupation (the type of work they engaged in for the longest period) of 76 percent of the community and 81 percent of the elderly home subjects was service or production work, and only 10 percent of both subjects were engaged in work related to agriculture. About half of the community and elderly home subjects claimed that the Old Age Allowance was their main source of income. Although the elderly generally had a low income, their access to facilities was excellent compared to their counterparts in other Asian countries. More

Table D. Percent distribution of elderly subjects by selected sociodemographic characteristics, according to residence: Hong Kong, 1986

Characteristic	*Community*	*Home for the elderly*
	Number	
Total	711	321
Age	Percent distribution	
70–74 years	57	17
75–79 years	28	29
80 years and over	15	54
Sex		
Male	36 (38)	13
Female	64 (62)	86
Marital status		
Single	7 (6)	17
Married	39 (52)	6
Widowed	52 (42)	72
Divorced or separated	2 (11)	4
Educational level		
No formal education	55 (54)	70
Some primary school	33 (32)	24
Secondary school and above	12 (14)	6
Place of origin		
Hong Kong	4	1
Guangdong	90	95
Other parts of China	6	4
Years in Hong Kong		
Less than 10 years	4	4
11–30 years	19	25
31–50 years	49	42
More than 50 years	28	29

NOTE: Except for sex, for which the distribution is for persons 70 years of age and over, numbers in parentheses indicate the percent distribution of the Hong Kong elderly population 65 years of age and over.

SOURCE: Census and Statistical Department. Hong Kong by-census. Hong Kong. 1986.

than 90 percent of the subjects had access to a telephone (which is an important tool for our followup survey of the cohort), and most of the subjects had access to both a refrigerator and a television (table E). Watching television was the most common leisuretime activity, not only for the elderly, but also for all age groups in Hong Kong.

Health behavior

Table F shows the distribution of health habits by sex. Forty-three percent of the men were current smokers, and 29 percent were ex-smokers. About one-quarter of the men drank alcohol, but most were only light or moderate drinkers. About two-thirds of the women never smoked, and few were drinkers. Walking was the major form of exercise among the subjects, but the majority of elderly women spent most of their time indoors.

Activities of daily living and instrumental activities of daily living

In general, their capacity to perform ADL's and instrumental ADL's decreased with age. Subjects residing in the homes for the elderly had more problems with mobility and in carrying a load and walking for any distance (tables G and H). A comparison was made between the Hong Kong and U.S. elderly ages 75–84 years residing in the community (table J). On the whole, the Hong Kong elderly seemed to function better within their homes and were also better with regard to their walking abilities. On the other hand, the U.S. subjects were better able to perform heavy housework and carry heavy loads.

Table E. Percent of elderly subjects, by residence and access to facilities: Hong Kong, 1985

Facility	*Community*	*Home for the elderly*
	Percent	
Washing machine	54	60
Refrigerator	91	91
Telephone	95	100
Television	95	100
Radio	89	68

Table F. Percent distribution of elderly subjects by selected health habits, according to sex: Hong Kong, 1985

Health habit	*Male*	*Female*
	Number	
Total	298	734
Smoking	Percent distribution	
Smoke	43	15
Used to smoke	29	16
Never smoked	28	69
Drinking		
Drink	24	8
Do not drink	76	92
Physical exercise		
Walk	52	56
Practice tai chi	2	2
Do other exercise	10	8
Do not exercise	36	33
Where spend most time		
Indoors	48	63
Outdoors	17	8
Both	35	29

Self-reported symptoms and diseases

Table K shows the 10 most common complaints or symptoms experienced in the past 2 weeks. A higher proportion of the subjects residing in the homes for the elderly reported symptoms of a psychosomatic nature, and the rate of complaints was higher in women than men. Joint pain, sleeping difficulty, tiredness or feelings of faintness, and an unwillingness to do things were the most commonly reported symptoms among those in the community. However, worsening memory was the major complaint among the subjects living in homes for the elderly. Many of the other complaints were also of a psychosomatic nature. Constipation was among the top 10 complaints for both men and women.

As shown in table L, musculoskeletal conditions seemed to be a major health problem in subjects living both in the community and in homes for the elderly. About two-thirds of the women and 40 percent of the men reported having arthritis. (Subjects with arthritis were also found to have lower daily functional abilities.) Cramps in legs, back pain, and stiffness were the

Table G. Percent of subjects 70 years and over living in the community with difficulty performing activities of daily living and instrumental activities of daily living, by sex, age, and type of activity: Hong Kong, 1985

	Female			*Male*		
Activity	*70–74 years*	*75–79 years*	*80 years and over*	*70–74 years*	*75–79 years*	*80 years and over*
				Number		
Total	244	134	77	163	66	25
				Percent		
Move outdoors	5	8	16	7	11	24
Walk between rooms	2	4	6	3	7	12
Use stairs	16	17	25	13	17	28
Walk 30 minutes	15	17	25	12	14	24
Carry 5 kilograms, walk 10 minutes	32	38	56	18	29	52
Use lavatory	1	4	6	1	5	12
Wash and bathe	2	4	8	4	6	12
Dress and undress	2	3	5	2	6	12
Get in and out of bed	2	4	5	1	6	8
Cook	3	4	5	2	5	16
Eat	0	2	4	2	2	0
Cut toenails	3	4	14	3	9	16
Do light housework[1]	5	9	19	7	13	20
Do heavy housework[1]	48	49	61	42	52	64

[1] Subjects who claimed that doing housework is not applicable to their situation are excluded.

Table H. Percent of subjects 70 years and over living in homes for the elderly with difficulty performing activities of daily living and instrumental activities of daily living, by sex, age, and type of activity: Hong Kong, 1985

	Female			*Male*		
Activity	*70–74 years*	*75–79 years*	*80 years and over*	*70–74 years*	*75–79 years*	*80 years and over*
				Number		
Total	41	81	154	12	13	19
				Percent		
Move outdoors	32	27	54	9	15	21
Walk between rooms	7	17	29	9	8	21
Use stairs	22	19	44	9	15	26
Walk 30 minutes	34	28	52	18	31	32
Carry 5 kilograms, walk 10 minutes	73	60	80	27	38	47
Use lavatory	2	6	19	9	8	0
Wash and bathe	12	7	18	9	8	0
Dress and undress	7	2	12	9	8	0
Get in and out of bed	7	6	12	0	8	0
Eat	2	5	6	9	8	11
Cut toenails	15	7	21	0	15	5
Do light housework[1]	13	13	27	11	8	7
Do heavy housework[1]	52	36	59	0	38	29

[1] Subjects who claimed that doing housework is not applicable to their situation are excluded.

NOTE: Cooking is not included, as meals were provided and the majority did not cook.

Table J. Percent of persons ages 75–84 years living in the community with difficulty performing selected activities: Hong Kong, 1985, and United States, 1984

Activity	*Hong Kong*	*United States*[1]
Activities of daily living	Percent	
Walk between rooms	11	22
Get outside	19	12
Bathe or shower	7	11
Transfer to or from bed or chair	6	9
Dress	5	7
Use toilet	6	5
Eat	4	3
Instrumental activities of daily living		
Do heavy housework	46	27
Prepare meals (cook)	6	8
Do light housework	13	9
Activities requiring higher level functioning		
Walk 30 minutes	23	34
Walk up steps	20	28
Carry 5 kilograms, walk 10 minutes or ½ mile	43	21

[1] Study results from: Fitti JE, Kovar MG. The Supplement on Aging to the 1984 National Health Interview Survey. National Center for Health Statistics. Vital Health Stat 1(21). 1987.

other major musculoskeletal complaints. Except for men in the community, about one-quarter of the subjects reported having hypertension. Another commonly reported disease of the circulatory system was varicose veins.

The prevalence of the complaints of diseases or conditions was similar in both groups of elderly, but the rates were higher in women than in men. However, more men than women had complaints of stomach ulcers, chronic cough, bronchitis, and asthma. Except for varicose veins, whose prevalence increased with age in women, there were little differences in the prevalences of self-reported symptoms or conditions among the different age groups. The rates actually declined with age for some conditions, such as hypertension and depression.

The prevalence of multiple conditions was also high, with about one-third of the women and one-quarter of the men having complained of five or more conditions in the past year (table M). Women, especially those in homes for the elderly, had a high score of psychosomatic symptoms. A higher proportion of those in homes for the elderly than those in the community had been hospitalized in the past year.

Self-reported health status

The subjects were also asked about their self-reported health status and health compared with others. About half of the subjects said they had average or bad health, and one-third thought their health was worse than that of others. Once again, more women reported poor health, with the distribution being similar between those in the community and those in homes for the elderly. A relatively high proportion of the group 80 years of age and over reported having good health.

Table K. Percent of elderly subjects reporting the 10 most common symptoms experienced in the past 2 weeks, by residence and sex: Hong Kong, 1985

	Community				*Home for the elderly*			
	Female		*Male*		*Female*		*Male*	
Rank	*Symptom*	*Percent*	*Symptom*	*Percent*	*Symptom*	*Percent*	*Symptom*	*Percent*
1	Joint pain	52	Sleep difficulty	34	Worsening memory	56	Worsening memory	41
2	Sleep difficulty	48	Joint pain	25	Sleep difficulty	56	Sleep difficulty	34
3	Tiredness	39	Tiredness	25	Tiredness	48	Tiredness	32
4	Unwilling to do things	30	Unwilling to do things	20	Joint pain	39	Unwilling to do things	30
5	Faintness	26	Nightmares	20	Unwilling to do things	37	Faintness	25
6	Headache	25	Worsening memory	17	Thirst or polyuria	36	No appetite	23
7	Nightmares	25	Faintness	16	Faintness	30	Depression	20
8	Constipation	22	Constipation	16	Headache	30	Constipation	20
9	No appetite	17	Headache	14	Depression	28	Headache	20
10	Nervousness	14	Irritability	12	Constipation	24	Nervousness	16

Table L. Percent of elderly subjects reporting the 11 most common complaints of diseases or conditions experienced in the past year, by residence and sex: Hong Kong, 1985

	Community				*Home for the elderly*			
	Female		*Male*		*Female*		*Male*	
Rank	*Complaint*	*Percent*	*Complaint*	*Percent*	*Complaint*	*Percent*	*Complaint*	*Percent*
1	Arthritis	65	Arthritis	43	Arthritis	60	Arthritis	36
2	Cramps in legs	63	Cramps in legs	43	Cramps in legs	56	Cramps in legs	30
3	Back pain	35	Constant cough	25	Back pain	34	Hypertension	30
4	Hypertension	26	Varicose vein	21	Tiredness	34	Constant cough	18
5	Tiredness	25	Back pain	20	Paralysis	28	Back pain	16
6	Varicose vein	24	Tiredness	17	Varicose vein	25	Stiffness	16
7	Frequent headache	24	Hypertension	15	Hypertension	24	Tiredness	14
8	Paralysis	19	Paralysis	15	Stiffness	21	Stomach ulcer	14
9	Constant cough	16	Stomach ulcer	13	Heart pain	17	Shortness of breath	14
10	Stiffness	16	Frequent headache	11	Constant cough	16	Chronic bronchitis	11
11	Swollen ankle	14	Stiffness	11	Frequent headache	15	Frequent headache	11

Discussion

Hong Kong has gone through a period of rapid industrialization in the past 40 years. The mortality pattern at present closely resembles that of Western countries, with cancer, heart disease, and cerebrovascular disease as the leading causes of death. The decline in the death rates from infectious diseases is largely related to the improvement in economic situations, environmental hygiene, sanitation, nutrition, health services, and immunization.

While deaths due to heart disease remain stable, those due to cerebrovascular disease have declined, and an increasing trend of cancer mortality has been observed. Such trends have also been reported in the United States and other countries (12–14). It has been suggested that the better detection and treatment of hypertensive diseases are related to the decline in deaths from cerebrovascular diseases (15). The high rate of lung cancer among Hong Kong men is probably related to smoking, but the high rate among women needs further investigation. Chinese women (Cantonese) in the United States and in Singapore have also been observed to have a high incidence of lung cancer (10).

Few data are available on the morbidity pattern of the Hong Kong elderly. This report is based on the baseline cross-sectional data of a longitudinal survey of the elderly population. Although the survey was carried out in Shatin and the sample was not entirely representative of the Hong Kong elderly as a whole, the sociodemographic characteristics of the community cohort were similar to those of the general Hong Kong elderly population (15). As the study was confined to the elderly 70 years of age and over, a large proportion of the subjects were widowed women. There are also high widowhood rates in the older population in other countries, probably because women have a longer life expectancy and tend to marry older men (1). As found in the Pacific Four-Country Study, the Hong Kong elderly also had a fairly low level of education, although they seemed to fare slightly better than their counterparts in Malaysia and Korea (16). Also, as in the Four-Country Study, more Hong Kong elderly women than men had no formal schooling. Unlike the elderly in other Asian countries, who were more likely to have engaged in agricultural work, the cohort subjects were mostly engaged in blue-collar work in the services and production sectors prior to retirement.

As self-reported health status can be more easily obtained than objective measurements and examinations in the community setting, the data reported in this paper are based on self-reported information. However, self-reported data have been found to be good indicators of health status or subsequent health outcomes. Sorensen (17) found subjective, self-reported status to provide even better predictors of health outcomes than objective measurements. Other studies also found self-reported health status

Table M. Percent of subjects 70 years and over, by sex, age, residence, and health status: Hong Kong, 1985

Residence and health status	*Female*			*Male*		
	70–74 years	*75–79 years*	*80 years and over*	*70–74 years*	*75–79 years*	*80 years and over*
Community				Number		
Total	244	134	77	163	66	25
				Percent		
Mental function score poor (less than 16)	28	32	46	10	15	24
Psychosomatic score high (8 or more)	32	25	29	21	18	20
Hospitalization in past year	11	14	19	14	30	24
Number of disease conditions:						
0–1	18	14	16	38	30	32
2–4	46	52	47	37	47	40
5 or more	36	34	37	25	23	28
Self-reported health:						
Good	46	50	43	55	39	36
Average	30	34	30	31	36	48
Bad	24	16	27	14	24	16
Health compared with others:						
Better	16	14	30	35	26	24
Same	49	48	32	43	42	32
Worse	35	37	38	22	32	44
Homes for the elderly				Number		
Total	41	81	154	12	13	19
				Percent		
Mental function score poor (less than 16)	61	64	75	50	38	37
Psychosomatic score high (8 or more)	54	36	42	33	38	26
Hospitalization	12	15	21	8	31	26
Number of disease conditions:						
0–1	34	25	17	58	46	42
2–4	24	40	44	8	38	47
5 or more	41	35	39	33	15	11
Self-reported health:						
Good	46	57	48	64	46	37
Average	32	21	29	18	23	47
Bad	22	22	23	18	31	16
Health compared with others:						
Better	17	36	29	42	31	42
Same	39	33	28	33	38	37
Worse	44	31	43	25	31	21

to be an important predictor of subsequent health outcomes (18,19).

As also found in other Pacific countries, a poor cognitive function score was associated with increasing age, and women had a poorer score than men. The generally poorer cognitive function in women could be related to their lower level of education. In the Philippines, where the disparity of the education level was not as great as in some of the other Asian countries, differences in cognitive scores between men and women seemed to be less (16).

Although with aging there was a consistent trend toward increasing prevalence of difficulty in performing ADL's and instrumental ADL's, most of the study subjects had little difficulty performing most of the self-care functions. The subjects' walking ability was generally good, better than that of their U.S. counterparts. However, the Chinese elderly were less able to do the heavier work, such as carrying a load for a distance and performing heavy housework. Private transportation is not a common asset among the Hong Kong elderly; most still rely on walking and public transportation if they need to go out or run errands. Walking, especially taking a morning walk, was also the most common form of exercise performed by half of the study cohort. Walking was also considered a form of social activity, as many perform the activity with friends or other household members. On the other hand, the Chinese elderly are not expected to carry out the heavy household duties; these are usually taken over by the younger members of the household. The differences in responses to the questions on instrumental ADL's could thus be related to the differences in cultural settings and expectations.

A number of studies have identified the loss of independence and autonomy (in the form of low physical activity, inability to work, impaired mobility, or being housebound) as predictors of mortality in both the elderly and younger age groups (20–23). It is also, therefore, a useful indicator of the active life and quality of living among the elderly. A general decline of functional ability with age was observed in this and other studies (7,16). With the rapid increase in the proportion of the older aged in the population, there will be an increasing need for the provision of services catering to rehabilitation and help in ADL's and instrumental ADL's for an older population with chronic diseases and disability.

Arthritis was the leading complaint of both men and women in the community and in homes for the elderly. The present study is based on self-reports, and it is not possible to assess what proportion of the arthritis was clinically defined. However, other reported symptoms, such as joint pain, stiffness, back pain, and leg cramps, are also conditions related to musculoskeletal problems. Studies have shown that arthritis and joint problems are associated with impaired independence and loss of function (24) and may also predispose the elderly to falls and injuries (25). The high prevalence of arthritis and musculoskeletal-related disorders certainly calls for urgent attention to the proper management and monitoring of these conditions.

Sleep disorders related to difficulties in either getting to sleep or staying asleep were among the two most common complaints of symptoms in both men and women. Such complaints are also quite prevalent among the elderly in other countries (26,27). Such disorders affect daytime functioning and the quality of living of the elderly to a great extent. Physical health problems, as well as psychological problems such as anxiety and depression, have also been found to be associated with sleep disorders (28). Sleeping difficulty, therefore, should not be considered lightly as part of the normal aging process, and the underlying causes should be investigated and managed in the primary health care setting.

Many of the complaints, such as forgetfulness, unwillingness to do things, feelings of tiredness, and difficulty sleeping, could be related to the psychological and mental well-being of the respondents. These were the most common complaints in both men and women in the community as well as in the homes for the elderly. These complaints represent vague symptoms and could be of a psychosomatic nature. The prevalence of multiple conditions and the frequent complaints of vague symptoms call for a better understanding of and differentiation between the normal and pathological processes of aging.

The subjects living in homes for the elderly seemed to be worse off in many aspects. With the changing traditional values and the large number of families emigrating, especially middle-aged people, there will be a great need to provide accommodations for the elderly, preferably in the community setting rather than in the old age homes.

Women seemed to be less healthy than men, but men were actually at a higher risk of mortality. Similar findings are also reported in studies of the elderly in other countries. This observation may reflect a greater readiness among women to report their problems. The use of active lifespan rather than just chronological lifespan has been suggested as a parameter for evaluating the differential health and mortality in both sexes (29).

Although it may seem that health declines with age, many conditions seem to remain at the same level across different age groups. The prevalence of some conditions—for instance, hypertension—may even decline with age. A fairly high proportion of the subjects 80 years of age and over perceived their health as being good. Therefore, although health and functional ability generally decline with age, there are certain groups who still remain healthy and active. It will be an important dimension of research to investigate the characteristics of this group of healthy and active elderly. Longitudinal data will be required, and attempts will be made to analyze the relationship of baseline information to mortality and subsequent health outcome in this cohort. Such analysis will be better able to delineate which of the baseline factors have important longer term consequences for health.

Acknowledgment

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Chapter 18
The utility of cross-national comparisons of diseases of older persons

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Much of the task of epidemiology of aging is focused on health promotion, including the identification of risk factors and the formulation of preventive programs. However, the scope of health promotion for older persons is broader than traditional transitions from risk factors to disease or death (figure 1) and includes transitions to disability as well (figure 2). All these transitions occur against a background of biologic aging and are influenced by the availability of health care and other health resources.

The goal of cross-national comparisons of diseases of older persons is similar to earlier work in younger populations (1,2): To delineate geographic differences in the prevalence of chronic diseases that could potentially aid in the development of testable hypotheses for programs aimed at prevention of disease and disability.

However, there are other uses for this type of cross-national comparison for older persons. Other International Collaborative Effort projects will consider differences in patterns of disability or patterns of service utilization, such as nursing home use, within geographic areas. Patterns of disease will be among the determinants of patterns of disability. Augmentation of knowledge regarding differences in patterns of disease may therefore help in understanding patterns of disability. This goal might be particularly interesting in view of differences in health care resources and social supports.

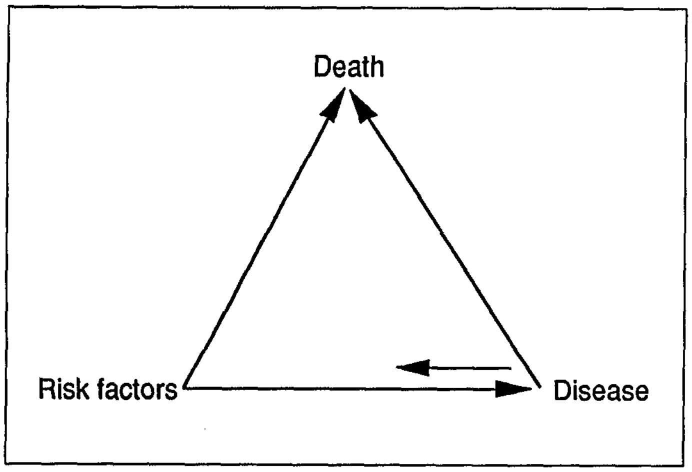


Figure 1. Traditional epidemiologic model

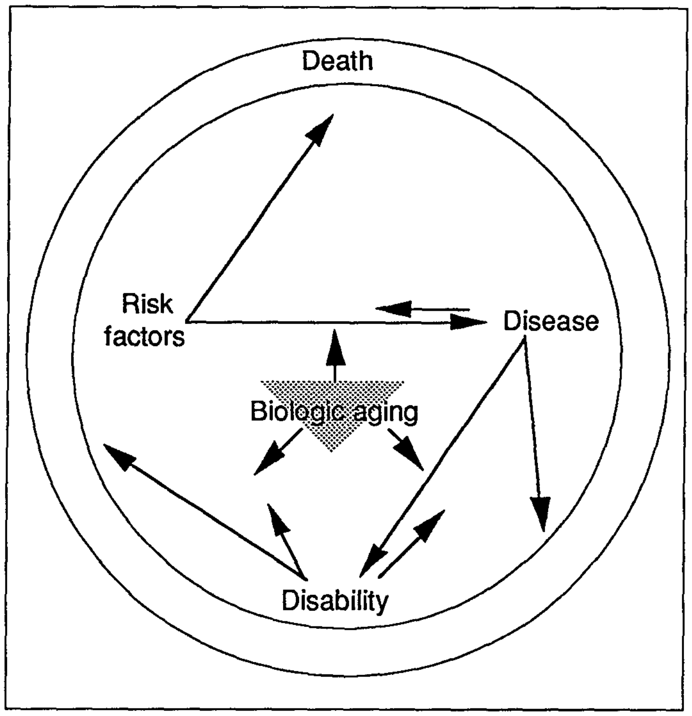


Figure 2. Epidemiologic model for older persons

Data from the Supplement on Aging to the 1984 National Health Interview Survey (3,4) provide an example of how data on disease patterns might affect our understanding of patterns of disability (5). These data were drawn from a group of 2,104 noninstitutionalized white persons ages 75–84 years (744 men and 1,360 women) and demonstrate aspects of the relationship of mobility-related function to patterns of reported cardiovascular disease and arthritis.

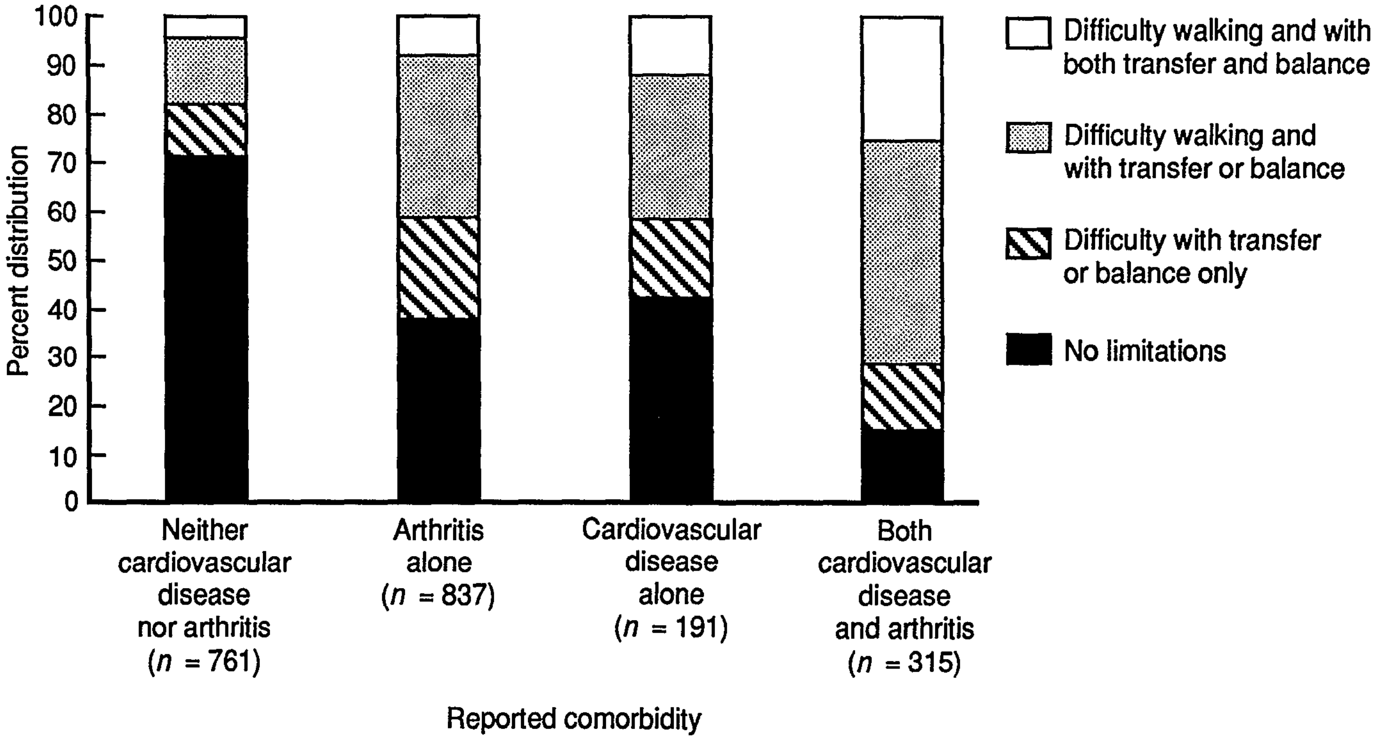
Mobility-related function was defined by responses to questions on functional status that related to lower extremity function. The three measures used to define mobility-related function included difficulty walking (defined as difficulty walking one-quarter of a mile or difficulty walking), difficulty transferring (defined as getting into or out of bed or chair), and difficulty with balance (defined as difficulty stooping, crouching, or kneeling). These measures were combined into a four-level variable expressing disability with mobility-related function: (a) no difficulty on any of the four measures, (b) difficulty with transfer or balance only, (c) difficulty walking and difficulty with either transfer or balance, and (d) difficulty walking and difficulty with both transfer and balance (table A).

Table A. Number and percent distribution of noninstitutionalized white persons ages 75–84 years, by sex and mobility-related function: United States, 1984

Mobility-related function	*Sample size*	*Total*	*Men*	*Women*
		Percent distribution		
No limitations	977	48	54	44
Difficulty with transfer or balance only.	298	15	15	14
Difficulty walking and with transfer or balance	622	28	24	31
Difficulty walking and with both transfer and balance	207	9	7	11

SOURCE: National Center for Health Statistics. Supplement on Aging, 1984.

A comparison was made between the four levels of mobility-related disability and patterns of reported diseases, specifically arthritis and cardiovascular disease. Those with neither disease had the lowest levels of disability (figure 3). Those with either arthritis or cardiovascular disease had similar levels of impairment in mobility-related function. Those with both arthritis and cardiovascular disease had the greatest disability, both in terms of percent disabled and in terms of the severity of the impairments. Not only were patterns of disability at baseline influenced by medical conditions, but those with arthritis or cardiovascular disease were more likely to incur new-onset mobility-related disability over short-term followup



SOURCE: National Center for Health Statistics. Supplement on Aging, 1984.

Figure 3. Percent distribution of noninstitutionalized white persons ages 75–84 years by mobility-related function, according to reported comorbidity: United States, 1984

(table B), even controlling for other health-related covariates.

These data suggest that patterns of mobility-related disability are conditioned on underlying patterns of disease and that comparison of the patterns of disease between countries may help to understand differences in observed patterns of disability relative to those diseases.

Another utility for cross-national comparisons of disease in old age relates to understanding the biology of aging. The research community has begun to carefully isolate the effects of genetically determined physiologic aging from physiologic aging that is conditioned on factors which covary with age and which therefore may be modifiable (6). Comparison of disease patterns geographically can help to delineate the core of biologic aging; i.e., if "disease" is an expression of genetically driven biologic changes with age, then the prevalence of that "disease" from one geographic area to another might be similar, given a similar age structure and controlling for other potential confounders. If the prevalence of the disease appears quite different, it would be less likely that genetically determined changes accounted for the "disease," but that environmental factors played a modifying role.

Benign prostatic hypertrophy might be an interesting example of this type of phenomenon. Prostatic hypertrophy is thought to affect most older men in the United States. Although the specific etiology is unknown, the disease is felt to represent a result of normative age changes that occur within the prostate, mediated by an intraprostatic accumulation of dihydrotestosterone (7). Epidemiologic efforts directed toward identification of environmental factors that modulate this process have not revealed factors leading to preventive strategies (8). Because prostatic hypertrophy can result in blockage of urine flow from the bladder, leading to urinary retention, increased risk of infection, incontinence, and even renal failure, surgery for removal of prostatic tissue is one of the most commonly conducted surgeries in the United States, with rates for hospital discharges, prostatectomy, and cystoscopy increasing with age (table C) at least through age 85 (9). The surgical intervention for prostatic hypertrophy has become the focus of outcomes research (10,11).

There is a relatively small amount of data available on prostate disease for comparison internationally; at the moment, there are no widely accepted screening procedures that could be implemented, nor is any set of interview questions pathognomonic for prostate disease. What little data exist suggest there may be some variation in rates of disease. Autopsy data comparing rates of prostatic enlargement among Chinese and foreigners in Hong Kong (12) suggest that prostatic hypertrophy was very uncommon among older Chinese men of that period (the 1930's). Data on mortality related to prostatic hypertrophy also suggest

Table B. Odds of developing new-onset mobility-related disability for noninstitutionalized white persons ages 75–84 years, by multivariate correlates: United States, 1986

Multivariate correlate [1]	*Relative odds*
Cardiovascular disease	1.6 (1.0, 2.4)
Vision	1.8 (1.0, 3.3)
Arthritis	2.0 (1.5, 2.8)
Body-mass index (4th quartile versus 2d)	1.5 (1.0, 2.2)
Social isolation—women	2.9 (1.6, 5.1)
Education (grades 7–12 versus grade 13 or higher)	1.6 (1.0, 2.5)
Older age ($X + 10$ versus X)	3.2 (2.7, 3.8)

[1] Controlling for sex, diabetes, and hearing impairments.

SOURCE: National Center for Health Statistics. Longitudinal Study of Aging, 1986.

Table C. Rate of hospital discharge for benign prostatic hypertrophy and rates of prostatectomy and cystoscopy, by age: United States, 1984

Age	*Benign prostatic hypertrophy hospital discharge*	*All-cause prostatectomy*	*All-cause cystoscopy*
	Rate per 10,000 men		
55–64 years	62	67.1	90.6
65–74 years	151	206.9	222.6
75–84 years	200	317.3	397.1
85 years and over	193	281.1	337.4

SOURCE: Moien M, Liu BM. Use of health care: Care in short-stay hospitals. In: Havlik RJ, Liu BM, Kovar MG, et al. Health statistics on older persons, United States, 1986. National Center for Health Statistics. Vital Health Stat 3(25). 1987.

wide geographic variation, with Asian countries reporting the lowest death rates (with rates ranging from 5.5 per 100,000 persons in Hong Kong and 7.1 in Japan) and European countries reporting the highest rates (with 50.5 for The Netherlands, 52.1 for Switzerland, and 75.1 for Germany, for example) (13). While there are multiple potential explanations for these data, it is of interest that both of these references suggest prostate disease is rare in Asian countries. If this variation were true, these findings would tend to undercut the argument that benign prostatic hypertrophy is largely genetically determined and would suggest that environmental influences, such as diet, may play a role. Comparative statistics on surgical rates might be quite interesting.

In summary, then, the task of this workshop regarding cross-national comparison of statistics for diseases common in old age is to focus on an index disease for international comparison and to develop minimum criteria for acceptable data. Two more diseases may be designated for additional data collections to compare their geographic variation with that of the index disease. There are multiple benefits to making a comparison of diseases common in old age; it remains to be seen if the methodologic problems of making those comparisons can be surmounted.

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Chapter 19
Utility of cross-national comparisons of diseases of older persons: Osteoporosis as an example

by Jennifer L. Kelsey, Ph.D., Head, Division of Epidemiology, Columbia University School of Public Health

My task at this workshop is to define the characteristics of a disease so as to make it suitable for international comparisons, using osteoporosis as an example. It appears that at least six characteristics are important:

- In countries where either mortality or hospital data are readily available, does the disease almost invariably result in hospitalization or cause death?
- If the disease results in hospitalization or causes death, does it do so quickly, so that death or hospitalization from other diseases does not complicate the situation?
- Can the disease be easily diagnosed?
- Is the necessary diagnostic equipment readily available?
- Can the disease be adequately defined?
- Is the disease socially acceptable, so to speak? If not, it may not be recorded, even if it is diagnosed.

It would seem that hip fracture does meet these criteria as well as any other common disease of the elderly. However, these criteria would not be met if one considered osteoporosis and falls specifically, two major contributors to hip fracture. The only one of these criteria met by osteoporosis is that it can be easily diagnosed. However, not many medical centers even in the United States have the necessary equipment. Falls, on the other hand, can be defined but do not meet any of the other criteria. Therefore, as one attempts to go beyond a simple comparison of hip fracture incidence statistics to consideration of potential etiologic factors for hip fracture, an international comparison may be considerably more complicated.

Some work has been done in making international comparisons of hip fracture incidence rates. Two papers that make these comparisons were published in 1980 (1, 2). Gallagher et al. (1) compared all published data available on hip fracture incidence; at that time, the United States, specifically Olmstead County, Minnesota, had the highest rates. The lowest rates were found in Hong Kong and Singapore and among the Bantu of South Africa. Reasons for this variation in rates are unclear, since known risk factors for hip fracture or osteoporosis do not correlate well with the hip fracture incidence rates, except perhaps for lack of physical activity. An additional feature of the geographic variation is that in the countries where the incidence rates are highest, the female-to-male ratio is highest. For instance, among the Bantu, a population in which the incidence rate is low, the female-to-male ratio is close to one. These differences in the ratio of female to male cases are unexplained as well.

The other 1980 report (2) attempted an ecologic correlation of certain variables with incidence rates in various countries. For instance, rank order of hip fracture incidence was compared with rank order of per capita motor vehicles for each country. The rank order was almost, although not quite, identical. These types of ecologic analyses are interesting but speculative.

In comparisons of international data, there appears to be a pattern that as countries become more industrialized, hip fracture rates rise and the incidence curve shifts to earlier ages. For instance, an increase in hip fracture incidence rates has been reported in England (3) and in Scandinavian countries (4–7) in recent years. In Oxford County, England, there was a doubling of incidence rates in each age group from 1954 to 1958 to 1983. This trend was seen for Scandinavian countries as well. More recent data from low-incidence areas such as Singapore and Hong Kong, especially for the oldest age groups, would be of great interest.

One other noteworthy observation from studies in Western Europe is that the incidence rates for trochanteric fractures seem to have increased markedly, while there has been little increase in incidence rates for fracture of the neck of the femur (5,7). It would be of interest to look at subtypes of fractures and regional variation within the United States as well as in some of the developing countries.

From a review of these issues, a list of critical questions that could be addressed by international comparisons of hip fracture can be developed. These questions include:

- Do hip fracture incidence rates in areas such as Hong Kong and Singapore stay relatively level throughout the age span, or is there a sharp increase in the oldest age groups?
- What are the trends over time in the low-risk countries? Both of these questions would be interesting to address in areas such as Hong Kong, where one could examine hip fracture incidence in persons in their eighties and nineties.
- Do almost all hip fractures come to medical attention, particularly in the low-risk countries? Even in developed countries, people in nursing homes who are very sick may not be considered suitable for surgery and may not be seen in a hospital.
- How do risk factors for osteoporosis correlate with geographic and temporal variations in hip fracture incidence rates? For instance, it is thought that the declining physical activity in some of the Western European countries is resulting in higher hip fracture rates; it would be worthwhile to look at these correlations across countries and also across time periods within countries. Likewise, examination of risk factors for falls in relation to the geographic and temporal variations in hip fracture incidence rates would be useful. It is of interest that in Japan, bone mineral density is generally low, but hip fracture rates are also low (8,9). It may be that people fall less frequently in Japan, or if they do fall, they fall in such a way that the fall seldom results in a hip fracture.
- Finally, it would be helpful to look at the distribution of bone mineral density at various body sites in countries with high and low incidence rates for hip fracture. Even if the measurements were not done on probability samples of the population, we would be able to obtain some useful information for comparative purposes.

For this International Collaborative Effort project, obtaining age- and gender-specific incidence rates for hip fracture by 5-year age groups would be important. Considering all persons 80 years and over as a group is a problem, because the incidence rates for hip fracture are so steep and mortality so high that smaller age groups are needed to make meaningful comparisons across countries. Examination of incidence rates in the oldest age groups—80–84 years, 85–89 years, and 90 years and over—would be interesting, since hip fracture is so important in these age groups and since the age-specific incidence rates are rising so rapidly.

It would also be useful to look at trends and incidence rates over the past few decades, both for low-risk countries and in the United States as a whole, as has been done for Olmstead County, Minnesota (10). I think the data are available, and trends for both cervical and trochanteric fractures should be studied.

For all countries it would be worthwhile to gather indicators of exposure for risk factors for osteoporosis and for falls. In addition, measurements of bone mineral density by 5-year age group, gender, and body size would be helpful in interpreting the data.

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Part VII

Measuring risk factors and outcomes of institutional long-term care

Introduction

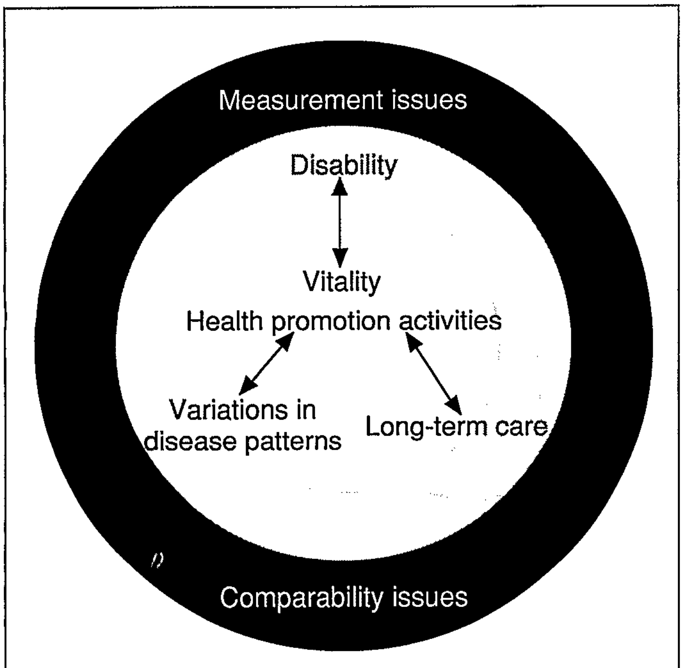
by Joan F. Van Nostrand, M.P.A., Coordinator of Data on Aging, National Center for Health Statistics

It is a pleasure to be able to introduce the topic Measuring Risk Factors and Outcomes of Institutional Long-Term Care (LTC). My introduction addresses two philosophical issues about the topic. They are: Why is long-term care part of a conference about vitality and wellness? Why is there a concentration on the outcomes of such care?

The model of the relationship of the International Collaborative Effort (ICE) topics, which Dr. Feinleib presented yesterday, can help to illustrate why LTC is included in the conference (figure 1). As the model shows, vitality is the central theme of the ICE on Aging. The areas of disability and variations in chronic disease constrain vitality. Further, a major consequence of severe disability is a need for long-term care, that is, care over an extended period of time to assist persons unable to care for themselves due to chronic physical or mental conditions.

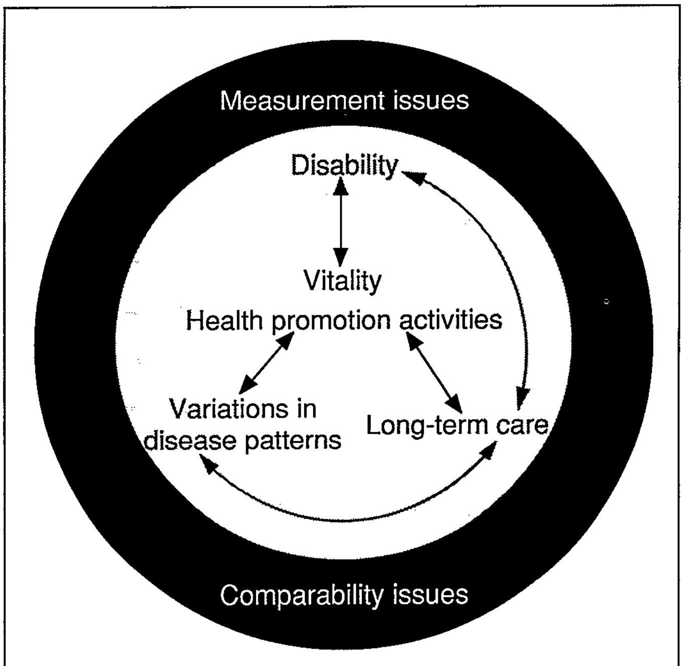
I would like to ask you to add mentally another set of arrows to this figure. Add a two-way arrow that directly connects disablility to long-term care. Add another that connects variations in disease patterns to long-term care. The new model (figure 2) emphasizes the interrelationship among these concepts. Disability and variations in chronic diseases can oftentimes lead to long-term care. These interrelationships are symbolized by two-way arrows to highlight the transition that can occur from long-term care to improved vitality. Although chronic conditions cannot be cured, their disabling effects can be mitigated so that long-term care is no longer needed.

In my initial discussions with international



SOURCE: National Center for Health Statistics.

Figure 1. Interrelationship of International Collaborative Effort on Aging topics



SOURCE: National Center for Health Statistics.

Figure 2. Relationship of long-term care to vitality in aging

collaborators who are members of the long-term care research team, I found that the generic label given to the project, "institutional long-term care," was soon translated into the more specific one of "nursing home care." In the United States, for instance, the bulk of formal long-term care is provided in nursing homes. I am looking forward to learning more from our international speakers about the situation as it exists in other countries.

Now I would like to turn to the second philosophical issue, why the ICE's emphasis is on the outcomes of long-term care. As many of you are aware, there has been considerable research in the United States on nursing home care. Most of it has concentrated on identifying risk factors for admission. The thinking behind this focus is that if risk factors could be changed in some way, then nursing home stays could be prevented, delayed, or reduced in length. While researchers have had considerable success in identifying risk factors, I think the success in preventing nursing home stays has been rather limited. Research as to why this is so is a subject for another conference.

Given an institutional bias to long-term care in the United States, there is a growing realization that for some elderly a nursing home stay, whether it is appropriate or not, will occur at some time during the lifespan. This realization calls attention to outcomes of nursing home care. It focuses attention, in particular, on outcomes that are positive; on why they occur and on how they can be achieved. The more positive the outcome of long-term care is, the greater is the vitality of the older person. Hence, this topic on outcomes of nursing home care is the application of the concept of vitality to long-term care.

As you know, the ICE objective for long-term care is to improve the measurement of nursing home outcomes. However, we should not lose sight of a broader goal. It is to use this increased knowledge to move toward improving outcomes for older persons in nursing homes and increasing their vitality.

My colleagues on this research team have all made important contributions to the area of long-term care. I know them to be knowledgeable, insightful, dedicated, and at times provocative. This strikes me as a winning combination in undertaking the challenges that this comparative research presents.

Chapter 20
Research on institutional long-term care in Australia

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Development of research on institutional long-term care

Research into long-term care for the aged, both residential and community care, is a relatively recent endeavor in Australia. Since the introduction of Federal Government benefits for nursing home care in 1963, the number of nursing home beds grew to some 75,000 by 1985, and expenditure grew to 1 billion Australian dollars. Until recently, remarkably little was known about the residents of these institutions, their patterns of utilization of long-term care, or the outcomes of that care. Early research through the 1970's indicated more diversity and dynamism in the long-term care system than was generally seen to be the case and pointed to ways in which measures for change might be introduced. Major policy reform was started in the mid-1980's, and restructuring of the system is now in progress, with research focusing on monitoring and evaluating the outcomes of these measures.

At the same time, there has been a growth in the information available on many aspects of long-term care provision and outcomes. Much of the data now generated through administrative systems provides an information base for monitoring and evaluation, and a close relationship is emerging between these activities and further policy development. Before detailing this current research, some brief background needs to be given on the context in which it is taking place.

Demographic context

In setting Australia in the context of other countries participating in the International Collaborative Effort, it is useful to outline some basic dimensions of the demography of aging (1). Australia has a small population, 15.6 million at the 1986 census, of which some 13 percent was 60 years of age and over. The proportion now this age is similar to that in the United States and Canada but lower than in many other advanced industrialized nations. Although the proportion of the population 60 years of age and over is projected to increase to 16 percent by 2001, Australia's demographic aging even then will be less pronounced than that currently experienced by most European countries and less rapid than that expected in North America over the next 20 years.

The very old population, over 80 years, which makes the greatest use of long-term care, accounted for 15 percent of the population 60 years of age and over in 1986. It is projected that this cohort will increase by 76 percent over the next two decades. This growth is much more rapid than the increase of 50 percent projected for the total aged population.

The long-term care system

As of 1985, there were 74,013 nursing home beds for the aged in Australia, a ratio of 70 beds per 1,000 persons 70 years of age and over. This level is seen to be higher than that in many countries, but caution is needed in comparing the variety of facilities and services that are labeled "nursing homes" in different countries. Nursing homes were first defined as separate entities in the Australian health care system in 1963, when Federal benefits were introduced; in a somewhat circular fashion, nursing homes were defined as those facilities approved for receipt of these benefits. Federal benefits are the major financial input to the nursing home system and are paid on the same basis to individuals in private for-profit and voluntary nonprofit homes; Federal funding to public sector beds operated by State governments is currently under review but can be expected to move to the same basis in the next few years. Benefits are paid irrespective of the recipient's income, and no spenddown of assets is required; the financing of long-term care is independent from either the system of universal health insurance for medical care or private health insurance schemes that provide supplementary cover mainly for hospital care.

The second element of the institutional care system comprises hostels, which provide personal care and social support but not nursing services. In 1985, there were 34,885 hostel places, a ratio of 33 places per 1,000 persons 70 years of age and over.

There is considerable variability among the Australian States in the overall level of institutional care, in the balance between nursing home and hostel provision, and in the share of beds in the private for-profit, voluntary nonprofit, and public sectors. The extent of variability in Federal funding among sectors and among States has also been considerable (2,3). Inequities arising from these variations constituted one of the main grounds for recent reforms.

Policy context

While demographic trends are commonly seen as prompting greater attention to issues of aged care on the part of policymakers, service providers, and researchers, initial policy attention predates the emergence of pronounced population aging. The Care of the Aged Report (4), presented in 1975, was prompted by the political climate of the early 1970's, which saw major reviews and reforms in Australia's health and welfare system. Since then, a series of policy reviews were mounted to address concerns about unsatisfactory outcomes of programs providing long-term care, despite rapid growth of expenditure. A full account of the development of policy on nursing homes in Australia (5) demonstrates that shifts in policy concerns have reflected the interplay among political, bureaucratic, provider, and public interests, with formal reports of policy reviews documenting the pressures for change and responses that were forthcoming at different periods.

It was one of these reports, of the House of Representatives Standing Committee on Expenditure Inquiry into Home Care and Accommodation for the Aged (6), that presaged the framework for reform that was adopted by the Labor Government, which came to office in early 1983. Added impetus for reform came from a report of a Senate Select Committee Inquiry into Private Nursing Homes (7), which was tabled in 1985. In response to the Senate report, a strategy for restructuring the long-term care system was set out in the Nursing Homes and Hostels Review (8), which reported in early 1986.

Restructuring is now in progress, with a series of measures being implemented to achieve clearly defined goals over a 10-year period. Principal among these measures are the following:

- Assessment for all those seeking admission to nursing home care by multidisciplinary Geriatric Assessment Teams (GAT's), which are able to make recommendations on a range of care options to meet individual needs, including referral to rehabilitation and community care services. Guidelines for assessment have been published (9), and teams have been established nationwide under the Geriatric Assessment Program.
- Changes in program structure in regard to the relative roles of nursing homes and hostels, with the former directed to the needs of highly dependent aged people and the latter directed to those needing moderate levels of assistance (10,11); expansion of home and community care services and housing programs were further means of achieving a better balance between needs and services (12–14).
- Control of growth of residential care to maintain an overall provision of 100 places per 1,000 persons 70 years of age and over (to be distributed between 40 nursing home beds and 60 hostel places) and to achieve greater equity in regional distribution.
- Innovative programs to address the needs of special groups, notably dementia sufferers, the ethnic aged and Aboriginals, and the aged in rural and remote areas.
- Standards of care to be defined with a view to developing a more effective system for the determination and enforcement of outcome standards (15) and protection of residents' rights (16).
- Recurrent funding of benefits to move from a cost-reimbursement basis to a system based on standard

infrastructure costs and variable care costs related to resident dependency and care needs (17).

- Capital funding to be directed to special needs groups, as noted above, and high-need areas.

In summary, policy initiatives aimed at controlling and redirecting institutional care are complemented by expansion and diversification of home and community care services, with assessment providing the key means of matching services to the needs of individuals. These separate measures are being pursued within an overall policy philosophy that is seeking to optimize the independence of frail older people by enabling them to choose the most appropriate options to meet their needs. That the outcomes being sought will require attitudinal change as well as structural adjustments in the institutional system is perhaps best signified by references to "patients in institutional care" being replaced with "residents in residential care."

Research context

Research has become increasingly closely linked to policy development in long-term care, not least because policymakers have had to commission research to provide an empirical basis to inform their deliberations. Applied studies in long-term care have been a significant component of research in aging in Australia (18), and four phases of research development can be identified from the mid-1970's to the present, as shown in table A.

Initial surveys—The initial dearth of data on long-term care was such that in the mid-1970's basic information such as the age distribution of nursing home residents was not known. A 1976 report of a census made in New South Wales (NSW) (19) gave some indications that the profile of residents was more variable than had been assumed and that some of this variation could be attributed to the level of provision of and interaction with other services, notably long-term psychiatric facilities. A 1978 census of nursing homes in Melbourne (20), which largely followed the format of the NSW survey, found that the Victoria nursing home population differed considerably from that in NSW, prompting questions about relationships between the structure of provision and characteristics of the resident population.

Table A. Development of research into long-term institutional care in Australia

Timespan	*Research development*
Mid-1970's	• Not even age distribution of nursing home residents known. • Initial censuses in New South Wales and Victoria.
1980–82	• Series of separate surveys of resident characteristics carried out by State health authorities. • Only item collected in standard was sex: Male or female.
1983–85	• More sophisticated measurement and classification of dependency. • Comparative analysis using combinational method.
1986–present	• Research into dynamics and outcomes: Utilization (individual nursing home)—length of stay, turnover, access, seasonality, longitudinal trends in dependency profiles. Care (nursing home system)—standards, staffing, quality of life, regulation.

State surveys and comparisons—The early 1980's saw a number of basic census-type surveys carried out by State health authorities. These accounts of the demographic profile of residents of nursing homes showed the significance of social support factors, indicated by marital status and sex ratios of residents. The data collected in these separate surveys were used in a comparative analysis of nursing home populations made in 1983–85 (21). This study sought to investigate the consequences of interstate differences in the provision of nursing homes for the composition of the resident population. In particular, it was concerned to examine the effect of higher levels of provision on the dependency profile of the resident population and on variations in rates of admission among the total aged population for demographic subgroups defined by age and sex.

The comparative analysis dealt with two methodological issues arising from these surveys. First, a regrettable feature of the basic surveys was the lack of comparability or standardization in most of the items collected; the only item collected in a standard way in six different surveys was recording of sex as male or female. Reconciliation of the definitions and categories adopted enabled satisfactory comparison of key variables, but the need for more systematic approaches to data collection was made readily apparent. Second, some attention was given to the development of descriptive classifications using combinations of key variables (22). This approach proved particularly useful for handling data sets characterized by presence-absence measures on a small number of basic variables for large populations. An example of the application of this method is given below in presenting some key findings of long-term care research. A further important achievement of this comparative study that has yet to be realized is that it provides a baseline for tracing subsequent change in the aged care system.

Understanding of utilization and outcomes of long-term care was also advanced at this time through analysis of other secondary data sets. Analysis of longitudinal data on separations produced a different account of length of stay than that based only on cross-sectional data (23), and analysis of death records challenged the view that the majority of the elderly would end their days in long-term care (24).

Policy-oriented research—Progress in the measurement and analysis of different aspects of the long-term care system advanced from the mid-1980's through research commissioned by the Federal Government. Major consultancies investigated relationships among dependency, staffing levels, and quality of care in both nursing homes (25) and hostels (26). The nursing home study was followed by the development of a five-tier classification of resident dependency that provided the basis of new arrangements for payment of nursing home benefits (17). Federal funding of pilot Geriatric Assessment Teams also supported monitoring and evaluation studies to be built on a standard data collection system (9).

Current investigations—Two strands of research now in progress are directed to examining outcomes of long-term care. Analyses of the dynamics of utilization of the long-term care system are concerned with:

- Changes in length of stay and resident turnover.
- The effects of short-term and seasonal fluctuations as compared to longer term trends in admission rates.
- Long-term shifts in the dependency profile of resident populations.

Analyses of standards are investigating:

- Standards of care.
- Aspects of staffing, particularly staff turnover as it affects the standards of care.
- Issues of quality of care and quality of life.

These studies are being carried out at varying levels of analysis, ranging from individual nursing homes to the aggregate nursing home system. An intermediate level of analysis in which nursing homes are grouped on the basis of variables expected to influence outcomes, such as size of home, ownership, and funding, should facilitate explanation of variations found at the system-wide level.

Current research is able to draw on a number of administrative systems set up in conjunction with the implementation of various policy measures. Evidence of the advances in data bases becoming available over the decade is seen in an account of nursing homes and their residents published by the Department of Community Services and Health in 1988 (27), which drew on the NH5–Application for Admission form for data on admissions and the NH3–Claim for Commonwealth Benefits form for turnover data. A further account to be released in mid-1990 (28) is to include data on dependency from the resident classification instrument (RCI). A standard minimum data set (MDS) being collected by all GAT's will provide information on clients presenting for assessment and outcomes. Information on standards of care will shortly be available from two sources, the formal schedules used by the Standards Monitoring Teams to monitor compliance with outcome standards, and returns from complaints units.

There is still scope for further development in two areas. First, moves are under way to standardize reporting across all long-term residential care services and to provide statistics comparable to acute care data bases (29). Second, the development and application of more sophisticated analytic techniques, including time-series analysis and disaggregation of the total nursing home population, need to be pursued.

The aged care system study

Research to monitor the operation and impact of GAT's began in late 1984, when a number of GAT's received Federal funding on a pilot basis. A group of researchers were identified in each State as the State Evaluation Unit, to work in conjunction with the GAT's and the relevant Commonwealth and State departments on the development of a research program. In Victoria, the group nominated as the State Evaluation Unit had carried out several studies that provided relevant background to the monitoring of the GAT's, and after preliminary work with the pilot teams, the research program was consolidated in mid-1987 as the Aged Care System Study (ACSS).

Systems framework

As assessment for admission to nursing home care is a central element in the restructuring of the aged care system, GAT's are the central focus of the ACSS. The GAT's can be seen as a valve controlling flows of older people between different services in the care system. The aged population makes up the content of the system, and relationships between the service components are conceptualized in a systems framework as a set of "stocks" and "flows," with changes in the stocks of residential and community services engendering and in turn responding to changes in the flows between the service components.

It is expected that while some of these changes will be evident in the short term, 1–2 years, others will emerge only in the medium to longer term, 5–10 years. The speed with which the different parts of the system adjust is itself an area of interest, as are blockages or barriers in the system that cause delays in adjustment or backlogs—for example, in the form of waiting lists for services that are inadequately available to meet need.

The aims of the ACSS are to provide baseline data on the system at the beginning of restructuring, to trace changes associated with the implementation of various policy measures, and to examine outcomes for clients moving through the system and also in terms of adjustments in the various service components. The "audience" for the ACSS is firstly the GAT's and other health care providers who are the participants in the project, secondly the Commonwealth and State Governments, and thirdly the wider academic research and gerontological communities.

Data sources

The range of research encompassed in the ACSS is achievable only through the use of a number of secondary data sources, with only limited primary data collection to be undertaken. The basic requirement of the monitoring of the GAT's set down by the Commonwealth was the collection of a common minimum data set. The development of the content of the MDS was discussed with the GAT's to maximize compatibility with their normal recording practices, and a trial collection period was instituted with the four pilot teams. This MDS was adopted by the additional teams as they came on stream with the expansion of the Geriatric Assessment Program. All 17 GAT's have been collecting the MDS since early 1987, and the data are forwarded to the Evaluation Unit for analysis. The MDS has yielded a substantial data base of high-quality data, with some 10,000 clients covered in each of five 6-month reporting periods to the end of 1990. Comparable data are also collected in other States.

The 15 items of the MDS are collected for all clients presenting to the GAT and cover demographic data (age, sex, marital status, country of birth, and functional knowledge of English), date of assessment and discharge from the team, whether a first assessment or reassessment, source of and reason for referral, usual living arrangements and location at assessment, use of community services, and recommended care plan. While each GAT collects disability and diagnosis data, it has proved difficult to arrive at a recording system that is acceptable to all teams. Further work in this area is ongoing.

The structure of the MDS makes it possible to compare the GAT clients with populations covered by a number of other data sources, ranging from census and other surveys of the Australian Bureau of Statistics to information systems generated in other parts of the health care system. The secondary sources used in various parts of the ACSS are detailed below, and the areas in which primary data collection was undertaken are also noted.

Structure of the study

The six components of the study are:

- Population studies aim to describe the population from which clients are drawn into the service system. Demographic studies have made extensive use of census data, Australia having a complete census conducted every 5 years (30). Particular attention has been given to the very old population (31–33) and to population change at the local level (34). Other high-risk groups have been investigated. For example, a study of tenants of public housing drew upon records held by the housing authority of transfers out of public housing to other forms of accommodation (35). Following on earlier analyses of data collected in the 1981 Handicapped Persons' Survey (36,37), further epidemiological work is using data collected in the 1988 Ageing and Disability Survey carried out by the Australian Bureau of Statistics (38).
- Following on from earlier work that has indicated the importance of acute care as a precipitator of admission to nursing home care, investigations are being made of the use of acute care by the elderly. The characteristics of long-stay aged patients, their utilization patterns, and eventual outcomes have been of particular interest. The Patient Reporting System, a comprehensive data base covering Victoria's public hospital system, has been used for these studies (39,40). A detailed study of the interaction between the GAT and acute care hospitals has been made in one region (41).
- The regional GAT's are the core of the ACSS, and the MDS generated by the GAT's is the core data base. Basic analyses of the MDS are prepared to show client flows and outcomes for the 17 GAT's, and more advanced analyses are carried out to investigate relationships between these key variables (42,43). In order to explain some of the variations among the GAT's stemming from differences in regional populations, team settings and staffing, and local service provision, additional data are collected on these areas, again using either census data or information held by the GAT's. Followup studies of clients recommended for different care plans have recently been instituted. Independent research by one of the GAT's has monitored the operation of a placement system for clients assessed as needing nursing home care (44) and investigated factors accounting for variations in waiting time to placement (45,46).
- Dynamics and standards of residential care are under investigation through studies using a variety of data bases. Early modeling of the dynamics of the system (47), a baseline study of turnover (48), and a comparative study of access to nursing home care using data from Australia, the United States, and Canada (49) can be extended to time-series analysis as further data on turnover are generated by administrative systems. The purpose of this work is to differentiate short-term fluctuations due to factors such as seasonality from long-term trends in turnover due to the impact of assessment and changes in the resident dependency profile. Approaches to regulating quality of care in Australia and the United States have been reviewed (50), and a method of measuring quality of care has been developed using population norms for various dependency and care-related outcomes (51). Several aspects of nursing home staffing are seen to be closely related to standards of care (52), and studies have been made of staff turnover and satisfaction (53,54). Surveys to collect data on factors affecting staff turnover, with followup over a 12-month period, were the main primary data collection exercise of the ACSS.
- Research into the dynamics and standards of community care has so far provided background information for developing new empirical studies. A review of a number of surveys of use of community care services identified the impact of methodological considerations on the findings (55), and interstate variations in funding and provision have been examined (56). The establishment of a national data base on services provided through the Home and Community Care Program by the Commonwealth Department of Community Services and Health will enable further work in this area, including the development of benchmarks for service provision.
- Recognizing that the kinds of information available and the methods used to analyze it will affect

the findings obtained, the final part of the ACSS is concerned with reviewing and refining data sources and research methodologies appropriate to long-term care. Issues range from overall research design to specific measurement questions—for example, how to measure length of stay and turnover in nursing homes—for a single home and for system-wide measures. Some attention is being given to the development of an inventory of Australian data bases on long-term care.

Key findings on residential care

Significant findings of the ACSS and the earlier studies on which it has built can be presented in six main areas of research into residential care. As well as reporting substantive findings of relevance to long-term residential care in Australia, each of these areas has involved consideration of some methodological issues.

Description of resident population by dependency groups

Adequate description of the population resident in long-term care institutions is a very basic and necessary starting point for the examination of outcomes. Dependency profiles of resident populations were compiled using data from the surveys conducted in the early 1980's, following the combinational method developed by Howe and Preston (21). Briefly, dependencies in mobility, continence, and mental impairment were coded 1/0, 2/0, and 4/0 in turn for presence/absence according to set criteria and when summed, unique scores result to define eight groups covering all possible combinations of dependencies. While the ± classification of the three variables loses a degree of detail, this method of description has several advantages: It has enabled data from several different surveys to be reconciled in a consistent manner; it is economical in data, focusing on crucial distinctions in key characteristics; the computation required to derive the groups is extremely simple; and the combination of variables in the groupings captures something of the interactive effects of multiple handicaps.

A summary of the Victorian and Tasmanian residential care populations described by this combinational method is set out in table B; these States have been selected as data were collected using the same survey schedule. The data presented on each of the three variables separately suggest that the Tasmanian population is less dependent than the Victorian, but a much clearer indication of the extent of potentially inappropriate residential care is given by the distribution of the population over the eight dependency groups. Fully 30 percent of the Tasmanian population were not dependent in any of the three key areas, and only 21 percent were dependent in all three; the respective proportions for Victoria were 11 percent and 43 percent. Considerable variations were also found in the dependency distributions in the other States.

Relationship between level of bed provision and dependency profile

As the level of nursing home provision varies considerably among the States, a major question was to determine whether these differences reflected variations in population dependency characteristics or

Table B. Percent and percent distribution of residential care population by dependency profile: Victoria and Tasmania, Australia

Dependency profile	*Victoria*	*Tasmania*
Individual dependency	Percent	
Nonambulant	79	56
Incontinent	61	39
Confused	58	39
Combination of dependencies	Percent distribution	
Total	100	100
Ambulant:		
Continent:		
Not confused	11	30
Confused	5	7
Incontinent:		
Not confused	2	2
Confused	4	5
Nonambulant:		
Continent:		
Not confused	16	17
Confused	7	7
Incontinent:		
Not confused	13	11
Confused	43	21

NOTE: Percent distributions may not add to 100 because of rounding.

whether the level of provision influenced the resident dependency profile. An analysis of the prevalence of disability in the aged population carried out as part of this study found no differences among the States (36); hence any variation in resident dependency profiles could not be attributed to underlying differences in disability.

Overall, an inverse relationship was found between the level of bed provision and the proportion of beds occupied by high-dependency residents. Victoria, the State with the lowest provision, had the highest proportion of beds occupied by high-dependency residents, while Tasmania, with the second highest provision of the six States, had a higher proportion of residents in the lowest dependency group. This pattern was generally consistent across the remaining States. Rates of institutional residence per 1,000 for population groups defined by sex and age (under and over 80 years) were also calculated for each dependency group. It was found that while these rates were relatively constant for the high-dependency groups, rates for low-dependency groups tended to increase with rising bed provision.

Three main conclusions were drawn from the study. First, dependency profiles of nursing home residents reflect the sensitivity of admission rates for different population groups to the level of bed provision. Second, the relatively constant rate of admission of high-dependency residents to institutional care suggests that even in the States with lower bed provision, that level is adequate to meet the needs of such people seeking nursing home admission. Third, where bed provision is in excess of this level, beds must be filled by individuals of lower dependency, since the "supply" of high-dependency residents has been exhausted.

The main policy implications arising from these findings were that limiting the number of nursing home beds would tend to exclude low-dependency residents, that the level of provision even in the low-bed States appeared sufficient to meet the needs of high-dependency residents, and that with control of bed growth, the dependency profile might be expected to converge toward that of the lower bed States as bed ratios elsewhere were reduced over time. Establishing these relationships laid some of the foundation for the measures for restructuring long-term care instituted through the Nursing Homes and Hostels Review, which was to restructure residential long-term care.

Length of stay

Analysis of data on length of stay of nursing home residents in Australia, as in the United States, has dispelled the myth that the typical stay is a long one, up to 2 years, ending only in death. This correction has come about by adjusting the picture of stays based on cross-sectional data on the duration of stay of current residents with analyses of data on separations over a period of time. The extent of underrepresentation of short stays in cross-sectional data is shown in an analysis of NSW data (22): The proportion of stays of less than 2 months shifted from only 9 percent for inpatients at a given date to 49 percent of separations over a year in NSW (22).

Short stays in Australian nursing homes are not, however, a product of reimbursement arrangements, as in the United States, and further research is required to differentiate short-stay and long-stay residents. To the extent that high-dependency residents can be expected to have shorter stays, changes in the dependency profile of residents can be expected to result in more short stays, with consequences for turnover and access to beds.

Analyzing access to long-term care

The preceding findings have been combined in analyzing access to nursing home care (48). Recognizing that access will depend not only on the number of beds available but also on the rate of turnover in those beds, nine different approaches to measuring aspects of utilization of long-term care were canvassed. An accessibility index was derived by multiplying average bed provision in a defined region by average annual turnover. The index obtained shows the number of admissions to available beds occurring per 1,000 aged persons in the region. Results for three Australian States set out in table C show that the interaction of bed numbers and turnover results in differences in access to care that are not evident from figures on bed provision alone. Other outcomes examined were the proportion of residents with short, medium, and long stays and the proportion of separations in each of these categories due to death.

The study pointed to the powerful distributional effects that could be exerted on the nursing home

Table C. Outcome measures for nursing homes: Victoria, Tasmania, and New South Wales, Australia, 1985

Outcome measure	*Victoria*	*Tasmania*	*New South Wales*
		Number	
Total beds per 1,000 persons 70 years of age and over	55	77	78
Length of stay		Percent distribution	
Less than 2 months	36	---	50
2–12 months	28	---	26
More than 12 months	36	---	26
Proportion of separations due to death		Percent	
All lengths of stay	57	---	57
Less than 2 months	25	---	25
2–12 months	55	---	41
More than 12 months	80	---	59
Accessibility			
Annual turnover	36	56	80
		Index	
Accessibility index	31	43	62

NOTE: Figures have been recalculated from previous published data to standardize for bed ratio per 1,000 persons 70 years of age and over. Percent distributions may not add to 100 because of rounding.

system by using assessment and reimbursement arrangements to influence the kinds of residents who gain access to long-term care. The accessibility index provides a quantitative measure of outcomes of policies aimed at changing utilization, although it remains to be judged whether increased access for more short-stay residents, achieved by higher turnover, is a "better" outcome than other uses of nursing home beds.

The potential for changing access to long-term care was demonstrated in modeling of the nursing home system, taking into account not only growth in the number of beds but also the distribution of admissions between short- and long-stay residents and the rate of turnover among long-stay residents (46). Thus, even with constant bed provision, an increase in the proportion of admissions who were short-stay residents from 30 to 50 percent would increase turnover and access by almost 30 percent. Assessment and community care were seen as means of achieving these outcomes insofar as they could forestall admission of low-dependency individuals who would otherwise become long-stay residents. Modeling of this kind provides a means of specifying alternative outcomes for the long-term care system and points to the measures required to achieve them.

Short-term and long-term changes

While little is known so far about the time scale over which adjustments in the nursing home care system can be expected to come about, it is recognized that the period over which measurement is made will influence the results observed. In attempting to evaluate the impact of GAT's on rates of admission to nursing homes, it is particularly important to separate short-term fluctuations due to other factors from longer term trends that can be attributed to assessment or other policy measures (56). Seasonality in death rates is the principal factor producing short-term changes in nursing home separations: A late winter peak has been observed, with separations in these months being 30-percent higher than in the midsummer months. The converse of these fluctuations is the emergence of queues over the summer months in the placement systems operated by GAT's, and unless there is an awareness of the underlying seasonal factors, the effectiveness of GAT's may be called into question. Measurement of long-term trends in turnover and access will need to take these short-term fluctuations into account and require measurement over a sufficient timespan for real trends to become evident (57).

Standards of care

An approach to monitoring standards of care in residential care was developed by Phillips (51). Population norms for prevalence of key indicators such as contractures, decubiti, and restraints were calculated and adjusted for case mix based on activities of daily living categories and demographic variables. Differences between predicted and observed prevalences were then interpreted as indicators of quality of care in individual homes. This developmental project, supported by a Gerontological Society of America fellowship, yielded results that were promising not only for application in the Rhode Island Department of Health, where the work was carried out, but also for use with other suitable data sets generated by standards monitoring systems in Australia.

Issues for development

Beyond consolidation of research activities already in progress, three areas can be identified as warranting further development, particularly in the context of international collaborating research.

First, a number of issues of data collection and methodology need to be addressed, with particular attention given to standardization in line with World Health Organization and other conventions. The work of the U. S. Panel on Statistics for an Aging Population (58) provides a model. An additional requirement is the disaggregation of large data bases into (a) meaningful subpopulations defined in terms of variables that are significantly related to outcomes and (b) geographic scales relevant to service planning. These advances are necessary if the impacts of interventions on risks of institutionalization are to be properly measured in local areas. Given that such risk is highly dependent on the structure of local long-term care provision, national averages, which may apply nowhere in particular, are of little relevance to this measurement task; more attention needs to be given to such local variability than has occurred to date.

Such information would have been useful in setting the context of the various channeling and case-management demonstration projects mounted across the United States with the objective of reducing institutionalization. The evaluation of these projects generally reported inconclusive findings (59), yet without an indication of the likely risk of admission to care and with its variation from one project locality to another, it is impossible to establish the margin of impact required. Further, aggregate comparisons of experimental and control groups may obscure marked differences between subgroups and fail to distinguish between individuals for whom successful outcomes may have been achieved and those for whom no amount of help would have prevented admission. Such differentiation is essential if community care programs are to be efficiently targeted. Where the phenomenon under consideration has a very low probability overall, with wide differences depending on individual characteristics, as is the case for institutional admission, the failure to measure significant outcomes in randomized control studies may be a fault of research design as much as a failure of the projects themselves. The need for careful consideration of these and other methodological issues has been flagged in the development of a strategy to evaluate the Community Options Projects now being established in Australia (60).

Second, quality of care and outcome standards are identified policy priorities in Australia that need supporting research. Recent research in Israel (61) provides a framework for complementary lines of investigation that can be built on data bases now becoming available in Australia. The RCI data might be used to develop the quantitative population norms approach to monitoring, with qualitative information from the Standards Monitoring Teams providing complementary measures of standards for individual homes and the system of residential care overall. Complaints units now being established will add further data on standards. Finally, search conference and focus group techniques might be used with groups of residents, relatives, direct-care staff, administrators, and community representatives to canvass their different perspectives on quality of care. The combination of these approaches should lead to the identification of homes that achieve preferred outcomes, the factors contributing to them, and ways in which they might be more widely promoted in the long-term care system.

Finally, comparative studies of the long-term care systems in Australia and the United States (62) and the United Kingdom (63) suggest several lines for future research. Most of the differences found between national systems have been attributed to funding and other administrative arrangements that reflect major differences in policy orientation. As it might be expected that recent initiatives in one system will give some indications of potential changes elsewhere, some areas are noted as of interest for more detailed comparative study. Replication studies will be useful in showing where variations in outcomes arise from differences in the structure of the aged care system or from differences in the populations under study. Thus, studies of the oldest old in the United States (64) provided a framework for analysis of census data and other sources on information on this cohort in Australia (31–33). Additionally, the kinds of incentives and outcomes generated by different reimbursement systems in the United States (65) demonstrate some of the effects that might eventuate from recent funding changes in Australia that separate the costs of patient-related and non-patient-related services. Moreover, the changing care needs of long-term care clients, particularly in relation to changes in acute hospital care occurring in response to implementation of diagnosis-related groups in the United States (66), may foreshadow similar trends in Australia.

Research in residential long-term care in Australia has made considerable advances since the early interest shown in the 1970's, and the rapid changes currently occurring make monitoring and evaluation research an essential adjunct to policy development. Participation in the International Collaborative Effort on Outcomes of Institutional Long-Term Care thus offers a timely opportunity for the further development of this research.

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Chapter 21
Long-term care in the United States: Issues in measuring nursing home outcomes

by Joan F. Van Nostrand, M.P.A., Coordinator of Data on Aging, National Center for Health Statistics

The purpose of this presentation is to explore several research issues in measuring nursing home outcomes within the context of long-term care (LTC) in the United States. My approach to this topic has four segments:

- To describe briefly the provision of nursing home care in the United States to enable comparisons to the presentations about LTC in Australia and Canada.
- To identify some of the salient data on nursing home outcomes available from the National Center for Health Statistics (NCHS).
- To develop a framework for studying outcomes using this NCHS data base.
- To present some examples of measurement issues on outcomes of nursing home care as potential research topics for international collaboration.

Note that the title of this presentation equates LTC in the United States with nursing home care. This is not an attempt at poetic license. The bulk of LTC in the United States is provided in nursing homes. This institutional bias exists for two reasons:

- Nursing home care is a benefit of government health programs, in particular Medicaid and, to a lesser extent, Medicare.
- The supply of substitute LTC services—that is, home health, adult day care, and hospice—is limited. In many geographic areas, it is virtually nonexistent.

Institutional LTC in the United States is provided in places generally called nursing homes or, sometimes, personal care homes. They are defined in a broad way as institutions providing rehabilitation, nursing care, or personal care. The clients are persons who require institutional services below the level of hospitals and above the level of room and board. It is a slippery definition, difficult to pin down in specifics.

Nursing home care in the United States is of particular relevance to the care of older persons. The oldest old are the greatest users. In 1985, 22 percent of those 85 years of age and over were nursing home residents (1). In that year, there were 1.6 million nursing home beds—more beds than in the acute care hospital sector. The oldest old are the most rapidly growing segment of the older population in the United States, as they are in most developed countries. Therefore, the heavy use of nursing home care by the oldest old has major implications for the future of the Nation as a whole as well as for the individual nursing home resident.

For the Nation as a whole, costs of care are a growing concern. About 8 percent of the health care dollar in the United States is spent on nursing home care. Nursing home care ranks as the third largest health care expenditure after hospital care and physician services (2). Half of the cost of nursing home care is paid by the government, mainly through the Medicaid program.

For the individual nursing home resident, the impact of nursing home care can be devastating in two ways. One impact is the loss of independence and autonomy. Decisions about everyday life—when to get up, when to eat, what to eat—are no longer made by the individual but by the administrator and staff of the nursing home. The second negative impact is impoverishment, often referred to as "spenddown."

That is the term used to designate the process by which persons deplete their assets in paying for care to such an extent that they qualify for Medicaid, i.e., the government health care program for those who meet welfare criteria. Spenddown is not an isolated phenomenon. Of persons discharged after at least a 6-month nursing home stay, 23 percent "spent down" so that Medicaid was the major payer at discharge (3). In summary, the bulk of LTC in the United States is provided in nursing homes. The heaviest users are the oldest old, who may face impoverishment in paying for care after a prolonged stay.

Now I would like to turn to the second segment of my presentation, namely, the identification of some of the salient data on nursing home outcomes as collected by NCHS. The source of the data is the National Nursing Home Survey (NNHS), which was initiated in the early 1970's. It is conducted periodically, most recently in 1985 (1). Data about a nationally representative sample of nursing homes, their residents, and discharges are collected from facilities' records and staff. The data about residents provide a cross-sectional profile of the population in nursing homes on any given day. NNHS is a rich source of information about residents because the data from each nursing home's records are augmented by the knowledge of the nursing home staff. The data about discharges, in contrast, represent discharge events that occurred in the 12 months prior to the survey. In comparison to data about residents, the amount of data about the characteristics and outcomes of discharges is limited. This is because the nursing home records are the only source of information. Available data focus on basic transitions in health and functioning and on outcomes of care. Serious gaps in data about outcomes and nursing home quality have been identified, and remedies have been proposed (4). Data about the characteristics of residents and discharges prior to admission were collected via telephone calls to the next-of-kin.

The availability of national data on nursing home discharges is relatively recent. Data were first collected in NNHS in 1977. The 1977 data on discharges (5) dispelled some negative myths about nursing home outcome. The prevailing myth about nursing home care was that most older persons were discharged dead after very long stays. According to the 1977 data, 72 percent of older persons were discharged alive. Furthermore, one-third of the discharges stayed 1 month or less, and the median stay was about 82 days. These data dispelled the notion that negative outcomes were inevitable and turned attention toward positive outcomes of nursing home care.

There is the potential to use two other data systems from NCHS to learn more about outcomes after discharge. One system is the National Death Index. It can provide data on whether the death of a discharge in the NNHS sample occurred, when it occurred, and the cause. The second system is the followup survey of the 1985 NNHS resident and discharge samples. Followup was conducted in 1987, again in 1988, and is planned for 1990. Data about the discharge sample collected at the time of followup included information on nursing home and hospital stays subsequent to the 1984–85 discharge event.

I would like to turn now to the third segment of my paper and present a framework that uses NNHS for studying outcomes. The framework borrows from the epidemiologic model in that it addresses risk factors and outcomes. It also borrows from Donabedian's work (6) in assessing quality in relation to the following concepts:

- *Structure*—the personnel, facilities, and medical technologies of the health care system and its components.
- *Process*—what and how services are delivered to the individual patient.
- *Outcome*—the impact of the structure and process of health care on health status.

Figure 1 presents my conceptual framework for addressing measurement issues of nursing home outcomes. It is a systems approach and emphasizes the relationship among its major components: Risk factors, nursing home structure and services, and outcomes. Note the multidimensional nature of each of the model's components. The model deals not with one risk factor or one outcome but with various risk factors and several outcomes. The small blocks within the larger cube emphasize the interaction among the individual dimensions of each of the components.

Figure 2 shows a detailed example of the framework with specific variables from the 1985 NNHS.

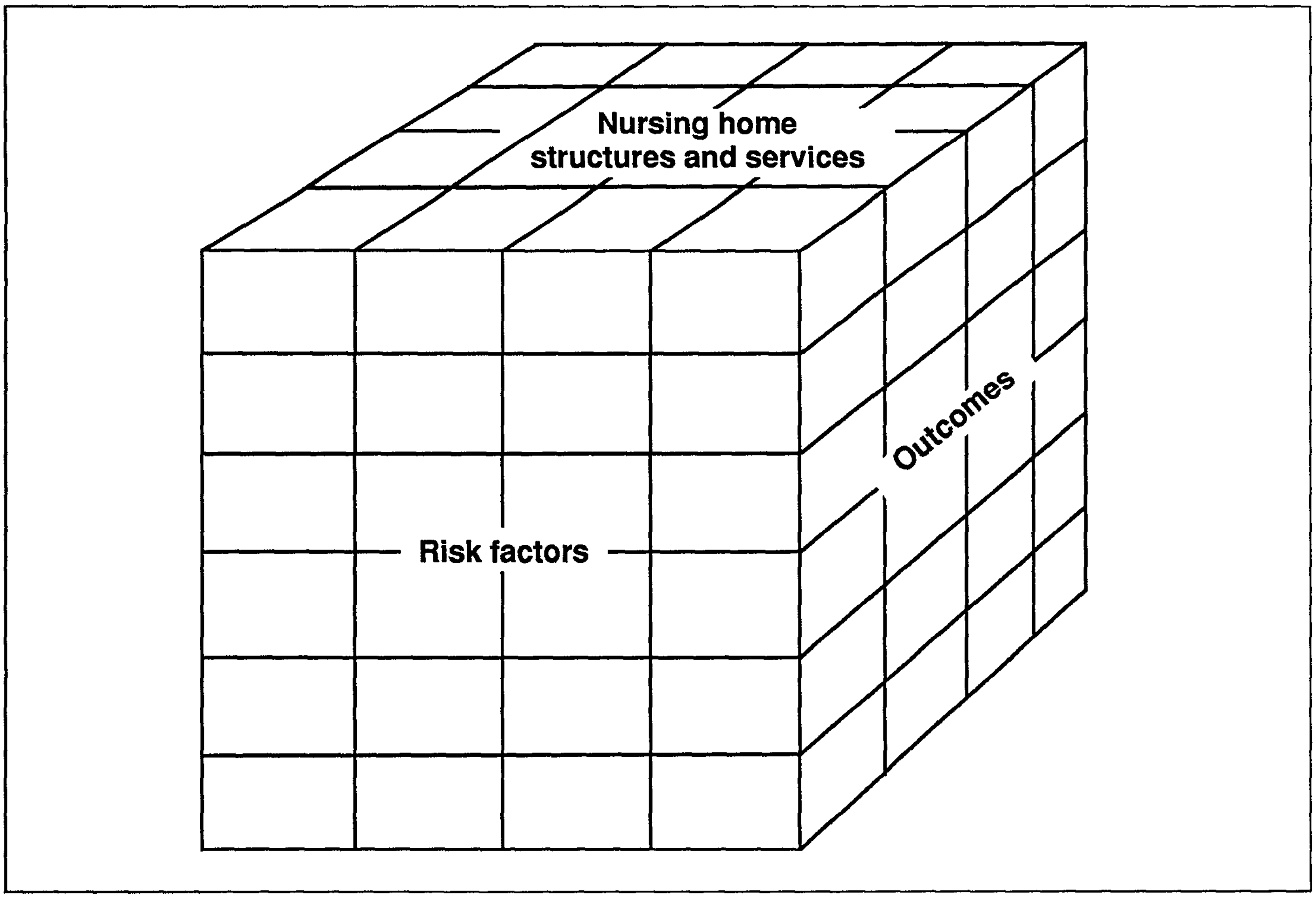

Figure 1. Conceptual framework for measuring nursing home outcomes

Note that the risk factors go beyond the biological processes of an epidemiologic model to include psychosocial variables and functioning. Note also that this detailed model does not include specific services. This reflects the fact that service data, although important to the conceptual model, are minimal in the 1985 NNHS. Some of the outcomes, such as functioning and death, are similar to those in the Donabedian model of quality. Other outcomes, such as subsequent need for care and the length of stay, have been included because they are of particular relevance to the delivery of nursing home care.

I would now like to turn to the fourth and final segment of my presentation. Using this model as background, I will present two proposals concerning the measurement of outcomes that could be possible topics for international research. My proposals are intended to stimulate discussion in the workshop on nursing home outcomes and to contribute to the development of a plan (see chapter 34) for collaborative measurement research.

One possible topic for collaborative research is the measurement of functioning as an outcome. There are two central measurement issues here. One is the valid assessment of functioning when facility policies direct staff to provide assistance regardless of whether it is needed. This issue was highlighted in the pretest to the 1985 NNHS. There were major differences between the report of patient functioning made by the family prior to admission and that made by the nursing staff immediately after admission. The next-of-kin generally reported better functioning of the patient than did the nursing home staff.

In some cases, these differences are possible. Some catastrophic events, such as stroke or hip fracture, could have caused a major reduction in functioning between the two points in time. However, this situation would account for only a small number of the

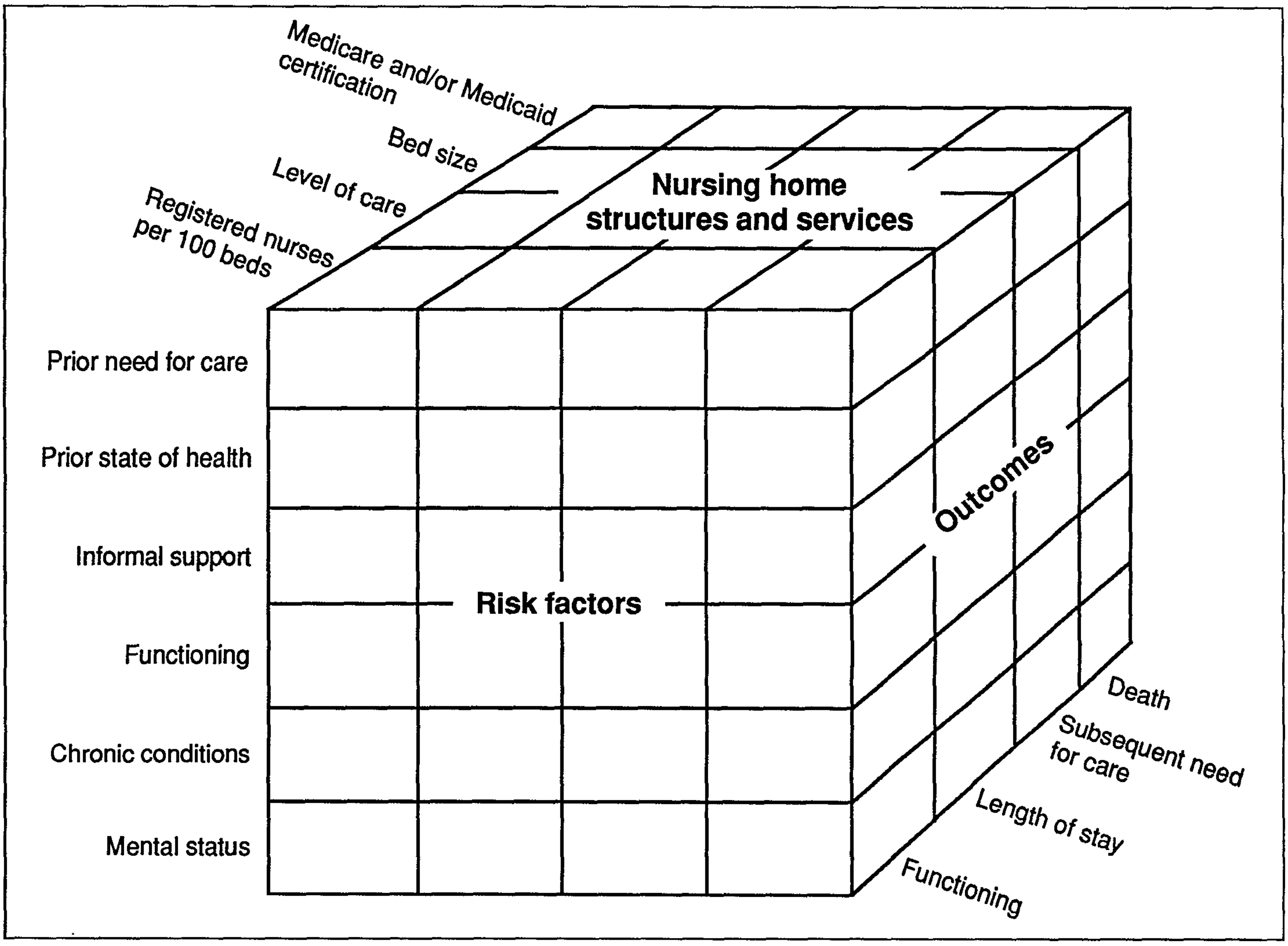

Figure 2. Detailed framework for measuring nursing home outcomes using National Nursing Home Survey variables

cases. One hypothesis to explain this discrepancy is the impact of nursing home policy. Many U. S. nursing homes have a policy to provide assistance, particularly in bathing and in walking, regardless of whether it is needed. It is a double-sided protection. It is intended to protect the patient from falling and the facility from being sued in the case of a patient injury due to a fall. The measurement question associated with this situation is how to determine the valid functioning of the patient when facility policy requires that assistance be provided. Possible solutions to research are to rely on next-of-kin reports or to ask staff to report the patient's capacity rather than actual performance.

The second measurement issue concerning functioning focuses on transitions. If measurement research is to assist in improving nursing home outcomes, then an important issue is determining which transitions in functioning are positive and should be replicated and which are negative and should be reduced. Table A shows transitions between admission and discharge in the two activities of daily living (ADL's) available from the 1985 NNHS, walking and incontinence. The outcomes on the diagonal of the matrix were easy to classify as stable because no change in ADL's occurred. Some transitions also were extremely easy to classify as positive or negative. The outcomes at the lower left of the matrix represent improvements, usually from limitations at admission in either walking or incontinence to no limitations in these ADL's at discharge. The outcomes at the upper right of the matrix represent deterioration, from no limitations at admission to one or both limitations at discharge.

Table A. Transitions in resident functioning from admission to discharge from nursing home, by limitation at discharge and at admission

Limitation at admission	Limitation at discharge			
	None	Trouble walking	Incontinence	Both
	Outcome			
None	S	D	D	D
Trouble walking	I	S	?	D
Incontinence	I	?	S	D
Both	I	I	I	S

NOTE: I = improved, S = stable, D = deteriorated, ? = undetermined outcome.

The question marks in the matrix pinpoint those transitions that are very difficult to classify as either a positive or negative outcome. Is it an improvement to shift from being incontinent at admission to being limited in walking at discharge? The care providers in nursing homes, the patients themselves, and their informal support systems may all have divergent views on this question. Their views may depend on the type and amount of care that is needed. Determining care needs, of course, raises another set of measurement issues. While such issues are beyond the scope of my presentation, they are critical to pursue in making judgments about positive or negative outcomes.

Another possible topic for collaborative research is identifying similar groups of nursing home patients among the collaborating countries and assessing if they have similar outcomes. If some countries have more favorable outcomes, can the reasons for positive outcomes be measured and replicated so that they might be applied in other countries? This research topic raises several challenging measurement issues. One challenge is to identify existing data that are comparable across countries to measure patient risks and outcomes. Another is to develop comparable profiles of similar groups of nursing home patients. A third is to determine, given the serious nature of chronic illness in this LTC population, which outcomes are "favorable." In some situations, for example, retardation in the rate of decline may be a favorable outcome.

While I have discussed functioning and comparability of patients and outcomes as possible topics for international research, this is not to imply that they are priority topics. Rather, they are illustrations of the variety of issues and the complexities inherent in measuring outcomes of nursing home care.

I will close my remarks by making some observations on the overarching goals of measurement research about nursing home outcomes. As you have heard these past few days, the central theme of the International Collaborative Effort on Aging is vitality and wellness of older persons. In a sense, the effort on outcomes of nursing home care is the application of the concepts of vitality and wellness to LTC. Our overarching goal is not only to strengthen measurement and increase international comparability of outcomes. It is also to use this information to gain insights into how outcomes for older people who experience nursing home stays can be improved.

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Chapter 22
Measuring outcomes of institutional long-term care: The problem of both the dependent and independent variables

by Rosalie A. Kane, D.S.W., School of Social Work and Health Services Research and Policy, School of Public Health, University of Minnesota

My task is somewhat more conceptual and less concrete than that of many of the other speakers at the conference. In the title to my remarks, I decided to emphasize the double problem of the independent and dependent variable. I do so not to be discouraging. International comparisons looking at outcomes of institutional care, and, for that matter, long-term care in general, will be extraordinarily important and could cast new light on how we might be able to improve the ways in which we serve functionally impaired elderly people. So, difficult as the task of measuring outcomes of institutional care may be, I am eager for us to do so.

The comments that I make emphasize measuring the outcomes of care more than measuring the risk of needing it. I think we understand quite a bit, at least in the United States, about the characteristics of those people who use nursing homes. Further, we can probably say something about the characteristics of people who use other kinds of long-term care services. So we can talk about sex, age, diagnosis, cognitive condition, marital status, and so on, and describe characteristics of those at risk of needing care.

Our ability to predict whether any particular man or woman who exceeds age 65 is likely to use a nursing home, however, is much harder. We must be aware as we embark on this kind of inquiry that the need for institutional care or the need for any kind of long-term care cannot be developed as a straight-line extrapolation from use patterns that already exist. Public policy has an inordinate effect on patterns of use of institutional care, so it is always important to tease out the context of care.

Independent variable

At this conference, nursing home care and personal care have been defined as anything in between an acute hospital and a room-and-board situation. That allows infinite variations within the definition. We have a welter of names, even in the United States, that we use for residential settings with some services attached, e.g., nursing homes, rest homes, homes for the aged, retirement homes, congregate housing, assisted living centers, adult foster care, board and care homes.

For example, adult foster homes have become a viable option for long-term care for the elderly, particularly in the State of Oregon, where we have studied them (1). Oregon's adult foster homes are private homes licensed for one to five residents; there is a full-time person living there preparing the meals, cleaning, giving personal care, and doing anything else that needs to be done. It is hard to know whether to call that institutional care, residential care, or home care. In other words, it is hard to know the players without a program.

In any one of the residential services, regardless of its name, one could have different personnel mixes. Moreover, the purpose of institutional care can be very different, even among facilities of the same name. In our U.S. nursing homes, the purpose for a given resident's care may be rehabilitation, or it may be terminal care, or it may be to provide efficiently those socially oriented personal care services that people need routinely. Depending on the purpose, a researcher would use a different independent variable and would want to measure outcomes somewhat differently.

All of these services with distinctly different purposes are taking place within what we in the United States call a nursing home. I imagine there is the same kind of variability in other countries. This makes it extremely hard to look at the black box of outcomes. If we start taking an international look at outcomes of institutional care, the endeavor might have the very desirable result of forcing researchers to stop confusing the place of care with the type of care. It is a very dangerous kind of shorthand to say "nursing home care," "home care," "day care," or for that matter "hospital care," because all sorts of things can happen under each of those rubrics.

Ultimately, what we really need are measures that will allow a comparison of outcomes across sites of care and modalities of care as well as over time. This also permits examining patterns in the way services are combined. It is very hard to attribute causality to outcomes observed for a particular slice of care. For instance, taking the practical example that we are now dealing with in our studies in Oregon, we find that people move from hospitals to nursing homes, sometimes for some recuperation, and then to foster homes, and then back to nursing homes—or vice versa. It is, therefore, really quite difficult to determine what outcomes should be attributed to which type of care.

With large longitudinal data sets capable of tracking people as they use different services, we can make comparisons of service settings, singly and in combination. We can also identify people who have certain characteristics and use care in different ways, for example, people with strokes.

Of course, the use of hospitals becomes a very important factor. It occurred to me, when hearing the previous presenters describe the large number of people who are discharged from nursing homes alive, that this might be a little misleading to some of our international visitors. That is because, although a surprisingly high number of people do leave nursing homes for the community, a goodly subset of those people are discharged alive to hospitals, where they either die or are discharged back to nursing homes. Again, it becomes important to be able to track users of long-term care and related acute care as they move from setting to setting.

Dependent variable

Turning to the dependent variable, it is extremely important to array the kinds of outcomes that we might measure, not only to look at those that are available in existing data sets, but also to consider which ones we might want to include. Functional abilities have already been discussed and are surely an important outcome to look at in long-term care.

It is easy enough to provide a laundry list of candidate measures, but none of them is unambiguous. Functional abilities, physiological health and survival, emotional health, social activities, and social participation are all possible. So too is satisfaction with the care received. We can also consider financial outcomes in terms of public outlays and financial outcomes in terms of personal outlays.

It is also necessary to divide personal outlays into those of the resident and those of family members. Family members' contributions come in terms of direct care as well as monetary support, and to our surprise, it is becoming apparent now that a great deal of family care goes on when people are in so-called institutional or residential settings. That in itself is something worthy of looking at. We cannot assume that informal family care occurs while people are in the community and ceases when the relative is in institutional care. Yet family care tends not to be measured for those living in nursing homes.

Each outcome may or may not be desired or expected for a particular long-term care recipient. Survival may not always be the goal, particularly for palliative care. Functional ability is clouded by the question of capacity versus performance, and it is difficult to decide which attribute of functioning one wants to measure; that is, does one measure what the subject can do or does do? Many facilities have policies against allowing people to bathe themselves or to take their own medicines, and if we measured performance, their functioning would be poor. We may be most interested in capacity if we are planning for discharge. But if we are interested in looking at the quality of institutional life, it may not matter that the capacity to bathe has been kept intact for 10 years if the resident has never been allowed to do it.

Satisfaction has a lot of measurement difficulties. People set their sights lower as they adjust to environments that have lower opportunities. Also, people complain a lot in some of the best kinds of environments because complaining is encouraged. Once again, the measure is difficult to use.

To operationalize these dependent variables in different countries, we will encounter fascinating cultural issues. Some years ago, I attended a very interesting meeting in Utrecht, where representatives of 9 or 10 countries sought universal agreement about how to measure a high quality of institutional care (2). Those of us from North America and Europe thought that privacy certainly would be one universal good, but it turned out it was not. Even autonomy as operationally defined did not win uniform approval. Eventually, something like "continuity with previous lifestyles" won considerable acceptance from all participants. That has face validity, because it seems we should be able to compare the people receiving various kinds of long-term care services in different kinds of residential facilities, including their own home, against some kinds of norms that are suitable for the country.

I have mentioned global measures—satisfaction, emotional well-being, functional abilities, and so on. Some process measures are, in themselves, worth looking at. For example, the use of psychoactive drugs or physical restraints are processes of care experienced as outcomes to the person who is experiencing that particular process. It is worth further explanation to see if there is any international agreement about collectable outcomes of that nature.

Technical issues

Let me conclude by summarizing some of the complications in measuring these outcomes of institutional care. There is, first of all, the heterogeneity of the population, including heterogeneity in prognosis, background, cognitive abilities, and value preferences.

This raises the question, then, of how outcomes should be interpreted. My hope is that we can look at actual outcomes compared to expected outcomes. Such expectations can be modeled, as we did some years ago in a Rand Corporation study (3). One can then look at statistics regarding what kinds of functional outcomes would be expected with a population with specific characteristics in a nursing home and examine the variance around that expected outcome.

It is probably useful, too, to look at actual outcomes compared to desired outcomes, which give rise to another kind of policy issue. We should be interested in the outcomes the people using care desire, as well as the outcomes that people paying for, organizing, and providing care desire.

Looking at actual outcomes against expected outcomes brings us back to the questions of functional measures that were discussed yesterday and to the questions of the risks of entering some kind of care. Thus, case-mix adjustment for outcomes is an important step. It would allow us to compare outcomes, adjusted for expectations across sites. In my opinion, case-mix adjustment is much more valuable for quality control and evaluation of outcomes than for reimbursement purposes, which carry so many negative incentives.

We must also consider the source of outcome information. Here we have a few choices. I would hope that we could make actual observations of demonstrated abilities whenever possible. A resident's self-report will be needed for some outcomes, such as satisfaction and emotional well-being, and self-reporting is indeed preferable to asking a staff member to rate the resident's happiness or mental state. A worrisome methodological issue is hidden in measurement of emotional well-being. I have seen measures of depression or anxious affect used to label the person as an unreliable informant about other things, such as satisfaction. This is troublesome because depression or anxiety may well be secondary to the person's living situation.

With all of this, one would hope for information systems that would allow us internationally to look at a group of people who are receiving care in various guises—residential care of different types, home care, and even no care—and see what happens to them over time, measured against their baseline functioning.

Other issues arise about the intervals of data collection, what will trigger the new assessment, and so on. Various States in this country have developed information systems that are quite rich that way. Again using Oregon as an example, at 6-month intervals, reassessments are done on multiple dimensions for people who are receiving any subsidized care offered in the State, including home care from agencies, home care managed directly by clients, foster care, care in residential care facilities that are less than nursing homes, and care in nursing homes themselves. With a huge data system like this, it is possible to construct homogeneous groups and look at their patterns of use over time.

I think there will be other such possibilities. In the United States, rich information systems will be biased toward low income. Almost all the State data systems have this bias, because systematic assessment and case management tend to occur only when people are eligible for publicly subsidized services. Income eligibility is still the norm, although it is not as stringent in some States for the community-based services as it is for the institutional-based services.

To conclude, it is an exciting prospect to do international comparisons of the characteristics and outcomes of the elderly in various forms of long-term care. We will need clear observable measures, ability to track patterns over time, ability to make comparisons across different kinds of care within a country as well as internationally, ability to compare actual outcomes to expected outcomes, and a very careful description of the programs themselves so we are clear what the independent variable is.

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Chapter 23
Outcomes of community and institutional long-term care

by Betty Havens, Manitoba Department of Health

Introduction

In this brief presentation, a short background to the Canadian long-term care system and the Manitoba Provincial long-term care system will be provided. This will be followed by a brief description of the Manitoba longitudinal data bases, leading to discussion of episodes of care and outcomes. The final portion of this presentation will deal with the data base potential in the areas of community long-term care and the comparison of outcomes across long-term care settings.

Canadian long-term care system

To quote Susan Fletcher 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. (1, p. 31)[a]

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 (2). 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.

The Federal Government contributes to long-term care in a variety of more indirect yet important ways.

> For example, guidelines for the provision of selected services have been prepared in consultation with the provinces and territories. These guidelines cover a wide variety of topics, such as long term institutional care, geriatric assessment units, palliative care units, and design considerations for geriatric care. A federal/provincial/territorial subcommittee on long term care also has been established to promote the development and coordination of long term care services on a provincial, national, and international level. The subcommittee addresses a variety of issues, including linkages between institutional and community-delivered long term care services. (1, p. 32)[a]
>
> Notwithstanding this wide-ranging federal involvement, constitutional responsibility for the actual provision of long term care services to the elderly rests with the ten provinces. The organization and delivery of these services programs are carried out mainly at the provincial and local levels. The federal government retains service delivery responsibility for certain special groups, such as native Canadians, veterans, and residents of the Territories. (1, p. 32)[a]

Unlike the American system:

> The long term care system in Canada depends heavily on donations and the free contribution of time on the part of a multitude of volunteers. Whether money donated by large corporations to furnish rooms or buy special equipment, or community groups raising funds to build a new old age home, or individuals giving of their time to drive people to doctor's appointments or bring them hot meals, all have an important role in the long term care system. (1, p. 33)[a]
>
> There are no off-the-shelf prescriptions or right ways of doing things. 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. (1, p. 39)[a]

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The Manitoba model of continuing care

The Manitoba Program is a Province-wide, universal, no-cost-to-consumer program initiated by the Provincial government in 1974 and gradually expanded throughout the Province by 1975. The Program assesses persons requiring care, whether for placement in nursing homes or for home care, and delivers services to those who remain at home. The model is a coordinated service program with a broad range of services to meet the needs of persons who require assistance or support to remain at home or whose functioning without home care is likely to deteriorate, making it impossible for the person to stay at home in the community. Upon identification of needs, services are organized to avoid deterioration and to maintain and enhance health. This purpose is accomplished within established policy guidelines.

The Program is delivered through regional offices and suboffices and through health centers and private voluntary agencies identified within the Program service delivery framework as coordinating agencies. These agencies are responsible for participating with the central Program office in Program planning and development and for providing coordinated quality service delivery within Program guidelines.

Service delivery frameworks are based on professionally coordinated and conducted need assessments, care planning, and service delivery supervision. Ongoing services provided in the home are delivered by both professionally skilled and paraprofessionally skilled persons.

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. Assessment is focused on identifying those who, without services, would be at risk of not being able to remain at home but who, with home-delivered services, could have their care needs managed appropriately. This Program model calls for each referred person to be served primarily by one staff person, the case coordinator, and for assessment and care planning to be multidisciplinary.

Program guidelines call for each person to be fully assessed, including identification of those activities that the person can perform; those that family members, friends, or neighbors can realistically perform; and those that require placement of services. A care plan is developed to provide for needed services existing within the Program. When needed services are not available within the Program, every effort is made, as part of the care plan, to secure such help from other community sources. Services provided by the Program are to be the minimum required to meet need and to foster independence. Delivery is to be organized so that services are provided by the person with the minimum skill required to perform the task. Throughout the Province, the Program utilizes professional and nonprofessional skills, including those of nurses, social workers, licensed practical nurses, aides, orderlies, therapists, home attendants, home helpers and personal care homemakers, volunteers, and the staff of voluntary agencies, as well as civil servants and hourly paid casual employees.

Seldom does a client need only a single service to remain in his or her own home in the community, so coordination of services becomes a major concern of both a providing agency and the client. If the community-based long-term care program does not include service coordination in its functions, clients or their families are left with the time- and energy-consuming task of trying to coordinate a variety of service deliverers. All of these providers are employed by and responsible to a variety of organizations. For the community-based program to coordinate health and social services from a variety of public, private, and voluntary agencies with those tasks performed by the client and his or her family, friends, and neighbors, a comprehensive multidimensional assessment is essential.

Assessments for long-term care normally concentrate on client weaknesses and functional deficits. By operating in the community from a premise of maintaining independence, however, assessments are more appropriately focused on strengths of the client and his or her informal support network. The ability of an assessment to identify strengths initially and then to proceed to identifying weaknesses that inhibit independence allows the assessment team to develop a care plan and assign a case coordinator to provide only those services that fill gaps in supporting a client's independence.

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 weaknesses of the client and the informal support network have been adequately assessed does the assessor begin to consider the site of care. In addition to the "total" solution of nursing home placement and the "minimum" solution of care in one's own home, many other potential sites of care should be considered as options in making a final assessment decision. New options are developed all the time, such as home sharing, supportive seniors housing, care cooperatives, and board and care homes. Consequently, long-term care assessment staff and case coordinators must keep up to date on new developments and options in their own communities to provide the broadest possible range of options to each potential client at the final stage of determining site of care.

Manitoba longitudinal data bases

The 1971, 1976, and 1983 samples and the identification of the panel members, who were 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 65 years of age and over, stratified on the basis of age, sex, and location. Simultaneously, each first sample respondent drawn was matched by a second sample respondent, identical to the first on the basis of age range, sex, location, and residential status (3). This technique of randomly assigning a second sample counterpart provided the means for maintaining appropriate sampling for statistical purposes while reducing the bias of sampling error in a high-risk population based on respondent loss for reasons of death, serious illness, migration, and changed residential status.

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 (4). The sample was drawn from persons 60 years of age and over who were resident in the community. A second matched sample was again drawn to minimize the loss of respondents.

In December 1982 a new stratified random sample of 2,854 Manitobans 60 years of age and over resident in the community was drawn for a third cross-sectional survey. This sample was also stratified on the basis of age, sex, and location, and again a matched second sample was drawn. The variables in the interviews are listed in figure 1.

At the same time, the records of the Manitoba Health Services Commission were searched for any participants in the 1971 and 1976 surveys who were still resident in the community in Manitoba, and identification information was printed for these panel members. The 1983 interviewers surveyed both members of the 1983 cross-sectional sample and community resident panel members. It was necessary to delay until 1984 the interviewing of panel members resident in care facilities, as it was not possible to identify those in residential facilities until after the community survey of survivors had been completed. During 1984 panel members resident in facilities and those in the community who had not been available for interviews in 1983 were surveyed. During 1983–84, 2,307 panel interviews were completed. Those who were reinterviewed, refused to be reinterviewed, could not be matched for administrative reasons, or were too ill to be reinterviewed in 1983–84 were deleted from the list of 1971 and 1976 respondents. 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. This search resulted in information on the date, cause, and place of death of 3,323 respondents.

By the end of 1985, the search for respondents in the 1971 and 1976 Aging in Manitoba surveys who either were living in Manitoba or had died in Manitoba was complete, and information had been obtained from or about all but 372 respondents, most of whom were believed to have left the Province. The records of the Canadian Mortality Data Base were then searched for these remaining respondents. The information

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
Religion

Psychosocial
Life satisfaction
Problems with visiting physician
Perceived income
Life Space Index

Assessed needs
Economic needs
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
Psychosocial needs

Family
Income
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[1]
Activities of daily living
Recent days in bed due to illness
Self-rated health
Number of conditions

Evaluated health
Mental status[2]
Specific disease prevalence

[1] Shanas E, Townsend P, Wedderburn D, et al. Old people in three industrial societies. London: Routledge and Kegan Paul. 1968.
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Figure 1. Aging in Manitoba survey variables: Canada, 1983

provided for this search included surname, given names, date of birth, country of birth, sex, spouse's name, last known year alive, last known place of residence, and last known marital status. The Canadian Mortality Data Base can provide information only on persons who have died in Canada or on Canadian residents who have died abroad. The names for those for whom the Canadian Mortality Data Base could not provide information, approximately 200, were forwarded to the Office of Old Age Security (OAS). This Office forwarded a letter from the study to the remaining participants in the 1971 and 1976 studies who were recipients of OAS, asking them to contact the researchers. Those who responded ($n = 72$) were interviewed in person, by telephone, or by mailed questionnaire, and the Mortality Data Base was searched again.

These processes yielded the final status shown in table A. Death has been confirmed for 3,556 of the respondents, including 61 for whom certificates have still not been secured. These include two deaths in Europe, three in the United States, and 17 in Canada outside Manitoba, as well as 39 who have died too recently for certificates to be secured through the Canadian Mortality Data Base. It is still anticipated that the certificates, with the exception of those for the two European deaths, will be obtained.

Interviews were conducted with 2,400 surviving panel members. It is of interest to note that death certificates have been secured for 270 of these respondents who have died since they were reinterviewed. The 89 refusals include 14 who were too ill to be interviewed and for whom no proxy could be located. Of the 28 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 seven respondents were lost during this process.

The longitudinal utilization portion of the study includes entirely service-based data. It contains all of the service consumption data based on the health services system. Included are all medical services, i.e., all of those services that are billed on a fee-for-service basis through the medical claims system, all hospital services, i.e., services in both acute and extended care

Table A. Number of persons who responded to the 1971 and 1976 Aging in Manitoba surveys, by record status and birth year: Canada

		Record status			
Birth year	*Original*[1]	*Death information*[2]	*Interviewed 1983–88*[3]	*Refused interview*[4]	*Lost*
Total	6,073	3,556 (61)	2,400 (270)	89 (14)	28
1912–16	405	75 (5)	318 (8)	11	1
1907–11	353	72 (7)	265 (25)	16 (4)	0
1902–06	1,517	626 (17)	854 (89)	33 (6)	4
1897–1901	1,315	733 (10)	558 (79)	18 (3)	6
1892–96	1,044	757 (11)	274 (41)	9 (1)	4
1887–91	771	661 (4)	102 (22)	1	7
Before 1887	668	632 (7)	29 (6)	1	6

[1] 1971—*n* = 4,803; 1976—*n* = 1,302, including 32 who were also interviewed in 1971.
[2] Numbers in parentheses indicate those for whom deaths are confirmed but certificates are not available (*n* = 61).
[3] Numbers in parentheses indicate those who have died since being reinterviewed (*n* = 270, which includes 144 males and 126 females).
[4] Numbers in parentheses indicate those who were too ill to be interviewed and for whom no proxy could be located (*n* = 14).

units, mental health and mental retardation facility and service consumption, and home care and personal care home services. (Personal care homes in Manitoba include all care levels; in the U.S. context, personal care homes are a combination of nursing homes, intermediate care facilities, and skilled nursing facilities.) In other words, if individuals have come into contact with the health service sector at all in Manitoba, and if they were in the original 1971, the 1976 followup, or the 1983 cross-sectional study, we have all their service consumption data. We also have the service consumption data on the spouses of our interviewees (5).

Therefore, the utilization data file includes 16,000 individuals—the original 4,803 cases (1971), the additional 1,302 cases (1976), and the 2,854 cases from 1983, plus their spouses. This file covers an 18-year timeframe, from 1970 through 1987. The major issue from the standpoint of dealing with these data is the sheer volume of data, in addition to a very large sample size. We have more than 500 interview items from the original sample, 96 from the second interview sample, and 250 items from the third sample, plus potentially as many as 30 separate interactions or data items on the individual within the health care system on each of 5,836 days. With a potential of up to 30 items of service information on each day of the 18 years, 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 allow us to deal and work with it without passing through the whole file every time (6).

Another important factor is that the 16,000 people have non-uniform-length utilization records. Everyone learns that in order to do analyses of this nature you should have uniform record size or uniform record length, but this cannot happen: That is, if someone did not get into the home care program, there are no home care data at all; hence, records cannot be uniform. Similarly, some people will be assessed three or four times within the personal care home placement file before they get into a personal care home, plus there will be subsequent assessments following placement. All of these conditions and others potentially vary the length of the record. We have had to develop rate variables in order to put all of these nonuniform data records into a uniform format for analysis. We have done this within three different categories. One of these categories is the data arranged in 3-month summary units rather than daily or monthly. A second category is based on the summary of data for 1 year. The third category is not a summary file at all; it is a locator file.

The locator file has been created because we lose some important data through summarizing to 3 months or a year; that is, we have maintained each of the 5,836 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 facility (a different value is used for each different type of facility); alive but not in Province; and, finally, dead. Because the files include the data on spouses, as well as on the individual respondents, the locator file contains information on whether the spouse is alive and living: Together with the respondent; in a facility (and what type of facility); out of Province; and, again, dead. The spouse, in a sense, really is not relevant to the use of the locator file, but by locating the spouse, we have more rapid access to locating some information in the summary files.

The interview materials were found to be extremely reliable and valid (7). The service utilization data have also been nonproblematic in terms of reliability and validity because these data were abstracted from fully functioning administratively maintained data systems. The reliability and validity of the data are part of the administrative responsibility of the system; consequently, as researchers using the data for secondary analyses, we do not have a problem (8). Given the volume of data involved in these analyses, it is very fortunate that we do not need to worry about reliability and validity.

Having identified some of the issues and concerns relative to having a very large sample, to having very detailed service records, and possibly to drowning in the data, we have found ways to compensate for these problems. In addition to the use of the timeframed summaries discussed above, we have operationally defined and developed or used summary variables; that is, wherever possible, we have constructed an index or a scale, as opposed to retaining multiple items. In this way, we have a new single-item variable rather than 10 variables. Researchers, particularly researchers who work with longitudinal data, are inveterate data hoarders. This characteristic does not seem to afflict cross-sectional analysts to the same extent that it does longitudinal researchers. Therefore, whenever summary variables are developed, all of the original items are retained on the raw data tapes. Consequently, should we wish to construct a different summary variable, we have the capacity to do so. From the standpoint of longitudinal studies, this produces an extremely important additional problem relative to coping with the data. Such studies usually begin with large volumes of data, then create both summary mechanisms for analytic purposes and summary variables. At the same time, each new data item must be added to the original tapes, which will also contain all of the original items. As the study progresses, it may be desirable or necessary to use different combinations of items and create new summary variables.

Episodes of care and outcomes

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, 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 episodes of care that we have analyzed are episodes of acute care hospitalization within the period of residence in a personal care home (9). Further, the major outcome variable that we have studied has been death (10–12). However, analysis of surgery as a specific case within acute hospitalization has begun (13,14).

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 (11,15). Further, outcomes of health service nonusers also can be studied within these combined data bases.

Research potential with community 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. It is my understanding that the National Center for Health Statistics will be undertaking a survey of home health care and hospices in the near future. As this effort moves forward, the possibility for even greater comparability and the opportunity for additional cross-national comparisons should increase.

The defining characteristics of personal care home entrants, which were referred to earlier, are the result of analyses of those whose health outcomes include institutional long-term care as opposed to or following community long-term care. We have also been able to look at a broader range of long-term care settings, i.e., own home, commercial apartments, seniors housing units, and residential care facilities, as well as personal care homes. All but the residents of personal care homes are consumers of community long-term care or home care. 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 these individuals differ from those who use institutional long-term care services? This information enables policymakers to develop more appropriate bases for fiscal decisions relative to long-term care over the next several years.

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Part VIII

Assessment of vitality and aging

Introduction

by Richard J. Havlik, M.D., Office of Planning and Extramural Programs, National Center for Health Statistics

I guess this position in the program order has disadvantages and advantages. We got a little break to go outside, but we got the postprandial lag. However, we will try to keep up the energy level and be vital! Also, I think we are at another disadvantage. I was home last night looking at the television coverage of Gorbachev's speech to the United Nations, and so we will try to duplicate that excitement as well. I think the other advantage of being late in the session is that we can build on what has gone on before and remind you about things, since it does all fit together.

I hope you are seeing a pattern here. Both yesterday and today you saw our logo with vitality and health promotion in the center, with the arrows going out to disability and disease. This interrelationship is, hopefully, something that we will keep in mind as we try to put all of this together in our session, and then tomorrow as well. I am going to call on some things that Dr. Cohen said—that is, the possible definitions of health, wellness, and vitality. He gave us some dictionary definitions, but I think he also indicated that we should not get hung up on the specific definitions. We will know vitality when we see it. Our presentations in this session will actually be about two studies in which we think we are going to see vitality and quality of life addressed.

In planning this session, there were two opposite sides to consider. One is the really immense effort that needs to be done in just defining the topic. Then there is being under the gun to come up with a protocol and to get something done that is very narrow. Sometimes when you have a broad topic it is easier to come right down. So we chose to be very, very specific in what we are going to discuss.

Chapter 24
Quality of life among the elderly in Veneto, Italy: A cross-sectional study

by Stefania Maggi, M.D., M.P.H., Department of Epidemiology, The Johns Hopkins University, and Institute of Internal Medicine, University of Padua; Trudy L. Bush, Ph.D., M.H.S., Department of Epidemiology, The Johns Hopkins University; and Giuliano Enzi, M.D., and Gaetano Crepaldi, M.D., Institute of Internal Medicine, University of Padua

Introduction

Italy, and all the developed countries, are aging. At the last census, in 1981, 13.2 percent of the total population was 65 years of age and over (1). According to the projections of the National Institute of Statistics, in the year 2021 elderly people will number about 11 million, or 20 percent of the total population (2). This increase in number and proportion implies an urgent need for collection of epidemiologic data in order to better understand the socioeconomic and health status of the elderly population.

The elderly are at higher risk of morbidity and disability and are in need of more medical services than younger individuals (3). The risks of isolation and of low social support are also higher for the elderly, and it is well documented that these factors are predictors of higher morbidity and mortality (4,5).

Measurements of health and of the quality of life in the older population are difficult to make, as these factors are affected by different definitions and methods of assessment and by cultural factors. I believe that a comprehensive assessment of the quality of life in elderly individuals should include four areas:

- Physical functioning.
- Cognitive functioning.
- Social functioning.
- Self-perceived health status.

Epidemiologic studies of the elderly in Veneto

Veneto is a region in the northeast of Italy with a total population of about 4,500,000, 13 percent of whom are 65 years of age and over (1). Veneto is considered representative of Northern Italy in terms of percentage of elderly in the total population, socioeconomic status, and health services availability and distribution in rural, suburban, and urban areas. In Padua, a city in Veneto, there is a large university with an active Department of Geriatrics and Gerontology that has coordinated previous epidemiologic studies of the elderly. One study done in this region is the assessment of the nutritional status of the population 65 years of age and over, a multicenter investigation supported by the National Council of Research. The objectives of the study were to assess nutritional and health status (by questionnaire and clinical visit) in order to identify subgroups of the elderly population with nutritional impairments (malnutrition, metabolic diseases). These individuals will then be targeted for therapeutic interventions. The data are being analyzed and will be published shortly.

Study on the quality of life among the elderly

In Italy, as in many other countries, there is little information on the quality of life among the elderly. Those studies that have been done often lack standardization and validation of the instruments. The project described in the rest of this paper will use standardized instruments to assess functioning. When possible, the reliability of the measurements and the validity of the instruments will be assessed.

Study design

The study design is cross-sectional and consists of a personal interview of 3,000 community-dwelling elderly persons living in 10 geographically different areas of Veneto. If a respondent is unable to be interviewed, a proxy will be asked to provide the basic information (demographic characteristics and functional status).

Objectives

The major objective of this study is to assess the quality of life of the elderly population. This includes measurement of functional capacity to perform physical activities and to participate in social events and assessment of cognitive status and self-reported health status. The information gathered will be used to plan health and social interventions.

Method

Each city or town in Italy has available a list of all the citizens resident in the area, with information on their date of birth, marital status, and current address. A random sample of individuals 65–84 years of age and all persons 85 years and over in the 10 defined areas of Veneto will be selected for the study.

The participants will be interviewed at home by a trained interviewer. The interviewers will be 30 physicians who are completing a residency in gerontology at the University of Padua. There are two reasons why we have chosen physicians as interviewers. First, residents in gerontology at the University of Padua are involved in clinical as well as in epidemiologic studies. In this project, particularly, the participants will be asked to do performance tests of physical functioning, and visual and hearing tests will also be administered. In case of falls or any other health problems during the tests, the interviewer will be able to intervene, avoiding medical and legal consequences. Second, in Italy, unlike the United States, we do not have nurses trained for health interview work.

There will be a 7-day training period for all of the interviewers. Random reinterviews will be done by the principal investigator to check the quality of the data collected. Moreover, each interview will be recorded on audiotape. At the end of each interview, the interviewer will fill in a form evaluating the respondents' attitude toward the questions and providing a general description of the living arrangements.

Questionnaire

The items used for the determination of the quality of life are:

- Demographic data.
- Living arrangements.
- Family composition and support.
- Social activities and support.
- Education and occupation.
- Retirement and income.
- Sensory impairments.
- Dental conditions.
- Chronic diseases.
- Fecal and urine incontinence.
- Sleeping problems.
- Activities of daily living (ADL's) and instrumental activities of daily living (IADL's)(6–8).
- Current health perception.
- Drug consumption.
- Alcohol and smoking habits.
- Health services use.
- Emotional and cognitive status (9,10).

Direct measurements to be made are:

- Visual acuity test.
- Maddox lens test.
- Hearing test.
- Physical performance test.
- Weight and height.

Validity and reliability

The respondents' self-assessment of the quality of life may raise questions about the validity and the reliability of the information gathered. However, our primary concern is not to obtain a detailed report on specific conditions in order to formulate a "diagnosis" but to assess the vitality of the elderly from the perspective of physical, mental, and social functioning. Even if it is impossible to validate each section of the interview, we will be able to validate information on the respondents' health status and on their physical functioning.

Several methods will be used to check the validity and the reliability of some of the self-reported information in a sample of participants:

- *Medical validation*—Physicians will be asked to provide medical information about health status, drug consumption, and hospitalization for the participants.
- *Clinical assessment*—Assessment of the visual and hearing functions will be done in a random sample to check the validity of the tests administered during the home visit.
- *Performance test*—During the interview, each individual will be asked to perform some physical function, such as walking, getting in or out of a chair, moving the arms above the shoulders, kneeling, or writing.
- *Interview of a proxy*—A proxy will be interviewed to assess the reliability of demographic data, family composition and support, social activities, physical functioning, drug consumption, and alcohol and smoking habits.

Conclusion

The assessment of the quality of life among the elderly is an important task in our aging societies. The information gathered by interview may have some shortcomings, but several studies, some of them very recent, have shown the accuracy of the data collected by questionnaire in the elderly to be quite good (11–14). Moreover, it has been shown that self-rated health status is a better predictor of mortality than a physician's assessment (15). The use of the methods previously presented for the validation of the self-reported information could also give more confidence in the accuracy of the data collected.

The study on the quality of life in the elderly population of the Veneto region will:

- Use standardized measurements for some relevant variable—ADL, IADL, Center for Epidemiological Studies–Depression (CES–D) scale, Mini Mental State—that allow comparisons with other major studies.
- Include a representative sample of the elderly population.
- Have staff responsible for the project who already have been involved in previous epidemiologic studies on aging.
- Provide common training for the interviewers.
- Work with international consultants from The Johns Hopkins University and the National Institute on Aging.

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Chapter 25
Physical, social, and mental vitality

by Richard J. Havlik, M.D., Office of Planning and Extramural Programs, National Center for Health Statistics

Introduction

"Vitality—Exuberant physical strength or mental vigor: A person of great vitality" (1).

The image of older persons is changing in both the popular press and the scientific literature. Articles in magazines and newspapers now emphasize the positive aspects of growing old rather than only the negative ones. For example, pictures of jogging older men are shown, as are aging chess players with grandchildren looking on (2). Also, reports are appearing about sexual aspects of the lives of older persons (3). This lay notion has been complemented by scientific inquiry using the concept of "successful aging" (4). The term "successful" is in contrast to usual or normal aging, which may be affected adversely by the environment or personal habits. These potentially negative factors could be reversible to some extent. "Productive aging" emphasizes the identification and encouragement of work equivalents in older persons, such as volunteerism, unpaid child care, or other such activities, but the concept also considers broader beneficial aspects of aging (5).

The idea of extolling a positive side to health and life experience is not a new one, but the application to older persons may be. The concept that health is a continuum from disease and disability at one extreme to maximal well-being at the other was written into the World Health Organization's definition of health as not only the absence of disease or infirmity but a state of complete physical, mental, and social well-being (6). The measurement of well-being, especially the mental or psychological aspects, has been challenging to investigators. Terms such as "happiness" are difficult to define or measure (7). Some investigators have raised an important question as to whether much of self-reported well-being might be considered a personality trait and therefore not susceptible to short-term manipulation. For example, when a well-being measure was applied to a nationally representative population of older persons at two points in time, there was minimal change in question responses with age or with time (8). Presumably, even in the face of the onset of diseases associated with aging, the measure of well-being did not change substantially. Those who scored high at baseline were commonly the same ones who scored high 10 years later. Some authors have suggested that health-related quality of life is a more appropriate focus of survey research (9). However, besides emphasizing morbidity measures, this construct includes, among other factors, social, psychological, and physical functioning as they might affect health.

The problem of describing psychosocial well-being or vitality becomes magnified when considering strategies for cross-national studies of older persons. There may be cultural differences in such concepts that must be addressed (10). However, cross-national studies offer the potential to measure true differences between groups of people and possibly to identify differences in other associated factors. One study approach is to take a concept such as vitality, translate relevant questions into different languages, and use similar interview techniques. However, care must be taken, because questions and techniques appropriate in a particular cultural setting may not be appropriate in another (11).

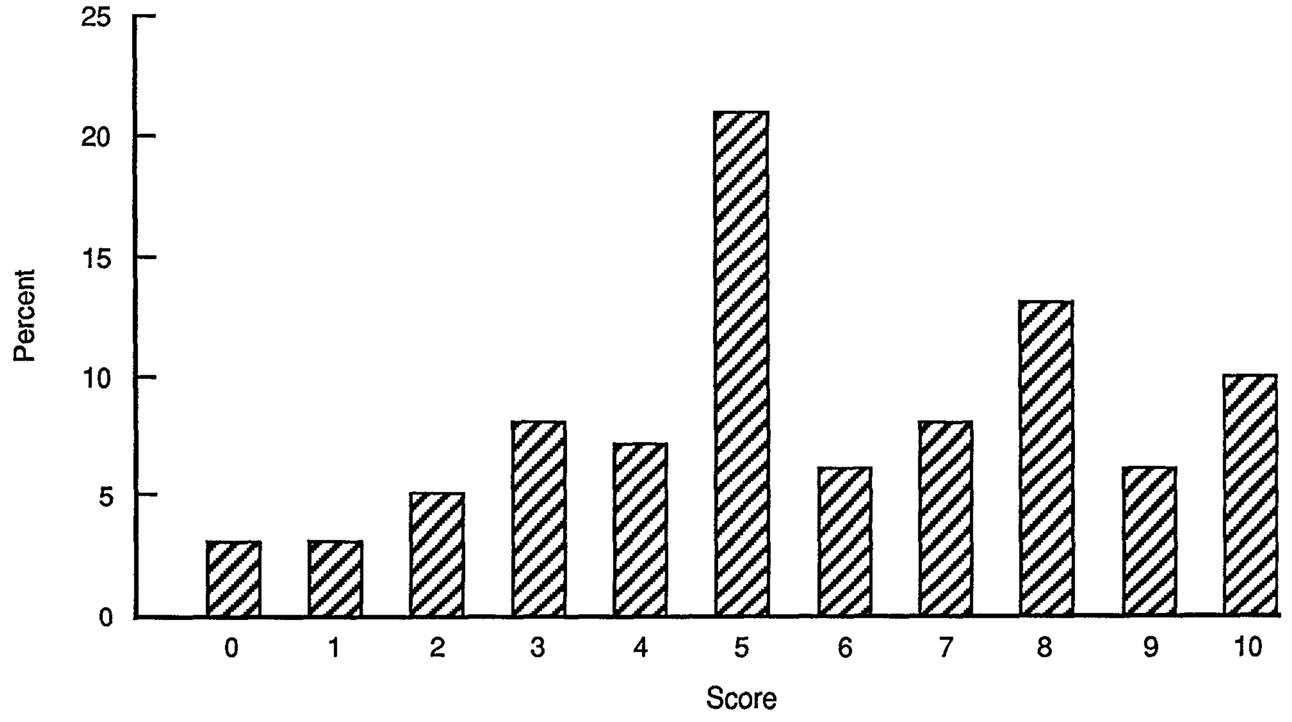
As an initial strategy it is possible to identify appropriate questions within the data systems of the National Center for Health Statistics (NCHS) for which comparable international data might be available. For example, some survey participants have been asked directly the following global question: "How much energy, pep, or vitality have you felt during the past month? Rate yourself from the extreme of 0 or no energy at all, listless, to very energetic or dynamic, or 10." This question was administered to the First National Health and Nutrition Examination Survey Epidemiologic Followup Study population in 1982–84 (12). Subjects were interviewed in their homes, and because of the original cohort's structure, the oldest members could be only 86 years of age. Figure 1 shows the distribution of responses for both sexes combined. Generally, more older people rate themselves on the positive side (scores of 7–10) than on the negative end of the continuum. Almost one-third are in the upper range. In other analyses, men tend to rate themselves higher than women do at older ages. If we compare this subpopulation to the group ages 32–64 years, there are fewer positive responders in the older group.

Clearly, for international comparisons, investigators must be much more specific in the entities they are attempting to study and use for comparisons. In fact, it would be wise to take a pragmatic approach and suggest questions that are currently in use and quite simple rather than complicated. However, it is evident that there is complexity in defining vitality. For example, regular physical activity can become fitness or physical vitality, which can lead to positive well-being, increased social function, and mental vitality. For discussion purposes, therefore, it may be best to disaggregate the general concept of vitality into its various components: Physical vitality first, then social vitality, and finally mental vitality.

Physical vitality

Background

There may be positive health effects for older persons who participate in regular physical activity. For example, walking at least 1 mile three times per week appeared to be associated with diminished fracture risk in a prospective study in Florida (13). In a California community, more than 90 percent of those 50–93 years of age reported some form of exercise in the previous 2-week period (14). Although physical



SOURCE: National Center for Health Statistics. National Health and Nutrition Examination Survey I Epidemiologic Followup Study. 1982–84.

Figure 1. Percent of persons ages 65–86 years, by self-rating of energy, pep, vitality in past month on a scale of 0–10: United States, 1982–84

activity and exercise are often used interchangeably, exercise usually connotes the improvement or maintenance of physical fitness (15). Physical vitality would be at this higher end of the performance continuum.

Representative questions and NCHS data

In the National Health Interview Survey (NHIS) Supplement on Aging in 1984, subjects were asked about difficulty in walking one-quarter of a mile or two to three blocks (16). About 20–25 percent of those ages 65–74 years and 50–60 percent of those 85 years of age and over had difficulty (table A). This distance translates to about 400 meters in Italy or The Netherlands, and a similar question is in the Veneto, Italy, study and the Health Interview Survey of The Netherlands. It is a very powerful predictor of health outcome 2 years later. One would like to measure individuals accurately along the continuum from low to high activity. However, there is the problem of self-selection, because medical problems such as pain, shortness of breath, or excessive fatigue might preclude walking.

Considering the positive side of the vitality continuum, the Health Promotion and Disease Prevention (HPDP) survey asked a question about activity in the past 2 weeks. Among those 65 years of age and over, 41 percent reported walking for exercise (17). Popular types of exercise for older persons were the following: First, walking for exercise; second, gardening; and third, calisthenics or general exercise. Such exercise is clearly on the opposite end from difficulty walking one-quarter of a mile. Certain questions about regular exercise were asked only of those participants in the 1984 Supplement on Aging capable of answering for themselves. There were rules for authorizing the use of a proxy. The assumption was made that if the individual needed a proxy, such as a spouse or family member, it was unlikely that the individual participated in regular exercise. At all the older ages, except in the oldest old females, about 25 percent reported exercising regularly (table B). By way of comparison, in the HPDP survey, 29 percent of those 65 years of age and over reported that they exercise or play sports regularly.

Table A. Percent of persons 65 years of age and over who have difficulty walking 1/4 mile (2 or 3 blocks or 400 meters), by age and sex: United States, 1984

Sex	65–74 years	75–84 years	85 years and over
		Percent	
Female	24.5	39.4	61.5
Male	21.9	29.1	48.3

SOURCE: National Center for Health Statistics. Supplement on Aging, National Health Interview Survey. 1984

Table B. Percent of persons 65 years of age and over who exercise regularly, by age and sex: United States, 1984

Sex	65–74 years	75–84 years	85 years and over
		Percent	
Female	27.7	23.7	15.4
Male	30.1	26.0	23.1

SOURCE: National Center for Health Statistics. Supplement on Aging, National Health Interview Survey. 1984.

Methodological issues

It is likely that the definition of exercise will vary between the United States and other countries, such as Italy. There are similarities and differences between physical activity and exercise. Generally, physical activity is bodily movement produced by skeletal muscles that results in energy expenditure. Exercise goes one step further because the bodily movement is done to improve or maintain one or more components of physical fitness (15). Such definitions of physical activity and exercise would need to be operationalized in various countries.

A general survey question is perhaps the easiest to ask but the most difficult to quantify. In particular, after you get beyond frequency and duration to intensity of exercise, this quantification becomes difficult. For example, one might have to time walking to estimate speed. This would have to be done in various countries, because the speed at which people walk may vary among countries. Because of the high prevalence of reported walking, it may be necessary to improve intensity estimates to obtain better differentiation in the population of older people.

As with any survey instrument, reliability and validity of even the simplest questions need to be assessed. Reliability is usually measured in a test-retest setting. As a routine part of NHIS, the U.S. Bureau of the Census reinterviews participants (18).

For the HPDP survey, there were about 1,300 individuals with repeat interviews. Unfortunately, the analysis was not stratified by age, but the general results are of interest. Four of the exercise questions were repeated within approximately the same month. Although the Census Bureau used special statistical tests, generally the results indicated that such exercise questions were in the moderate to high inconsistency range. Among the questions, "Do you exercise or play regularly?" scored slightly better than those in which more detailed responses were necessary. There is no doubt that care will have to be taken in interpreting results with questions of low reliability.

However, validity measures might be more important and more difficult to complete. The validation criterion, or "gold standard," would need to vary depending on what was being measured. If cardiovascular fitness were measured, then some oxygen consumption studies would be necessary. More appropriately for a walking survey, it may be necessary to use a pedometer or an inshoe step counter. Performance tests for walking are part of the current National Health and Nutrition Examination Survey III.

Social vitality

Background

Measures of social support and social functioning have been used in epidemiologic studies as variables that predict a favorable mortality or morbidity outcome (19). It has been suggested that this concept needs refinement and focus for use with older persons by emphasizing, for example, questions specifically about social networks (20). However, in the present context of possible indicators of social vitality, such measures are not used as descriptors but as outcomes themselves. They are measures of important family and social contributions as well as social activities that could represent a construct for social vitality. Social vitality has been described in various terms, including a description of types of social organizations or social life worlds, e.g., collecting stamps or listening to music at one extreme and formal work organizations at the other (21). Within such social organizations, there might be a hierarchy that represents at one end social dependency, as exemplified by consuming things or receiving services, versus evaluating and goal setting at the higher level. Thus, judging ballroom dancing could be an indicator of social vitality.

Representative questions and NCHS data

In the Supplement on Aging, a nationally representative sample of persons ages 55 and over were asked a special battery of questions beyond the usual NHIS core questions (16). They are consistent with the Social Health Battery developed by Rand Health Insurance Corporation investigators (22). However, the timeframe of reference is the past 2 weeks rather than month, as in the Rand instrument. For example, during the past 2 weeks, 80–86 percent telephoned a friend or relative (figure 2). Also, about 50 percent attended church or synagogue or related activities, and about 25 percent went to a show or movie, sports event, club meeting, class, or other group event.

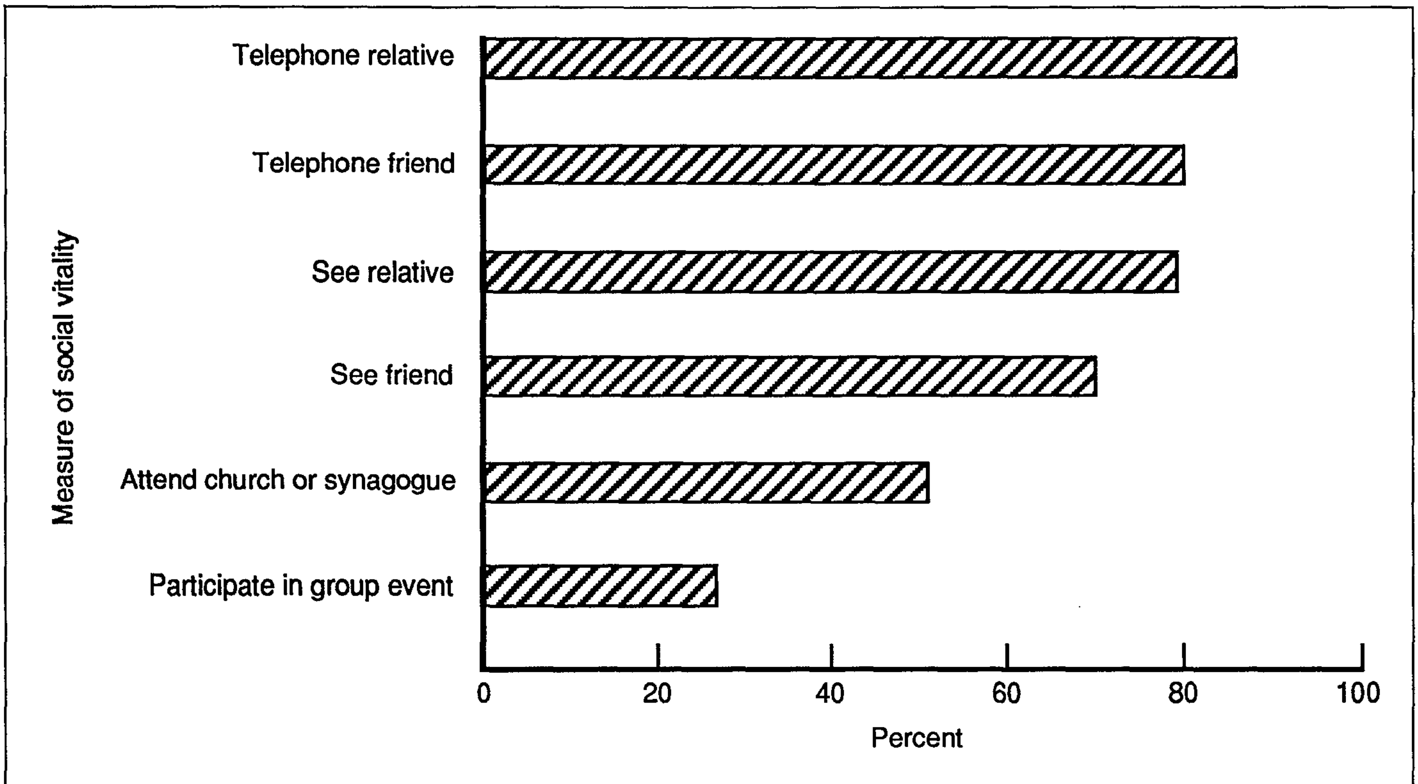
Methodological issues

Donald and Ware have done reliability studies on similar questions in a younger population (22). Over a year's time there was a test-retest correlation of about 0.6–0.7. More detail and other commentary are included in (22), a valuable reference source. With such questions, there should be measures of construct validity or the consistency of a number of questions in the social area, not just a single question. In addition, family contact should probably be confirmed with the children. Also, it needs to be determined who initiated the contact. Cross-sectional studies between the United States and countries, such as Italy, with known strong family orientation, large families, and religious traditions would have to be interpreted carefully to avoid a cultural bias in comparisons.

Mental vitality

Background

There is potential overlap among the related concepts of cognitive functioning, intelligence, psychological well-being, mental well-being, and mental vitality. Even quality of life and satisfaction are interrelated. A general well-being schedule was developed for use with national health surveys (12). "Pep or



SOURCE: National Center for Health Statistics. Supplement on Aging, National Health Interview Survey. 1984.

Figure 2. Percent of persons 65 years of age and over, by selected measures of social vitality during the past 2 weeks: United States, 1984

vitality" is one of the 18 factors that make up the general well-being scale. However, there is a vitality score that combines the question on pep or vitality with "waking fresh and rested," in contradistinction to "feeling tired and worn out." Practically, there could be overlap with the presence of underlying depression. On the opposite pole, there are the concepts of happiness, the difference between positive and negative affect, and the presence of high morale. Because of the complex nature and large number of potential questions, a summary of various approaches is helpful (22). The use of extant questionnaires with known validity and reliability is recommended.

Representative questions and NCHS data

In the context of the NHANES I Epidemiologic Followup Study, the National Institute of Mental Health Center for Epidemiological Studies–Depression (CES–D) scale was administered (12). Although the CES–D consists of 20 questions directed at manifestations of depression, 4 of the questions involve positive rather than negative factors. Subjects are asked if they can rate their past week's experience on feeling happy, feeling as good as others, enjoying life, and feeling hopeful about the future. In older persons, 50–63 percent reported positive feelings for 5–7 days per week (table C). When older persons are compared

Table C. Percent of persons ages 65–86 years who had positive feelings in the past week based on the Center for Epidemiological Studies–Depression (CES–D) scale, by number of days and type of positive feeling: United States, 1982–84

Positive feeling	*Less than 1 day*	*1–2 days*	*3–4 days*	*5–7 days*
	Percent			
Feeling happy	12.1	8.7	11.7	57.2
Feeling hopeful about the future	18.3	10.4	11.3	49.6
Feeling as good as others..............	16.7	4.8	4.8	63.3
Enjoying life	12.1	5.6	8.6	63.1

SOURCE: National Center for Health Statistics. National Health and Nutrition Examination Survey I Epidemiologic Followup Study. 1982–84.

with younger ones on this measure, responses are slightly lower in the older group, but not markedly so. Men are generally more positive than women, except for the category "feeling as good as others." The reasons for these differences are not apparent.

Methodological issues

If problems with international comparisons in physical and social activity can be anticipated, problems with mental vitality will be even more severe. This is because of the potential effect of culture and language that could distort comparisons. Using only recognized instruments that have been validated in various countries is a preferred strategy. For example, the CES–D questionnaire has been translated into a number of languages (23). Specifically, validity studies for depression and replication of the scaling have been done in Northern Italy (24). Clearly, there are other questions related to mental vitality that could be asked. There are higher order mental functions, including creativity, not just in the arts but in business and in science. Education for the Third Age, a program existing in France and elsewhere in Europe, emphasizes learning opportunities for older persons. A comparable program, Elderhostels, is found in the United States. In the latter program, older persons study at universities during the summer. If participation in such programs becomes common enough, specific questions could be developed. Finally, at least in the popular press, some have suggested that sexual function represents a good indicator of not only mental vitality but general vitality, including physical and social aspects (3).

Conclusions

The concepts of quality of life, general well-being, productive aging, and successful aging are topics of intense interest in the lay and scientific communities. There are a variety of possible constructs for scientific inquiry addressing the higher end of functioning in older persons. Although there is a natural resistance to adding yet another approach to the many existing ones, a natural extension of the World Health Organization definition of health is the construct of physical, social, and mental vitality. Although well-being or vitality must be considered a holistic entity, there should be subdomains that interrelate. Individuals could have a different mix of the physical, mental, and social components, but more descriptive data are necessary.

In order to contemplate the study of vitality in countries with differing cultures and languages, the use of well-validated and reliable measures is mandatory. Although the approach outlined (of using available questions and data) appears straightforward, it will still be necessary to evaluate various methodological issues in participating countries. Such a strategy would allow a start to the problem of defining vitality.

If successful, such an approach might provide valuable data that would allow studies of different levels of vitality and further allow the identification of correlates and causes. This information might then lead to interventions which, if successful, could lead to changes in policy and a better life for older Americans.

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Chapter 26
Measurement of vitality in the Americans' Changing Lives study

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Introduction

Efforts in the medical tradition to conceptualize physical and mental health define good health as the absence of symptoms, impairments, and illness conditions. The definition by the World Health Organization (WHO) (1) suggests that good health is more than the absence of disease and infirmity—namely a state of complete physical, mental, and social well-being. In other words, persons who do not suffer any known illness condition or impairment can exhibit quite a range of levels of functioning. For example, older people who compete in athletic events, hold full-time responsible employment positions, or contribute their expertise to political or social causes are quite different from fully retired, largely passive and sedentary older persons, even if the latter are healthy by traditional definitions. The former, who function at a high level of competence, exemplify what is meant by vitality or successful aging and what is intended by the WHO definition of good health.

The concept of vitality serves to refocus the study of health in older age, which for too long has been focused exclusively on those older adults whose failing physical health and mental competence make their daily functioning difficult and number their days. At the same time, the study of those older adults who do exceptionally well has been neglected and, consequently, it is not well understood what differentiates them from those who do "just average." The point is that the conceptualization of health needs to span the entire range from severe impairments to high levels of competence.

Two observations underscore the advantage of a broad definition of health. First, the projections are for a longer lived and, some believe, healthier older population (2,3). According to this view, major chronic conditions and impairments will have later onsets and, if those are the major definers of illness and health, a larger proportion of the older population will be termed "healthy." This suggests that it might prove fruitful to examine more closely those termed "healthy," to explore the range of functioning among them, and to investigate predictors and trajectories for those who function exceptionally well.

Second, the description of the progression from health to death is a research objective of prime importance (4). Obviously, health starts to deteriorate in subtle ways long before major symptoms of chronic conditions and impairments become evident to individuals and their physicians. Identifying and tracing early indications of deteriorating health will provide critical information about the nature of the progression from health to death. Even slight declines in vigor and speed of functioning or in the extent and breadth of social and leisure activities may be forerunners of more traditionally defined health problems.

This conceptualization of vitality will be illustrated here by presenting some measurement efforts from the study entitled Americans' Changing Lives (ACL) and by displaying some of the data collected with those measures. The ACL is a program project at the University of Michigan's Survey Research Center that focuses on productivity, stress, and health across the lifespan. It is sponsored by the National Institute on Aging (NIA) and directed by James House. The major data source is a national survey of about 3,600 noninstitutionalized adults 25 years of age and over who were originally interviewed in 1986 and reinterviewed in early 1989. The survey oversampled persons 60 years of age and over, and thus includes more than 1,600 older persons. Only data from ACL respondents 60 years of age or over interviewed in 1986 are used in this paper.

Measurement

Measurement of physical health

Some of the traditional and widely used measures of physical health, such as scales of the ability to perform basic activities of daily living (ADL's) or of chronic conditions, yield very skewed distributions toward the healthy extreme in the community-residing older population. In the ACL study, a series of questions were asked to measure functional impairment. They included a question on bed- or chair-boundness, one on difficulty bathing, one on difficulty climbing stairs, one on difficulty walking several blocks, and one on difficulty with heavy housework. Respondents who reported no difficulty with any of these activities were termed not functionally impaired, those who reported difficulties with heavy housework only were termed a little functionally impaired, those who reported difficulties with climbing stairs and/or walking several blocks were termed modestly functionally impaired, and those who reported difficulty with bathing or that they spend most of the day in bed or a chair were termed severely functionally impaired. Also asked were questions about a number of chronic conditions. The full list included arthritis or rheumatism, lung disease, high blood pressure, heart attack or heart trouble, diabetes or high blood sugar, cancer or malignant tumor, foot problems, stroke, broken or fractured bones, and urine loss. The response distributions for ACL respondents 60 years of age and over are indeed rather skewed: About two-thirds of all respondents report no functional impairment, and over 40 percent report no chronic condition or only one.

A further differentiation among those who report no ADL difficulties, or report no chronic condition or only one, is achieved by asking for a self-rating of physical health and for a self-assessment of functional impairment because of health problems. Questions like these are standard questions in health surveys. The ACL data show that these questions do indeed provide further differentiation of the respondents termed healthy according to the questions on functional impairment and chronic conditions, because they show considerable variation among respondents who report no impairments or at most one chronic condition (table A).

Table A. Percent distribution of persons 60 years of age and over by self-assessed health and activity limitation, according to functional limitation and chronic conditions: United States, 1986

	Functional limitation		*Chronic conditions*	
Measure	*None*	*Any*	*0–1*	*2 or more*
Health status		Number		
Unweighted total	1,019	650	618	1,051
		Percent distribution		
Total	100	100	100	100
Excellent	14	3	20	4
Very good	44	18	46	26
Good	29	25	23	31
Fair	12	37	10	28
Poor	1	17	1	11
Activity limitation because of health problems		Number		
Unweighted total	1,019	650	618	1,051
		Percent distribution		
Total	100	100	100	100
Not at all	68	12	70	34
A little	14	14	14	14
Some	14	28	10	25
Quite a bit	3	23	3	15
A great deal	1	23	3	12

Based on the same rationale, three questions about the frequency of working in the yard, engaging in active sports or exercise, and taking walks were included. These measures are typically referred to as risk factors, or health-promoting behaviors. The frequencies with which these activities are performed may also be used to further differentiate among healthy respondents because they show considerable variation among those respondents without any functional limitations or at most one chronic condition (table B).

However, the measures of physical activities illustrate a common problem with broadening the measurement of health: It is difficult to establish the capacity for challenging activities that might be considered reflections of a vital person because, unlike bathing and eating, many of the more demanding physical activities, such as sports and exercises, are performed by only a subset of all respondents. Persons who for reasons of personal choice or role prescriptions do not perform the activity in question will often be unable to report how much difficulty they would have performing it. In the ACL survey, the only measured function that was considered relatively physically demanding, yet is performed by most adults in this society, is heavy housework (such as shoveling snow or washing walls). The capacity for heavy housework was used to establish the mildest level of functional impairment in the ACL measure. If capacity cannot be measured because of a lack of relevant experiences, one is often forced to measure performance—such as when one uses measures of physical activity. See Branch (5) for further discussion of this point.

Table B. Percent distribution of persons 60 years of age and over by physical activity, according to functional limitation and chronic conditions: United States, 1986

	Functional limitation		*Chronic conditions*	
Physical activity	*None*	*Any*	*0–1*	*2 or more*
Yardwork		Number		
Unweighted total	1,018	648	616	1,050
		Percent distribution		
Total	100	100	100	100
Often	55	31	54	41
Sometimes	20	15	19	18
Rarely	9	10	8	10
Never	16	44	19	31
Sports and exercise		Number		
Unweighted total	1,018	647	617	1,048
		Percent distribution		
Total	100	100	100	100
Often	32	14	33	20
Sometimes	16	8	15	12
Rarely	19	11	17	15
Never	33	67	35	53
Walks		Number		
Unweighted total	1,018	649	617	1,050
		Percent distribution		
Total	100	100	100	100
Often	47	26	45	36
Sometimes	22	20	21	21
Rarely	17	18	17	17
Never	14	36	17	26

The fact that measures of self-reported health and physical activities can provide additional differentiation among elderly people with no functional impairments or chronic conditions is a necessary but not a sufficient condition to establish usefulness as measures of physical vitality; validity as measures of physical health status also needs to be established. Correlations of the self-reported health and activity measures with the measures of functional impairment and chronic conditions speak to the former's validity. In the ACL study, these correlations range from 0.25 to 0.60, except for correlations between the number of chronic conditions and the frequency of physical activities, which are in the 0.10's to 0.20's. These findings are consistent with other reports (6) and provide empirical support for the validity of self-reported health and activity measures as measures of physical health status. The validity of these measures has also been suggested by their relationship to the timing of subsequent mortality and to physician assessment (7,8).

Measurement of mental health

Mental health measures include measures of affective mental health, indexed by concepts such as depression or psychological well-being, and of cognitive functioning, indexed by concepts such as intelligence and cognitive impairment.

A similar argument may be made for cognitive functioning as that just presented for physical health. Traditional measures for cognitive status in older age are the Mental Status Questionnaire (MSQ) (9) and the Mini Mental State Examination (10). These measures identify major cognitive impairments of orientation and memory. However, in the absence of such impairments, these measures do not further differentiate cognitive functioning in terms of high functioning. In the ACL, one-third of all respondents made no mistakes on a slightly abbreviated version of the MSQ; another third made only one mistake. According to the instructions, respondents who give zero or one incorrect answer to a total of seven questions would be considered cognitively intact. Accordingly, at least two-thirds of all older ACL respondents are not cognitively impaired. Yet, aside from this fact, the level of their cognitive functioning has not been established.

Tests of general intelligence are designed to provide differentiation among the general adult population, who for the most part have no major cognitive impairments. In the ACL, we included a brief test of verbal aptitude from the Lorge-Thorndike scale (11). The test consists of a sentence completion task with six items. This represents a subset of one of the subscales of the Lorge-Thorndike, or what, according to Horn (12), may be called a test of crystallized intelligence. Respondents who made at most one mistake on the MSQ varied considerably on the brief Lorge-Thorndike subtest (table C). In other words, those who do not have even a minor cognitive impairment according to the MSQ still show quite a range of verbal aptitude according to the Lorge-Thorndike subtest. Nevertheless, the two tests seem to measure a similar underlying concept, because they are significantly correlated with each other ($r = 0.35$).

Traditional scales of affective mental health probe for symptoms of mental distress and often provide cutoff points beyond which a mental health problem is considered clinically significant. In line with the argument developed so far, such measures of affective mental health have at least two limitations. They do not provide for a differentiation in the positive direction of happiness and elation because they include only items of distress, and they further limit the differentiation by using a cutoff that reduces the overall score to a dichotomy.

Table C. Percent distribution of persons 60 years of age and over by Lorge-Thorndike subtest score, according to Mental Status Questionnaire score: United States, 1986

	Mental Status Questionnaire score		
Lorge-Thorndike subtest score	*All correct*	*1 mistake*	*2 or more mistakes*
		Number	
Unweighted total . . .	548	544	577
		Percent distribution	
Total	100	100	100
All items correct. . . .	4	3	1
1 mistake	11	8	7
2 mistakes	29	23	19
3 mistakes	44	48	34
4 mistakes	9	13	21
5 mistakes	1	2	5
6 mistakes	2	3	13

Table D. Number and percent distribution of persons 60 years of age and over by satisfaction with life and depression: United States, 1986

Measure	*Percent distribution*	*Unweighted total*
Satisfaction with life		
Total	100	1,653
Completely satisfied	32	492
Very satisfied	41	668
Somewhat satisfied	21	368
Not very satisfied	5	95
Not at all satisfied	1	30
Depression		
Total	100	1,659
3.00–2.51 (most)	1	15
2.50–2.01	4	91
2.00–1.51	23	422
1.50–1.01	57	901
1.00 (least)	15	230

More recent scales have addressed these limitations. First, several scales have incorporated at least some positively worded items that array respondents between a neutral and positive extreme, rather than between a neutral and a negative extreme. An example is the often-used Center for Epidemiological Studies–Depression (CES–D) scale, which contains four positively worded items among its 20 items. Probably the most systematically developed scale in this regard is Bradburn's Affect Balance Scale (13), which contains a balanced set of positively and negatively worded items. Bradburn has demonstrated that the positively and the negatively worded items form two dimensions that are independent of each other and relate differentially to various predictors. However, more recent work has suggested that the well-replicated independence may be a function of the dichotomized response scale and that a frequency response scale would yield negative correlations between positive and negative affect (14).

Another approach, which is based on the assumption of one dimension ranging from a positive to a negative pole, is the measurement of satisfaction or quality of life developed at the Institute for Social Research (15,16). Satisfaction with life in general and with several specific life domains are probed using scales ranging from "completely dissatisfied" to "completely satisfied" or from "terrible" to "delighted." For more detail on the validity of these measures, see the above-mentioned references. For more detail on the validity of the CES–D scale with the general population, see Radloff (17); with older adults, see Himmelfarb and Murrell (18).

Secondly, the CES–D—as well as other scales—can also be used as a continuous variable by summing or averaging responses across items and utilizing the full range of scores, rather than by using a somewhat arbitrary cutoff point. This was done in the ACL, where an abbreviated version of the CES–D depression scale (19) was included, along with several satisfaction questions. Response categories were (a) hardly ever, (b) some of the time, and (c) most of the time, and scores were averaged across the depression items. The frequency distributions for both types of measures are shown in table D.

Measurement of social functioning

Alternative measures of physical and mental health discussed so far correspond fairly closely to those concepts, while at the same time providing more variation toward the healthy extreme. However, in moving from illness and impairment to health, the concepts become broader. Concepts such as competence, successful aging, effective functioning, and vitality, which are often used to describe the positive extreme of functioning, suggest a blend of social, mental, and physical functioning. The example of the measure of instrumental activities of daily living (IADL's) will illustrate this point. The IADL measure (20) is generally regarded as a measure of more subtle functional impairment than the measures of ADL. The IADL measure includes activities such as managing money, making a telephone call, or cooking a meal. All are activities that are not restricted to narrowly defined physical health but include social and cognitive functioning and competencies.

In the ACL, we have made an effort to measure social functioning from two different but intersecting perspectives. First and foremost, we have tried to conceptualize and measure the extent of productive activities—that is, activities that generate goods or services. Special emphasis was placed on "nonwork" activities that occur outside of paid employment and the conventional market economy, although paid employment was also included. We view productive activity to be at the very core of effective social functioning: It indicates the contributions an individual makes to maintaining the functioning of this society. It derives from the social-gerontological concern with social and other activities of older adults and with socially useful roles that can impart a sense of usefulness at a stage of life when paid work is often no longer a major activity (21). Second, we also included in the ACL study measures of interpersonal contacts that intersect—and occasionally overlap—with measures of informal productive activity. Although it is not quite as obvious that high social activity implies high vitality as it is that good physical, affective, and cognitive functioning do, the general public considers social and role functioning to be important indicators of health (22).

To describe the measures briefly, the ACL questions on productive activities cover three main domains: (a) paid work either in the regular or irregular economy; (b) unpaid work at home (i.e., housework, child care, and home maintenance) and unpaid work for organizations; (c) informal help to friends, neighbors, and relatives. Performance of these activities (rather than capacity) is measured in the form of hours spent in each of nine productive activities during the past 12 months. The productivity of these activities has been demonstrated by various methods (23). A sense of the validity of the measures was obtained by comparing the estimates of average hours spent by various subgroups with published information from similar and dissimilar (i.e., time budget) measures (24).

The number of hours that older adults spend in the various productive activities is shown in table E. The response distributions show considerable variation, with larger variations in unpaid work and helping others, smaller variations in paid work. This confirms one of the basic hypotheses that led to our interest in productive activities: Paid employment is not a good indicator of productive involvement among older adults because retirement at a certain age is largely societally regulated. If one broadens the measurement of productive activities by including unpaid work and helping others in the manner suggested here, one finds that many older persons are quite productive (24).

Table E. Number and percent distribution of persons 60 years of age and over, by hours of productive activity in past 12 months: United States, 1986

Hours of productive activity	*Percent distribution*	*Unweighted total*
Paid work		
Total	100	1,669
None	75	1,263
1–200	5	77
201 or more	20	329
Unpaid work		
Total	100	1,669
None	3	46
1–200	10	131
201–500	20	293
501–1,000	27	495
1,001–1,500	19	327
1,501 or more	21	377
Helping activities		
Total	100	1,669
None	24	456
1–200	63	1,005
201 or more	13	208

Correlations between productive activities and the two physical health measures are generally lower than those reported before, confirming the impression that the concepts of physical and social health are different.

The ACL questions on interpersonal contacts (or social integration) include three items on the frequencies of interacting with others on the telephone and in person and of attending meetings of groups and organizations. Response distributions among older respondents again show some variation (table F). Again, however, correlations between physical health and social activities are generally low, rarely exceeding 0.10, suggesting little similarity between the concepts.

International comparisons

Quite obviously, without a special data collection, international comparisons will depend on the availability of relevant information. Several possible data sources are discussed in this publication. Others may be available.

Several considerations, in addition to general issues of data quality, are important when examining

Table F. Number and percent distribution of persons 60 years of age and over, by frequency of social activity: United States, 1986

Frequency of social activity	*Percent distribution*	*Unweighted total*
Telephone conversation		
Total	100	1,665
Once a day or more	52	900
Once a week or more	38	582
Less than once a week	6	110
Never	4	73
Visits with friends		
Total	100	1,668
Once a week or more	56	900
Once a month or more	29	473
Less than once a month	10	192
Never	5	103
Attending meetings		
Total	100	1,666
Once a week or more	24	404
Once a month or more	27	443
Less than once a month	7	126
Never	42	693

data sets for international comparisons. First and foremost, surveys must include large enough numbers of older persons to allow for reliable results. Ideally, surveys cover the entire older population of a nation and use a scientific sample in order to represent the population within well-defined error margins. If they do not cover the entire older population, they should cover comparable subpopulations, such as the community-residing population, women, or metropolitan elderly, to name just a few examples. Local surveys or other surveys of noncomparable subgroups yield statistics in which national comparisons are confounded with other differences between the specific populations.

Survey procedures must also be comparable. While the wording of the questions is the most obvious example, the mode of data collection, the rate and handling of survey nonresponse, the training of interviewers, and missing data can introduce further confounders if they are not comparable.

Although identical measures across nations may suggest confidence in the validity of the comparisons, such confidence often may not be justified for the measures of vitality suggested here. In order to maintain equivalence of concepts across nations, different measures may have to be used (25). Consider the following examples from the conceptualization of vitality. Because of laws and/or customs that regulate behaviors such as employment, heavy housework, walking, or yardwork, these behaviors may not be pure expressions of individual vitality. For example, depending on the retirement laws in a particular country, larger or smaller numbers of older adults will be gainfully employed. Walking and yardwork, which are among the most popular physical exercises for older adults in this society (26), may not have many followers in other societies. Likewise, interpersonal contacts may assume very different forms in different societies depending on the geography, architecture, lifestyle, economy, and customs of a society.

Cultural equivalence of concepts becomes even more difficult when concepts are relatively abstract, such as in cognitive functioning and mental health. Measures of cognitive functioning and intelligence are very much influenced by the culture and the experiences to which an individual is exposed. As an example, consider the questions about the names of the current and past Presidents that are part of standard cognitive impairment measures. In a society without a president of such high profile as the one in the United States, giving a correct answer may be much more difficult than in this society. Consequently, lower proportions of correct answers are not necessarily indicative of lesser cognitive functioning. Likewise, the meaning and symptoms of depression may vary across societies; if this is the case, translations from and back to the original languages will not be sufficient to establish the cultural equivalence. Even when measures indicate the same concept across nations, their metric and structural equivalence remains to be established (27).

Conclusions

In this paper, the argument was developed that the traditional measures of physical and mental health can be expanded to further differentiate among older adults who have no major health and cognitive problems.

The ultimate goal of such efforts at reconceptualizing the measurement of health is to identify those older adults who maintain a high level of functioning, to pinpoint the factors that are related to such vitality and effective functioning, and to examine the decline in vitality as a possible forerunner of deteriorating health.

To summarize, it is important to measure a broader range of health and effective functioning than is often accomplished, because the study of older people who function particularly well is likely to yield equally important insights into the progression from age to death as will the study of those whose functioning is significantly impaired. This paper documents the ACL efforts at broadening the measurement of health. Other conceptualizations and measures are possible. To establish such measures with cultural invariance for cross-cultural comparisons presents a formidable challenge because the performance and reporting of most of the proposed behaviors, affects, and cognitive processes are culture-bound. Nevertheless, the concept of vitality is an important extension of the concepts of illness and impairment. It is to be hoped that the International Collaborative Effort accepts the challenge to identify measures of vitality and effective functioning in older age across societies and to mount whatever modest cross-cultural comparisons may be warranted as a start.

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Part IX

Special activities related to measuring health and health care

Chapter 27

Contribution of the World Health Organization Program for Research on Aging to activities related to measuring health and health care

by Jorge Litvak, M.D., Chief, Program for Research on Aging, World Health Organization

The world is growing older, but it is growing older very unevenly. The number of persons 60 years of age and over has been projected to reach 1 billion by the year 2020, but 72 percent of them are expected to live in developing countries. Also, elderly women outnumber men in most countries of the world: The social, economic, and health problems of older persons, therefore, are largely the problems of elderly women (1).

These demographic projections raise a considerable challenge to public policy, particularly in developing countries. The projections demand the institution of policies and programs to ensure the availability of health, social, and economic services for the elderly, promoting their continued participation in a socially and economically productive life.

The World Health Organization (WHO) Program for Research on Aging is an integral part of the Organization's Global Program on Health of the Elderly. The Medium-Term Program of the Global Program for the period 1990–95 identified as one of its main objectives support to Member States in undertaking a situational analysis of the health and health care of the elderly for the formulation of national policies and programs.

In 1985 an advisory group made a first attempt to prepare a prototype of a national demographic and health profile of the elderly in support of the development of national policies related to aging. Basic health monitoring statistics and population projections are available from a number of international data banks, such as the WHO Mortality Data Base, the United Nations (U.N.) Demographic Yearbook Data Base, and the U.N. Disability Statistics Data Base.

The research and the development of the data are currently a joint exercise between the WHO Programs on Health Statistics and Epidemiological Trends Assessment and the Program on Health of the Elderly. The aim of this work is to make health data policy related and intelligible to planners.

Profiles of social, demographic, and mortality data by country are being prepared as partially completed templates for verification and completion by countries. Data are provided on diskette, country by country, in a WHO-standard and portable data format exactly as printed. These data are already available for about 50 countries and ready for submission to these countries for revision, correction, and filling in of missing values from national data. This project received a new impetus from the U.N. Statistical Office and the Department of International Economic and Social Affairs: The impetus was to produce these data as Special Topics in the 1989 Demographic Yearbook and the 1990 World Health Statistics Annual.

The assessment of health status among the elderly on an international basis is essentially limited to mortality data. With few exceptions, comprehensive data for the elderly population on morbidity, self-perceived health, use of services, and indexes of activities of daily living are not available.

It became obvious, therefore, that WHO had to seek the collaboration of the world scientific community to generate, collect, and disseminate knowledge gained through research on aging on a cross-national basis. Cross-national research has been shown to be a powerful method to understand both the determinants of healthy aging and, particularly, the appropriate technologies to apply this knowledge optimally with a view to formulating, evaluating, and implementing policies and programs for older persons.

WHO has undertaken epidemiological activities since 1978 through studies of the situation and the needs of the elderly in different regions of the world: The 11-country study in Europe, the 4-country study in the Western Pacific, the 13-country study in the Americas, and ongoing studies in 5 countries of the Eastern Mediterranean and 4 countries of Southeast Asia.

In May 1987, the World Health Assembly, acting upon the recommendation of the WHO Advisory Committee on Health Research, requested that the Director General establish an international research program on aging. The WHO Research Program on Aging is now based at the National Institute on Aging, following an agreement signed between WHO and the National Institutes of Health (2).

The WHO Advisory Committee on Health Research recommended the following four initial priority areas for the Program: Determinants of healthy aging; age-associated dementias; age-related changes in immune function; and nutritional changes associated with aging, with special emphasis on osteoporosis (3). Consultation groups of international experts for each of these four initial priority areas made specific recommendations that were adopted by the Program's Scientific Advisory Committee.

The project on determinants of healthy aging will explore the biomedical, social, cultural, economic, behavioral, and environmental factors that contribute to the achievement of healthy aging. The elucidation of those factors that are important in influencing transitions among health, morbidity, and disability in an aging population will require that data be gathered over time. The project will undertake rigorously designed longitudinal and cross-sectional studies of aging in at least six sites in developed and developing countries. It will address agreed-upon research questions and specific hypotheses relevant to the primary aims of the project.

The determinants of the healthy aging project will have ramifications well beyond its direct outcomes. The methodological aspects of the project have relevance for many current and planned research endeavors on population aging worldwide. The project will provide the background data and a population base for pursuing studies relevant to the other Program priority areas. Finally, the information that the proposed studies will generate will add a new and vital dimension to world knowledge of aging in areas of direct relevance to the formulation of national plans of action in response to the projected global demographic and epidemiologic transition.

The cross-national project on age-associated dementias is a multiphase, population-based epidemiological study with specific emphasis on etiology, standardization of instruments, determination of age- and sex-specific prevalence and incidence rates, and assessment of risk factors in different nations, cultures, and ethnic groups. The coordinating center for the project is in Florence, Italy, and the participating countries are Canada, Chile, Malta, Nigeria, and Spain.

The project on age-related changes in immune function will furnish new knowledge with regard to the basis of the immune senescence and thereby provide insights into the development of more effective vaccines and immunization techniques.

The cross-national research project on osteoporosis will be conducted in six countries representing Asia, Latin America, Africa, and Europe. The project will focus on international comparison of the frequency of hip fractures as it relates to relevant risk and protective factors.

Strengthening of national research capability is an important goal of the Program. The emphasis centers on cooperation and exchanges among industrialized and developing countries. Related measures to strengthen the national research capability of developing countries have been identified as an effective point of entry to promote the development of national policies and programs.

The Program's Scientific Advisory Committee strongly endorsed research on measurement of health care as a needed contribution to policymakers in developing countries (4). Advancing age brings more susceptibility to chronic and long-term disease and disability, with a greater demand for services in the most complex levels of care. This entails the threat of higher health care service costs. On the one hand, therefore, plans with targeted measures that promote health and prevent disease at later ages are essential for these countries in order to avoid the staggering burdens of expensive medical care now experienced by developed countries. On the other hand, the aging of the population makes it essential to investigate a wider range of health care options than are now in place. These should include innovative strategies to achieve efficiency and efficacy of services, including preventive care, home and community care, and primary health care, as well as long-term and institutional care for acute, chronic, and rehabilitation cases.

To this end, the WHO Global Program for Health Care of the Elderly and the Research Program on Aging are preparing a multiphase project to be implemented in three developing countries. In the initial phase, the project intends to identify the information necessary to create the data base that will give service providers and policymakers the basis for reorienting the traditional models of health care to cope with the needs of the growing number of older persons.

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Chapter 28

Health for the elderly by the year 2000: Statistical needs

by Ronald G. Blankenbaker, M.D., Vice President for Medical Affairs, St. Vincent Hospital and Health Care Center

Introduction

Today, we live in a health care environment that is changing so rapidly that health planners, policymakers, and researchers find it very difficult to keep up. Much of this change is the result of the push toward maintaining or improving the quality of health care while significantly decreasing the expense. In response to this dilemma, local, State, national, and international agencies are beginning to create health policies and plans that are more proactive and less reactive. Their thirst for data is rapidly surpassing the public and private sectors' ability to assess the health status of their various populations and subpopulations. Consequently, the stress on the scientific community to develop meaningful studies that provide accurate results in a timely fashion is intense. This is particularly true for studies of the elderly segment of our society.

I am associated with two quite different organizations that are keenly interested in efforts of the International Collaborative Effort (ICE) on Aging to measure health and health care of older persons. The first is the National Committee on Vital and Health Statistics (NCVHS, 6525 Belcrest Road, Hyattsville, Maryland 20782), an advisory committee to the Secretary of the U.S. Department of Health and Human Services (DHHS) on broad matters of vital and health statistics. The second is the Society of Prospective Medicine (P.O. Box 55110, Indianapolis, Indiana 46205; phone (317) 549–3600), a group of health professionals committed to the concept that the strategy of preventive medicine can and should be applied to all persons regardless of age, sex, race, socioeconomic status, or nationality. From these two perspectives, I will attempt to present to you what is being done and/or what we perceive is statistically needed to evaluate the health status of the elderly population of the United States as well as the world.

In a sense, I am representing the user committees for the work being done by the ICE on Aging project. If we are successful in our efforts, the resulting information will need to be converted into appropriate health policy for the elderly, as well as to be put into effective practice by health workers in the United States and other countries.

National Committee on Vital and Health Statistics

NCVHS was created as the result of a 1948 recommendation by the World Health Assembly to all member countries, and it has provided an important advisory role to a variety of Federal health agencies since that time.

In 1974, Public Law 93–353 (Public Health Service Act) broadened the role of NCVHS to include essentially all matters regarding vital and health statistics, and officially made the Committee advisory to the Secretary of what is now DHHS. The interest and expertise of those selected to be members of the Committee have been broadened over the past 6 years to include individuals interested in public policy, clinical medicine and nursing, and hospital administration, along with a variety of other health and statistically related areas. The 1987 amendments to the Public Health Service Act increased the Committee membership to 16, with a turnover of 4 members each year. Currently, the Committee has determined that its function is to monitor, as best it can, the full spectrum of issues regarding vital and health statistics. This includes the evaluation of available data and advice on the development of new data necessary for the creation of effective public policy.

To accomplish these broad mandates, NCVHS had developed an ongoing and dynamic 2-year work plan that is updated every 3 months, and it encourages formal reports every 1–2 years from each of its areas of activity. The Committee receives regular brief but informative updates on broad statistical issues from a variety of public and private agencies, as well as from individuals. In addition, individual members of the Committee have been assigned to special areas of interest to monitor and provide regular reports to the Committee. The gathering of data related to the aging population is an example of one of these areas.

To deal in depth with key areas of interest, the Committee functions through formal subcommittees, composed of members of the parent National Committee, and informal work groups that give regular reports to the main Committee. The National Committee works closely with the various agencies, the Secretary, and the key staff, and it regularly seeks public views on current issues (1).

International Classification of Diseases

As you well know, the International Classification of Diseases (ICD) is the basis for cause-specific death rates among countries. For example, for those 65 years of age and over, cardiovascular disease is usually the most common cause of death in developed countries. More recently, the clinical modification of the 9th revision of the ICD (2) has been used for comparison of hospital statistics between the United States and other countries. Of course, the use of these diagnoses for payment systems is specific to the United States.

A major effort of our Subcommittee on Medical Classification Systems has been support of the efforts of the National Center for Health Statistics (NCHS) to review the content of the 10th revision of the ICD, which is scheduled for implementation in 1993; evaluate the need for a clinical modification; and consider the implications of using such instruments. Obviously, this system will continue to be the backbone of international comparisons of mortality and morbidity in older persons. Cooperation of all of us will be imperative as we move toward the implementation of the 10th revision.

Death certificate conference

Recently there has been increased concern over the validity or accuracy of the identification of cause of death on death certificates. This may be compounded by inadequate education of certifiers; a very low autopsy rate; social pressures, such as underreporting of acquired immunodeficiency syndrome (AIDS); and certain laws that might affect the diagnoses used on death certificates. NCVHS is planning a national meeting in 1989 to address this dilemma.

Prior to the meeting, staff at NCHS and others will prepare summaries of the various issues, which will be made available to the invitees for review and discussion at the meeting. During the 1- to 2-day meeting there will be an open, frank discussion of these review papers and related concerns by invited representatives of the appropriate national organizations.

The summary and final recommendations from this meeting will be presented to NCVHS for review and comment. NCVHS will then prepare a transmittal document with critique to be sent to the Office of the Secretary of DHHS. The summary and recommendations of the meeting, along with NCVHS response and reaction of the Department, should ultimately be published through the appropriate public and private sources.

Finally, we plan to have a followup meeting 2–3 years later to assess progress, along with continuing and emerging problems, and to make additional recommendations as necessary. We anticipate that many countries may be having similar problems. We would be happy to communicate with you about your efforts to improve this situation and to keep you apprised of our progress.

Other National Committee on Vital and Health Statistics interests

Other relevant ICE on Aging issues are being addressed by standing subcommittees of NCVHS. For example, the National Health Care Statistics Subcommittee is evaluating the comparability of health statistics in different sites, such as hospitals, doctors' offices, and nursing homes. The Ambulatory Care Subcommittee is attempting to work with governmental agencies to agree on a uniform data set for recording outpatient data. The Long-Term Care Subcommittee is considering possible quality-of-life measures for those in nursing homes. Additionally, members of this subcommittee have been investigating the improvement of current instruments for measuring disability.

Disease prevention and health promotion, especially the establishment of U.S. goals for the year 2000, have been an ongoing interest of NCVHS. This relates quite well to the World Health Organization's activities regarding Health for All by the Year 2000 (3). In the past, the elderly subgroup has been targeted for special attention, and this will likely be the case in the future.

This brings me to my second "hat" at this meeting, the Society of Prospective Medicine.

Society of Prospective Medicine

The Society of Prospective Medicine (SPM) is an international organization that was founded almost 15 years ago on the premise that useful life expectancy can be increased through the assessment and reduction of individual health risks. The original means of accomplishing the Society's goals was through the use of the Health Hazard Appraisal (HHA), developed by Drs. Lewis Robbins and Jack Hall in Indianapolis, Indiana, in 1970 (4). I had the good fortune of working with these two pioneers during that time and have been a strong proponent of those concepts ever since.

While the HHA is still considered the best basic instrument available to assess individual health risks, there have been a number of modifications to the original HHA by a variety of sources. However, none has approached the issue in such a comprehensive, innovative, and open manner as has The Carter Center, with its Health Risk Appraisal (HRA) Update of 1987 (5). Many of us believe that the concepts developed in this new HRA have set the stage for a model HRA that can be easily modified for use in any country. In turn, such a model could be used as a basic instrument for the development of disease prevention and health promotion programs worldwide. Regardless of the importance of this new update and its worth to future appraisals, there is much yet to be done, in our opinion, to prove to the world that HRA is valid and effective.

The problem we face in the further implementation of health assessment programs from which health providers can serve effectively and health policymakers can plan appropriately are that:

1. Much needs to be done to better understand the natural history of disease and the precursors (predictors) of these diseases.
    a. There are many situations in which it is difficult to assess individual risk based on group data, e.g., the speed, size, and quality of construction of the automobile in relation to a predictable motor vehicle accident fatality.
    b. Many risk factors are solid predictors, e.g., smoking and lung cancer, while others are soft, such as high-density lipoprotein and heart disease.
    c. There are multiple gaps in the available data, e.g., the effect of exercise on health.
    d. There is much to be done to determine the impact of race, sex, and sociocultural and economic factors on the disease process so that the HRA can be used in the various world populations.
    e. As our concern for the elderly moves from acute to chronic diseases and from death to quality of life, our need for statistics on morbidity must be emphasized. This will be a strong challenge to all of us and extremely costly, but one that we cannot ignore.
2. Each time we update the HRA we create a "snapshot" of an ever-changing, dynamic process. The HRA that is valid today may not be tomorrow.
3. HRA is a young, inexact science, which probably will always utilize a sprinkling of judgment and assumption that requires the interpretation of a clinician. Because of this it will always seem that there are not enough available data.
4. Multiple approaches and studies are currently being carried out by organizations and agencies at all levels. This often results in confusion, duplication, and inefficiency due to a lack of appropriate coordination.
5. Most of the data we accumulate regarding mortality come from death certificates, with the concerns for accuracy and validity already addressed.
6. It is very expensive to implement a long-term prospective study that will stand up to scientific

scrutiny. Consequently, many of these good, important efforts do not reach the refereed journals.

In spite of these difficulties, the future has never appeared brighter for HRA. The American public and many other populations are developing a very supportive attitude toward disease prevention and health promotion, and the scientific world is becoming more and more receptive. To continue this momentum, we must:

1. Develop the resources (funding and expertise) necessary to collect accurate and relevant data that can be effectively translated to proactive health policymaking and planning. This should include our best efforts to encourage physicians to carefully and accurately complete each death certificate so that it truly reflects the actual disease(s) involved, plus any contributing conditions, e.g., smoking related to lung cancer.
2. Create longitudinal prospective studies that will meet the scrutiny of the scientific world, e.g., the Framingham studies. Approaches to this could include:
    a. Isolated studies of individual diseases and risk factors.
    b. International, national, or regional comprehensive evaluation of all diseases.
    c. A combination of the two.
3. Seek funding for these prospective studies and assist in the publication of the results in the appropriate scientific literature. While the Proceedings of SPM's annual meetings are still the single best source of such information, these efforts must be presented in the regular disease prevention and health promotion journals.
4. Develop a mechanism to maintain and continually update the policies and procedures for HRA. This should be accomplished on an annual or biennial basis at the least and may be the most important of these recommendations. The Carter Center in Atlanta is making this an ongoing project.
5. Encourage DHHS and other appropriate national and international agencies to continue to move in the direction of proactive health policies that are based upon a sound intelligence system. This will require coordination and cooperation among all of the agencies involved in this arena.
6. Modify our medical education system so that it teaches how to prevent disease and promote health. Once this is accomplished we will be able to develop a much more effective working relationship between clinical medicine and health education. This will enhance disease prevention and health promotion programs and provide the cooperation necessary to see us into the 21st century.
7. Continually evaluate and reevaluate the results of our plans and programs. To do this will provide an automatic mechanism that will direct the need for plan changes and the necessary improvements or modifications in the way we collect data. We will then be able to assess the productivity of these efforts as well as their accountability. This should move us into the creditable position we all are seeking.

Conclusion

NCVHS and SPM have vested interests that are complementary to those of the ICE on Aging, and I hope we can be supportive of each other's efforts. We would like to remain involved with these activities and commit our resources whenever possible to assist in a successful outcome.

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Part X

Summary

Chapter 29
Overview

by Manning Feinleib, M.D., Dr.P.H., Director, National Center for Health Statistics

We have had a very informative 3 days here. We have learned a good deal from the splendid presentations at the plenary sessions, and the working group sessions have been very productive. The issues that have been brought up involve a number of methodological issues as well as several substantive ones. One of the main challenges of this International Collaborative Effort on Aging is to redirect the primarily substantively oriented research toward the methodological and data collection issues that can enhance the measurement aspects of a wide variety of health and health care projects.

Virtually every speaker at this Symposium stressed the need for better data on the elderly population and the need to develop and test new instruments to measure the many diverse and complex aspects of aging. There was clear recognition of the need to enhance current data collection systems, such as improving the quality of death certificate information for the aging; obtaining more detailed information from hospitals, nursing homes, and other health care providers; and achieving wider use of population-based examination and interview surveys of the elderly. Before implementing all of these improvements, however, we should first examine to what extent the currently available instruments and data bases in our several countries are comparable and, where there are differences, which ones are the most useful and whether standardized methods can be achieved.

The working groups have deliberated vigorously and have come up with several dozen different research proposals. We now have to flesh out these proposals and decide which of them—undoubtedly a relatively small number—can actually be implemented during the next 3 or 4 years. During the next few months the planning group will review the suggestions from the working groups, discuss them with our colleagues at the National Institute on Aging and other Federal agencies, and recommend which of them should be implemented during the next few years. Joan Van Nostrand, Bob Hartford, and Sam Notzon will be in touch in a few months to let you know which are the priority projects that have been approved and to seek your enlistment for the joint collaborative activities that will ensue. I am optimistic that we will forge a successful international collaborative effort.

Thank you all again for your efforts and splendid contributions, which have made this Symposium such a success.

Chapter 30
Comparing cardiovascular and cancer statistics

by Harry M. Rosenberg, Ph.D., Chief, Mortality Statistics Branch, National Center for Health Statistics

In preparing the notes of the report of the working group, I would like to thank my colleague Mr. Kenneth Kochanek, also of the National Center for Health Statistics (NCHS), as well as the members of the working group, which included Dr. Harvey J. Cohen, Dr. Tamara Harris, Dr. Millicent Higgins, Mr. James Lubitz, Dr. David MacFadyen, Dr. Callum Muir, Ms. Constance Percy, Dr. Thomas Strasser, Mr. Thomas Thom, and Ms. Valerie Van Holten. The purpose of our working group's activities was to develop a research proposal on the comparability of diagnostic statistics in international studies, focusing on cancer and cardiovascular diseases, the two leading causes of death among the elderly.

To achieve international comparability in diagnostic statistics requires a high degree of standardization in definitions, measurement instruments, data processing and quality control, and data presentation. This is being accomplished by a number of ongoing efforts, such as the MONICA (Multinational Monitoring of Trends and Determinants in Cardiovascular Diseases) study described by Dr. Millicent Higgins, which focuses on cardiovascular diseases, as well as the recently initiated World Health Organization (WHO) Special Program for Research on Aging, described by Dr. Jorge Litvak, which focuses on age-associated dementias, age-related changes in immune function, and osteoporosis. Such large-scale initiatives—through which new data are being collected—are the principal mechanisms for ensuring international comparability in diagnostic statistics for specified medical conditions.

In addition to such efforts, improvements in international comparability can be achieved through international agreements such as the International Classification of Diseases (ICD) of WHO. Since the beginning of this century, the ICD has played a key role in promoting the international comparability of diagnostic statistics, particularly in the area of mortality, and now increasingly in morbidity statistics. International compacts such as ICD are central to promoting international comparability in health statistics, particularly for ongoing data collection mechanisms, such as vital statistics and hospital discharge statistics, that serve both administrative and statistical purposes. Specially designed studies such as MONICA are important for generating internationally comparable health statistics through standardized data collection instruments, diagnostic protocols, data presentation and analysis, and data quality assurance activities.

Further promoting international comparability of diagnostic statistics are national evaluation studies on the reliability and validity of diagnostic information on health records. Many such studies have been carried out for mortality. These compare information from the death certificate with other sources, such as autopsies, clinical records, and clinical-pathological correlations. International efforts such as the ICD and the new WHO Special Program for Research on Aging, as well as national efforts such as evaluation studies of cause of death, are important to enhancing the international comparability of diagnostic statistics.

Within the context of these considerations and guided by the operating principle that this International Collaborative Effort (ICE) on Aging initiative will use existing data, with few if any additional resources, our working group explored the following areas:

- Data bases.
- Methodological approaches.
- Conceptual frameworks.
- Methodological considerations.
- Potential research collaborators.

While there was a far-ranging discussion of these topics, closure was not achieved on a specific research proposal within the working group deliberations. However, Dr. Callum Muir developed a specific proposal that will be presented after my general presentation of the working group recommendations.

The working group identified a number of areas that may be the basis for further activities. These include the analysis of existing national data, both underlying and multiple cause-of-death data, as well as literature surveys in a number of areas related to the comparability of diagnostic statistics. The areas need to be prioritized and their feasibility determined. The principal areas of consideration follow.

Data bases

A number of data bases were proposed for consideration, including the following:

1. The SEER (Surveillance, Epidemiology, and End Results) program (in the United States) and its international equivalents.
2. Hospital and physician use and expenditure data from the Health Care Financing Administration, possibly linked with other data sets. It is not known if this U.S. data base has counterparts in other countries.
3. The Global Epidemiological Surveillance Program of WHO, which may have useful information for cause-of-death validation studies based on consistency checks, time and age trend checks, etc.
4. Existing data bases from international studies such as MONICA, which have the advantage of highly standardized methods and good quality control. It is believed that participants and researchers in the ICE on Aging could have access to these data.
5. The Intersalt Study (sodium and blood pressure); however, the numbers in the data base are quite small for the elderly population.
6. ARIC (Atherosclerosis Risk in Communities).
7. The CARDIA (Coronary Artery Risk Factors Development in Young Adults) Study, which also is limited by small numbers.
8. Other international community registries, although they often have a low age limit.

Methodological approaches

A number of methodological approaches were suggested, as follows:

1. Literature review of existing studies of cancer and cardiovascular diseases to determine if findings for younger old can be extended to oldest old. MONICA is one example; however, the age cutoff for MONICA is under 85 years.
2. Literature review of existing studies of clinical-pathological confrontations; however, it is recognized that these data bases may be biased.
3. Analysis of trends, such as the work currently being done by Thomas Thom of the National Heart, Lung and Blood Institute (NHLBI), with Dr. Fred Epstein and Dr. Paul Leaverton. This is a monograph that compares trends in death rates from 1950 through 1985 for 27 countries by sex for the age groups 35–44, 45–54, 55–64, and 65–74 years for all causes of death combined and for heart disease, stroke, and cancer. One aspect of this work is Dr. Epstein's analysis of these data in terms of concordance or discordance of trends among the three causes of death (actually four, since lung cancer and all other cancers are being tracked separately). For ages 65–74 years, this work might be relevant to the thrust of the Symposium and this working group. However, the analysis is based on the underlying cause-of-death data compiled by WHO, and the data are taken at face value.
4. Use of linked records, as in the Oxford study; however, linked record information is not widely available internationally, and issues of confidentiality are even more pressing in Europe than in the United States. The workshop did not thoroughly explore what types of linked records are available for this purpose.
5. Literature review of cause-of-death validity and reliability studies, drawing, for example, on Constance Percy's knowledge of international differences with respect to applying ICD coding principles to cancer mortality.

6. Analysis of existing data bases, such as the Framingham Heart Study, to determine the extent to which cause of death reported on the death certificate is consistent with diagnostic information collected in the study. A focus of such an analysis is to determine if such comparisons change with increasing age, with a focus on the elderly population.
   Another type of analysis would use multiple cause-of-death data, available for the United States and possibly some other countries. The data would be used to tabulate the leading causes of death not only in terms of the traditional underlying cause of death but also in terms of combinations of causes of death for the older population. While it is recognized that the issue of quality and completeness of reporting is even more critical for multiple than for underlying cause of death, such applications seem relevant to the elderly, many of whom have a number of concurrent chronic conditions at the time of death.
7. Analysis of age curves of mortality among countries, with an emphasis on comparisons between the old and the oldest old. This would reveal how variable death rates are among countries and find some way to judge the quality of numerators and denominators, that is, to see if the differences are spurious or real.
8. Analysis of indicators of quality in cause-of-death data, such as the percent of deaths classified to the category "symptoms and ill-defined conditions." This could be extended to categories such as "sudden death" and "cardiac arrest" and tabulated by age, with an emphasis on the old and oldest old.

Conceptual frameworks

Two broad conceptual frameworks were suggested, as follows:

1. A framework based on avoidable diseases and causes of death, such as the work by Walter Holland. The question was raised whether this can be related to service utilization.
2. A framework based on the validity of the survey instrument and its impact on different diagnoses in terms of morbidity, mortality, survival, risk, and burden.

Methodological considerations

Methodological considerations were considered by the workshop to be of overriding importance in examining the international comparability of diagnostic statistics. They include the following:

1. Examining data for the oldest old (85 years of age and over), possibly in comparison with the younger age groups (65–74 and 75–84 years). It was noted that, for the United States, age curves show unusually low death rates for the oldest old compared with those in other countries.
2. Consider severity and staging of disease, if possible.
3. Focus on specific diseases, such as cancer of breast, prostate, stomach, and lung, chronic obstructive pulmonary disease (COPD), sudden death, acute myocardial infarction, fatal coronary heart disease, and stroke, for which very reliable data are available.
4. Look at treatment comparisons (e.g., angioplasty); however, this was considered difficult to carry out.
5. Look at both mortality and morbidity data, although the latter are very limited internationally.
6. Take into account overlapping categories, such as COPD and congestive heart failure.
7. Examine the role of physicians' attitudes and knowledge in the comparability of diagnostic statistics. The WHO/World Hypertension League Hypertension Management Audit Project may provide a model for this.
8. Take into account selection bias and differences in coding when looking at the comparability of diagnostic statistics.
9. Attempt to identify the basis for diagnoses on the death certificate. This may be a basic area that needs to be addressed, drawing on existing literature. NCHS is currently undertaking a feasibility study on this subject.
10. Consider whether differential access to medical care may have an impact on the international comparability of diagnostic data.

11. Consider possible settings for which data may be available. They include: For cancer, United States, Japan (Osaka), Norway, France (Strasbourg), Sicily, Shanghai, and India (Bangalore); for cardiovascular disease (CVD), the MONICA countries.
12. Take into account the fact that, for developing countries, information from registries tends to be better than data on mortality from vital statistics.
13. Consider that treatment for CVD among the elderly population is increasingly taking on the characteristics of treatment for cancer. Also, with time, procedures that were developed using younger patients are being applied to the elderly. Examples are coronary bypass, kidney dialysis, and angioplasty.
14. Consider whether methodologies and results for the younger population are applicable to the elderly.
15. Consider what indexes should be used for international comparisons, for example, mortality-incidence ratios.
16. Make a special effort to identify possible sources of data on morbidity and comorbidity for both cancer and cardiovascular diseases. Such data could be used to address the issue of avoidable morbidity. For the elderly population, such an approach could also provide some clues related to item no. 13 above and may provide guidance to clinicians in their approach to treatment and ethical decisions for elderly patients with these common diseases.

Potential research collaborators (including workshop participants)

The following are potential research collaborators on studies of international comparability of diagnostic statistics with emphasis on cardiovascular diseases and cancer:

1. MONICA network out of Helsinki.
2. Ruth Hegyeli (NHLBI).
3. CVD unit in Geneva (the replacement for Dr. Bothig).
4. Avoidable mortality and morbidity: Oliver Stamburg, Gary Andrews, and Alan Lopez.
5. Japan: Hiroshi Shibata, Tokyo Metropolitan Institute of Gerontology; Shigematsu, Fukuoka Medical School, Fukuoka; Isabura Fujimoto, Osaka Cancer Registry, Osaka.
6. Strasbourg: Paul Schaffer, Bas Rhin Cancer Registry.
7. Sicily: Luigi Dardenoni, Ragusa Cancer Registry, Ragusa.
8. Bangalore: Krishna Bherghava, Kidwai Memorial Cancer Institute.
9. Germany: Wahrendorf, Cancer Research Center, Heidelberg.
10. U.S-Federal Republic of Germany Collaborative Agreement (G. Payne, E. Greiser) and other collaborative agreements (Z. Pisa).
11. Additional addresses can be found in *Cancer Incidence in Five Continents*, Vol. V, International Agency for Research on Cancer.

Proposal for an international study of precision of diagnosis

by C.S. Muir, M.B., Ph.D., Deputy Director, International Agency for Research on Cancer

The aim of the proposed study is to determine whether apparent differences in the precision of diagnosis of cancer or heart disease influence the validity of estimates of incidence and survival at national and international levels. The study would be carried out in two phases. The first phase would use existing data to examine the definitions used for histological verification of diagnosis for solid tumors, for lymphomas, for leukemias, and cytological specimens—needle biopsies, for example; to examine the varying interpretations of cause of death as recorded on death certificates only; and to examine the clinical diagnosis—the precision and accuracy assigned to radiological modes of diagnosis, for example, computerized axial tomography (CAT) scanners, nuclear magnetic resonance, and biochemical estimation. Having looked at the definitions used in various parts of the world, ask whether these can be standardized, that is, can one promulgate a standard set of definitions? If one cannot, can differences be adjusted for when one is comparing data? The first phase of the proposed study, then, would use existing data to examine existing definitions and practices.

The second phase would require new data, which often requires funding. We want to assess whether these apparent differences identified in the first phase in the diagnosis of cancer and heart disease influence the validity of the estimates of incidence and survival. This could be done by examining the validity and basis of the clinical-only diagnosis in various settings. How different are the clinical-only diagnoses in various parts of the world? We could examine the reasons for failure to have histological verification of diagnosis, which is so common in the United States but much less common elsewhere.

We could examine reasons for differences in the mortality-to-incidence ratios. Are these due to better treatment? Are they due to a more favorable stage of the tumor at the time of presentation across countries? Are they due to some other factors, perhaps more subtle, such as differences in the definition of malignancy? If we are to carry out these second phase studies, then we need to meet the following criteria. First, we must conduct our studies in areas where there are reasonably large numbers of older persons with cancers. We would probably confine ourselves to selected sites. We need to have the ability to access medical records on a nominal basis to get out an individual's medical record. We need to have access to histological material for some of the studies that have been proposed. We need to be able to link the incidence and health records with death certificates, something that is not possible in a considerable number of big countries today.

To sum up, the aims are to determine whether apparent differences in the precision of diagnosis of cancer and heart disease influence the validity of estimates of incidence and survival at the national and international level. We are going to do this in two phases: First looking at how these things are defined using existing data and then going on to a series of ad hoc studies to find out whether these really do have an influence on the endpoints of interest. Let me end by quoting from an article that appeared in the *New Scientist* in the middle of this year, written by Richard Smith, the assistant editor of the *British Medical Journal*, who was talking about the failure of the British Health Service "to use the vast amount of data which is available to our universal state funded health service for epidemiological purposes." He concluded, "the further from the molecule, the more difficult it is to get funding." I was glad to hear from Dr. Feinleib that there may be a chance of having some funding.

Chapter 31
Health promotion and disease prevention among the aged

by Gerry E. Hendershot, Ph.D., Chief, Illness and Disability Statistics Branch, National Center for Health Statistics

I want to do three things: (a) briefly review the presentations that were made in the plenary session on health promotion and disease prevention; (b) then summarize the discussions that took place in the workshop on that topic the same afternoon; (c) and, finally, summarize some discussions that took place after the workshop, both among individuals and in a small group meeting that we held this morning before the opening plenary session.

Plenary session

In the first plenary session on health promotion and disease prevention, I suggested that these could be thought of—for the purposes of this project—as including efforts by communities and governments to intervene in the lives of individuals to improve their use of preventive services and their personal habits related to health. I asked the question, Why are we at the National Center for Health Statistics, particularly in the Division of Health Interview Statistics, interested in health promotion and disease prevention among the aged?

First of all, health promotion is a major emphasis in U.S. public health policy. The National Center for Health Statistics (NCHS) has a commitment to providing statistics to track the progress of programs on health promotion and disease prevention. The National Health Interview Survey is a major component of NCHS activities in tracking health promotion and disease prevention objectives. Finally, the measures we have for many behaviors related to health promotion and disease prevention are inadequate for the aged population. They were developed for other age groups and simply do not do a good job of measuring those activities among the elderly.

I said that in this international collaborative effort on measuring health promotion and disease prevention among the aging, my vote would be that we improve and standardize measures across nations, enabling us to do some comparative analysis of health promotion and disease prevention among the elderly in different countries. As a beginning, we hope to establish a collaborative relationship with The Netherlands' Health Interview Survey and the United States' National Health Interview Survey and some others which may be mentioned later. We then heard from Henk Swinkels of The Netherlands Health Interview Survey, who talked about health promotion and disease prevention policy and data in that country.

I would like to touch just briefly on John McKinlay's provocative discussion of measuring behavior related to health promotion and disease prevention among the elderly and some possible solutions to those problems. He pointed out that the social situation of elderly people is often such that it is difficult to conduct household personal interviews successfully, and that impairments in hearing and vision add to the difficulty. He pointed out that telephone and mail survey techniques have improved substantially in recent years and are now competitive with personal household interviews for some purposes. He said we lack a total design approach to selecting the best mix of data collection techniques for elderly subjects, and choice of methods is complicated by the impairments and social situations of the elderly. Thus he indicated that we need a very flexible approach to data collection techniques among this population.

This flexible approach should improve the response in general and may be essential, he argued, for attaining some kinds of information from the elderly, especially the older old. Such a change in approach to data collection has some very important effects, because the questionnaire and protocol development must be very different if you are using different methods in the same survey. The training of interviewers is greatly complicated, I should suspect. There is a problem of having different responses in different modes used in the same survey. This is not something that is easy to do, but I think Dr. McKinlay made a good case for looking into the possibility of using mixed-mode surveys, especially with the older population.

He also suggested that for some kinds of surveys, especially among the older old, surveys should be done at the convenience of the respondent, meaning that they should be conducted in the home or at work. That might not have been practical until the recent development of a variety of portable equipment that makes possible inhome electrocardiogram and blood pressure tests, for example. He argued that those inhome test techniques are often as good as a clinical test and that the only way to get some kinds of data, especially for the oldest old, is through the use of these portable tests.

Workshop summation

Our workshop was attended by about 25, a very lively group, and we had what seemed at the time to be a very complex discussion.

I set out some assumptions for the workshop. In this international collaborative effort, I am assuming that we have limited resources of staff and dollars, that there will be a logistical problem in coordinating a project across countries, and that all of us will have competing priorities. This is not the only project and probably not the most important project we will be doing in the next few years. These assumptions suggested that our strategy in planning projects should be to focus on good existing data sets, select a few variables, and look for some short-run payoffs.

When asked what I meant by short-run payoffs, my answer was that over the next 10–12 years we will be doing probably four surveys on health promotion and disease prevention, including among the elderly. Health promotion among the elderly is going to be a priority area for the U.S. Year 2000 Health Objectives, so we have a real need in the near future to develop good techniques for measuring health promotion variables among the elderly. If I could get from this project some input for our planning process, that would be a short-run payoff that would be very valuable to the outcome and also justify my efforts and those of my staff.

I said that we should then ask some questions, which I addressed to the workshop. First, What good national data sets on health promotion and disease prevention are available? Right away, I got questions. What did I mean by "national"? Is Hong Kong national? Scotland? The Province of Veneto in Italy? We did not resolve that question. I said that, from my point of view, the major payoff in the long run and in the short run is a benefit to the statistical systems of NCHS, particularly the National Health Interview Survey, and these are national data systems. It would be most beneficial to focus on national data sets, meaning a nation, not a province. However, I thought that Dr. Maggi made a good case that Veneto, even though it is one province of Italy, is representative of a whole nation and therefore might be a comparable data set.

Then it was asked what I meant by "available." We decided that available meant that actual data would be available to look at during the course of this International Collaborative Effort project, which means that while they might not yet be available, they would be available soon. Also, there would be opportunities for persons to participate who hope to benefit from the efforts of the project for future projects of their own.

We then tried to list a good many national data sets that are available. They represented Scotland, Hong Kong, the United States, Canada, Australia, The Netherlands, Finland, and Italy. The workshop attendees thought that there were data sets from these nations that would be useful in a cross-national study of health promotion and disease prevention among the elderly.

My second question was, In those data sets, which behaviors are measured by two or more data sets? The behaviors, of course, are those related to health promotion and disease prevention. We listed them first but then observed that they fell into a number of categories that are useful to recognize. Personal characteristics make up one category of variables related to health promotion available in these data sets that should be considered. We are thinking here of things such as age and marital status. Personal behaviors affecting health, such as smoking and exercise, make up another category. These are examples; there were more in the list that the workshop made up.

Use of preventive services such as breast examinations and dental care on a regular basis is another category. Then disease and functional outcomes of health conditions and measures of those, such as activities of daily living and chronic conditions, form another category. Another is personal satisfaction, such as self-reported health and perceived control of health.

These are categories of variables that were listed by the workshop participants and can be found in two or more of the data sets that you saw previously. I would consider some of these—the personal behaviors and preventive services—as most central to the health promotion issues with which I am concerned. I would see the personal characteristics as control variables or stratification variables, and the disease and function outcomes and the personal satisfaction outcomes as consequences of the health promotion variables that we are studying. My preference, and this is not necessarily that of the workshop, would be to focus our attention on these two categories of variables: Personal behaviors and preventive services.

My next question to the work group was, Which of these behaviors are important? Immediately I was asked, What is "important"? So we discussed what we meant by the importance of behaviors, health promotion, and disease-related behaviors. One point that was made is that to be important a variable or behavior must be related in some significant way to the health outcomes. If it is not related, then it is questionable as to whether it is important. The magnitude of that relationship is also important. Participants also made the point that an important variable should be amenable to change for health promotion and disease prevention purposes. If the behavior is not amenable to change, then it may not be relevant to health promotion and disease prevention activities. The objective of health promotion and disease prevention is to alter behavior in such a way as to improve the outcomes.

We then looked at some particular behaviors that we consider important. There were more than these by far, but among the behaviors mentioned were smoking, drinking, physical activities, and weight control. Among the services, some of the candidates were breast, eye, physical, and dental examinations on a regular basis.

We had an interesting discussion on the question, Is smoking cessation among the elderly really important? It had been noted by Dr. Harvey Jay Cohen in the opening address that a recent article in the *New England Journal of Medicine* suggested that smoking cessation even late in life had some important effects on the improvement of health. Larry Branch, at the request of one of the other participants, summarized that article and critiqued it. He suggested that because of the number of cases on which it was based and the selectivity of the population studied, the results may not be statistically reliable.

We then got into the question of what criteria we have to apply in order to determine that there really is a relationship between a health-related behavior and an outcome. Should the criteria be strictly statistical? Dr. Branch emphasized that if one assesses all the available evidence, even though it is not statistically conclusive, it supports the epidemiological conclusion that smoking cessation is an important factor in later life. I would like to draw a moral from this: Statistics are an aid to good judgment, not a substitute.

The next question we turned to was, Can these measures be improved? We concluded that for this project, simple and direct measures may be adequate for some of the health-related behaviors we want to look at. To ask for more than that, even though improvement could be made, may be more than we should attempt at this time.

The example we spent some time on was smoking and smoking cessation as a health promotion objective. I think there was a consensus that for the kind of purpose that we are undertaking here, it would be sufficient to get good information from older people on whether they had ever smoked and whether they now smoked. Those two items would be very useful for cross-national health analysis and for improvement in measures. Additionally, if we could find out when these people began smoking and when they stopped, this would be information that we would like to have.

We did turn very briefly in the closing minutes to the question, If we decided on a few measures that we think are important, how can they be improved?

Suggestions by workshop participants were to improve the operationalization of concepts and to improve the methods of data collection. By operationalization, we are talking about questionnaire design and testing of questionnaires; by methods, we mean the kinds of things Dr. McKinlay talked about, multimode, mixed-mode surveys. It was also suggested that we need to improve our analytical techniques and develop modeling techniques, and we need to improve the reporting of our data, especially access to data.

Informal discussion

I asked a group this morning to comment on an understanding of the relationship between health promotion and disease prevention which is developing in my own mind as a result of the presentations and workshop on assessment of vitality and aging. That health promotion and disease prevention are related was demonstrated in a very effective sociological way by the fact that the workshop participants for those two topics were almost identical. There may have been one or two who were not in one or the other, but they were almost the same set of people.

Very simply put, by health promotion and disease prevention we mean programs to change behavior, health habits, and the use of health care services. To do that we have to change people's knowledge, their intentions, and finally their behavior. If we do that, I think what we are aiming at is vitality. So the ultimate objective of health promotion and disease prevention is to improve vitality in the older population through programs that result in a change of behavior. Health promotion interests are in how programs affect knowledge, intentions, and behavior, but not about ultimate outcome.

The vitality issue, I think, is more general and includes the health promotion activities but includes physical, social, and mental factors other than health promotion and disease prevention that affect vitality. There was a long discussion yesterday about what is meant by vitality, and I am sure there will be more of that today.

Bernard Wells made a valuable suggestion, that the behaviors we select for intensive study in this project should be related to age in the older population. We should select age-related risk factors for this project. The affected behaviors or vitality change rapidly with age among the elderly. When we are developing measures, it is important to understand what the effect of differences in age in the sample population will be on our procedures. It was suggested that we select one or two behaviors whose effect is greatest for the young old, and one or two whose effect is greatest for the old old.

We had some discussion of important behaviors that might be selected in each of these two age groups. For the young old, for instance, smoking was discussed, because the cessation of smoking at the younger old ages will have some health benefits and improve vitality later on. Also, overweight is a problem in the young old. Whereas smoking is less of a problem in the old old, falls become a much more important problem than they are in the young old. Malnutrition rather than overweight may be an important problem in the old old. The idea is to select a few variables that vary with age among the older population for intensive study in this project.

What steps are we going to take now? One idea that is emerging is to consolidate the health promotion and vitality projects. In the opinion of some of us in the work groups, these two things rightly belong together in some way. We will consider that. We will then select for the health promotion part, if it is a two-part project, one to four important behaviors that are available in data sets in different countries and are age related in the sense I just discussed.

Chapter 32
Functional disability

by Mary Grace Kovar, Dr.P.H., Special
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A strategy for studying functional ability

All of the members of the work group contributed to the discussions. The strategy owes much to their generous willingness to contribute their intellectual and data resources. Although I am presenting this paper, we are all authors.

We regard our work as very much part of the continuum from health promotion through vitality, successful aging, healthy aging, decreased functioning, and functional disability. Functional ability should not be separated from that continuum. On the other hand, we recognize that there are separate needs for data on functional ability. Very specific measures are needed to be used as end points in themselves as well as part of that continuum.

Work group discussions

As background, I want to report briefly on what the work group discussion encompassed. The members of the work group:

1. Briefly reviewed available data sets, focusing particularly on the national data sets, but with some attention to subnational data and to longitudinal studies.
2. Recognized that there are major questions that must be kept in mind as we move toward more international collaboration:
   a. How do you define and measure disability, health, or autonomy?
   b. What is the purpose of collecting the data? What is the purpose of cross-national comparisons? Some of the possibilities include:
      i. To make prevalence estimates.
      ii. To study interrelationships and correlations.
      iii. To make estimates and projections of the need for health and medical services.
      iv. To determine eligibility for services.
   c. How can we redefine and expand the measures:
      i. To distinguish between physical and social ability.
      ii. To include cognitive functioning.
      iii. To include emotional health.

Strategy

With those issues in mind, and based on conversations and miniworkshops that have been held during this conference, we have developed a strategy.

1. Develop comparable tabulations from national surveys or systems.
   Purpose: To estimate the prevalence of functional disability.
   Presentation: Symposium in 1992, work in progress at intermediate meeting, and presentations at other national and international meetings.
   Publication: *Vital and Health Statistics*, Series 5.
   Format: Each report will have data for the United States and one other country. The reports will have several sections.
   a. Demographic and, insofar as possible, social, economic, geographic, housing, and other characteristics of the noninstitutionalized population of older people.
   b. Pertinent information about the health care systems that might influence the estimates. For example, the proportions of the people

in institutions and the policies for institutionalization and provision of formal long-term care in the community could influence the estimates.

   c. Information about the prevalence of functional disability.
      i. Core data available for all countries.
      ii. Other data comparable for the two countries.
      iii. Data on higher level functioning (and other measures), if obtainable.
   d. Technical information.
      i. Statistical—sampling, estimation, response rates.
      ii. Survey—question wording, who answered.

   Procedure: Identify researchers and authors; the people for three projects have already been identified at this Symposium. Countries to be studied in the first reports are the United States and Canada, Hungary, and Israel. Note that starting with these three areas does not preclude adding others if resources (people and data) permit.

   The authors will:

   - Examine questions for comparability (control and dependent variables).
   - Define table formats.
   - Prepare preliminary tables. (Each country will do its own.)
   - Exchange tables.
   - Compare and adjust tables (using intermediate symposium).
   - Prepare final tables and text.
   - Compare and adjust (using intermediate symposium).
   - Publish and present.

   This will provide something that is not now available for any two countries—a comparison based on comparable, carefully examined and evaluated data from the data files rather than from published data.

2. Perform sophisticated analyses from exploratory data analysis provided in first step.
   a. Multivariate analyses and modeling.
   b. Incorporation of explanatory variables.
      i. Beds, physicians, climate—from other sources.
      ii. Smoking, alcohol consumption—from other surveys.

   These more sophisticated analyses are what many people want to have done. There was a great deal of excitement about the possibilities of really understanding what we do and do not know. However, the comparative analyses must come first to make certain that sophisticated techniques are not applied to inappropriate data.

3. Encourage and support analyses of subnational data.

   Because the National Center for Health Statistics does not conduct subnational surveys, we should not take the lead role in comparative analyses of such data. However, we can participate and be supportive by tabulating national data by, for example, a geographic area or an ethnic group to facilitate comparisons of subnational data and to help make certain that the local area in the United States is not atypical.

4. Enlarge and update the roster of longitudinal studies of aging, paying special attention to studies designed to measure change (or having data that can be used to measure change) in functioning.

   The roster would not be simply a list. It would include, for example, the sample size and whether there was a defined population of inference. (Studies without such a population would probably not be included.) It would have detail on measures of functioning and include a checklist on whether data on covariates were available. It would include information about linkages with other records such as death records or hospital records.

5. If feasible, begin collaborative analyses of longitudinal data.

   Such analyses are badly needed to show when repeated cross-sectional data are sufficient and when longitudinal studies are essential. Comparative analyses are needed within the United States as well as among nations.

6. Encourage and participate in the development of better measures, better question wording, and better analytic techniques.

   The ideas and techniques of the Cognitive Laboratory at the National Center for Health Statistics are exportable. The United States and other nations can use them to understand the data better and to improve the wording of questions. Within the United States, those techniques can and should be used with different population groups—Hispanic, black, and inner-city and rural poor people—so that we can learn whether we are actually measuring what we think we are measuring.

Performance measures are being incorporated in the third National Health and Nutrition Examination Survey and in the Established Populations for Epidemiological Studies of the Elderly. The measures could be incorporated into subsamples of other studies, especially studies in other countries. Using performance measures would also help us learn more about what the questions actually measure.

We are convinced that the postponement (or amelioration) of disability depends on better information about the disease (or injury) leading to the disability and the specific nature of the disability. Incorporation of covariates into questions, more analysis of the data now available, and more specific measures will help us know what we need to know. These are smaller projects that should be incorporated into the ongoing analyses.

7. Encourage and participate in the writing and publication of a book or handbook of techniques for collecting information about older people.

   The people in this room have participated in collecting data from and about older people. We have used various techniques, and we have learned a lot. Among other things, we have learned that the techniques, procedures, sampling frames, and wording of questions that are appropriate for the younger adult population are not necessarily appropriate for older adults.

   In fact, some of the findings from survey research that were based on studies of younger adults are not correct for older people. For example, such studies show that proxy respondents report lower levels of disability and medical care use than self-respondents. That is not necessarily true for older people when the older person is too sick, disabled, or cognitively impaired to respond for himself or herself.

8. Facilitate informal communication.

   The field is moving fast, and the issues are important. We need to share what we learn as rapidly as we can. I have learned as I have gone along, and I suspect that everyone else doing studies of aging has done the same. Much of what we learn does not appear in print. Even when it does, it is too late to help many others. Therefore, if we are to improve the measurement of functional ability and contribute to healthy aging, we must facilitate the rapid informal exchange of information. We urge that everyone involved in cross-national research be on an electronic network such as BITNET so that we can talk with one another.

That is a summary of what we have discussed, accomplished, and planned. It was a work group with probably three times as many opinions as there were people present and with a wealth of experience.

Chapter 33
Comparative analysis of health statistics for selected diseases common in older persons in the United States

by Tamara Harris, M.D., M.S., Medical Officer,
National Center for Health Statistics

Studies of geographic variation in rates of cancer and coronary heart disease and in patterns of risk factors for these diseases have been useful in formulating etiologic hypotheses (1,2). However, these studies frequently provide scanty information on the old, especially in view of potential bias in measurement of diseases due to differential patterns of diagnosis or medical service (3). In addition, there have been relatively few systematic comparisons of data on diseases, other than cancer or coronary heart disease, that are major sources of morbidity and mortality in older populations in the United States.

For this project, hip fracture was selected as the main condition for which data would be collected cross-nationally for comparative analyses, with the understanding that hip fracture rates would serve as a proxy for osteoporosis prevalence from country to country. Hip fracture was selected because it met criteria enumerated by Dr. Kelsey (Part VI, Chapter 19):

- Are cases readily identifiable? (Does the disease cause those affected to come to hospital or does it cause death?)
- Are mechanisms for diagnosis readily available?
- Are diagnostic criteria adequately defined?
- Is a comparison of this outcome of sufficient epidemiologic interest?

Hip fracture is a disease of public health importance. Not only is it common in old age (4), but the consequences are important in terms of morbidity, mortality, and disability (5). The etiologies of both osteoporosis and hip fracture are not well understood, but fracture has been observed to be an age-related process modified by environmental factors (6,7). These environmental factors, which are thought to include lack of exercise, smoking, and low dietary calcium, would be amenable to intervention programs; therefore, this research has practical applications for health promotion for older persons as well.

Potential benefits to the National Center for Health Statistics (NCHS) in terms of this project could include identification of sources of bias in assessment of outcomes from administrative records, application of these issues related to bias in an area of increasing public health importance, and development of a case model for study of measurement of nonfatal diseases of interest in older populations.

To develop this project, the following major activities will need to be undertaken:

1. A comprehensive review of the literature on cross-national comparisons of hip fracture will be performed to identify factors that need to be accounted for in the study design and to identify existing sources of data.
2. Candidate countries will need to be identified. Criteria will involve availability of population-based data, including age-sex specific denominator data, so that rates can be computed. The goal would be to have a wide breadth of geographic and ethnic variation. Suggested countries included Sweden, Finland, Iceland, Great Britain, Spain, Hungary, Poland, Yugoslavia, Japan, China, Hong Kong, Singapore, Israel, Egypt, Kenya, United States, Canada, Barbados, Chile, Brazil, and India. While it may not be possible in developing countries to obtain reliable data for the entire country, it may be possible to obtain very useful State or county information.

3. The data format for the request will include, where possible, sex-specific data on persons 40–90 years of age, by 5-year age groups, with special attention to data for those 70 years of age and over. Age-sex distributions in the same format for the denominator population would have to be available. Information would be requested on numbers of hip fractures, numbers of deaths due to hip fractures, and numbers of hip replacements. It is unclear whether statistics can be generated by location of hip fracture on femur. Obtaining data on hip fracture from previous years would be a priority. If these data were available, they could be used for cohort and trend analyses.
4. It is not within the immediate scope of this project to perform a validity study. The World Health Organization plans to perform a series of validity studies for hip fracture as part of the project on osteoporosis. As part of this International Collaborative Effort project, a short questionnaire will be sent with the request for information. Recommended questions include:
    a. What is the source of data for diagnosis, i.e., what percent of the data is derived from x-ray-proven fractures?
    b. What is the general impression of the respondent regarding whether those with hip fracture come to medical attention? Are there any data for that location that would bear on this question?
    c. Are there data on how quickly those with hip fracture present for treatment? Are there any data on what proportion of hip fractures seen in hospital are recent and what proportion are partially healed? (If there were a large proportion of partially healed fractures, this might indicate that the overall rate would undercount the prevalence of hip fracture.)
    d. Who pays for the care of hip fracture? If data are available, what percent of the health budget goes for this?
    e. Can the respondent identify potential sources of data on bone density for the population?
    f. Can the respondent provide or suggest a source for grouped risk factor information from the same population, i.e., weight-height distributions, patterns of smoking, general diet information in terms of percent fat, general diet information in terms of calcium intake, physical activity? For women, it would also be useful to have population data on patterns of estrogen use post menopause, trends in fertility rates, trends in age at menarche and age at menopause, and percent oophorectomy before age 50.
5. Information on two other diagnoses as well as hip fracture will be ascertained. The same steps in defining information, the measurement issues to be addressed, and the sources of information will be followed for these companion diagnoses. The most likely candidates are breast cancer, especially focusing on the issue of estrogen receptor status in old age, and prostate disease, comparing prostatectomy rates.

The principal NCHS collaborator will be Dr. Tamara Harris, Office of Analysis and Epidemiology. The two principal collaborators for this project are Dr. Jennifer Kelsey, epidemiologist, Columbia Faculty of Medicine, School of Public Health, and Dr. Suzanne Ho, epidemiologist, The Chinese University of Hong Kong. Dr. Jacob Brody, epidemiologist and Dean, University of Illinois at Chicago, School of Public Health, may also participate. At NCHS, plans are to involve Dr. Anne Looker, of the Division of Health Examination Statistics, and Dr. Edward Bacon, of the Division of Health Care Statistics, in the execution of this project.

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Chapter 34
International collaboration in measuring outcomes of nursing home care

by Joan F. Van Nostrand, M.P.A., Coordinator of Data on Aging, National Center for Health Statistics

I would like to acknowledge the members of the work group because their contributions were significant. I would like to thank Bob Clark, from the Department of Health and Human Services of the Office of the Secretary; Jack Habib, from Brookdale in Israel; Betty Havens, from Canada; Anna Howe, from Australia; Raymond Illsley, from the United Kingdom; Rosalie Kane, from Minnesota; Phyllis Thorburn, from the Veterans' Administration; and Jack Feldman, Jennifer Madans, and Evelyn Mathis, from the National Center for Health Statistics (NCHS). Thank you for your sage advice.

The overall objective of this project is to conduct international research into measuring outcomes of nursing home care. The goals of this research are:

- To improve the measurement of outcomes and related patient characteristics for frail older persons.
- To strengthen the comparability of such data among collaborating countries.
- To disseminate the results of the research to encourage its international application.

Strengthening measurement and prediction of nursing home outcomes in an international context can lead to the development of approaches to improve outcomes. For those approaches that do improve outcomes, comparable international measures can facilitate cross-national applications.

The approach developed by the work group to measuring outcomes of nursing home care has three tiers, or levels. Each builds on the work of the preceding tier, as in a pyramid in which tier I is the base and tier III is the apex. For each of these research tiers, I will outline the purpose, some analytic issues, and the outputs of the activity.

Tier I addresses the context of the measurement research. This activity describes the context of nursing home outcomes in each collaborating country. It provides a background for understanding the structural and cultural framework within which long-term care (LTC) is provided. A major focus is the analysis of service levels and populations served. This analysis will identify classes of nursing homes for which appropriate comparisons can be made across collaborating countries. The goal is to assure that comparisons made in research tiers II and III are valid.

The context of the nursing home outcomes research is described by several classes of variables:

- Variables about the system of LTC services (e.g., kinds and mix of LTC services, utilization and payment for nursing home care, links to the acute care system and social welfare system).
- Cultural variables (e.g., demography, resources allocated to LTC, role of the family).
- Descriptions of populations served and service levels in nursing homes.

The descriptions of populations served and service levels are important for identifying which types of nursing homes should be grouped for appropriate comparisons across the collaborating countries.

Tier I activities are the initial step of the measurement research. Descriptions of the service populations and service levels will be emphasized. Proposed outputs are (a) a *Vital and Health Statistics* series report comparing nursing home care in the collaborating countries and (b) a determination of groupings of nursing homes for analyses appropriate for cross-national comparisons in tier II.

Tier II addresses research issues in measuring the outcomes of nursing home care. Its goal is to provide measures of outcomes and risk factors that can be used in cross-national comparisons. Such comparisons can facilitate the application of successful approaches from one nation to another.

There are several components to the measurement research activities in tier II. The first component deals with variables to measure outcomes. This component will develop measures of nursing home outcomes and related patient characteristics to improve our understanding of outcomes, to improve our ability to predict outcomes, and to strengthen cross-national comparisons. It will examine classes of outcomes (e.g., death, short stays, discharges to hospital) to determine if particular patient characteristics, singly and in combination, are related to and can predict specific outcomes. A major focus of this research is the analysis of variables defining outcome classes and associated patient characteristics and how they are measured. An initial list of outcomes and patient characteristics was identified by the work group and will be the starting point for the analysis.

The second component deals with comparable measurement of outcomes between LTC in institutions and at home. For many older persons, home health care is viewed as a substitute for nursing home care, a substitute that provides greater independence to the LTC client. This measurement research will identify the key variables for comparing both outcomes and patient characteristics between the two settings. The goal is to identify measures that would provide comparable data among countries and between the major LTC settings as well. Because data from Canada are rich in outcome and patient data for both nursing home and home health care, they will be the basis of initial analysis.

The third component of tier II research deals with measuring actual versus expected outcomes. Increasing attention is being given to measuring the quality of nursing home care. A major approach to defining quality is to compare the actual outcome of care with the expected outcome for patients with similar characteristics. In this measurement research, patient characteristics will be analyzed to determine (a) which variables should be measured to determine the expected outcome and (b) how they should be measured. Once the expected outcome is determined, approaches for measuring the extent to which it has been achieved will be examined. This research must address the continuum of outcomes for nursing home care ranging from rehabilitation to pain control for the dying. Australia has developed an approach for identifying expected outcomes. This will provide a framework for developing the research.

There are several proposed outputs for the three research components of tier II. Results will be presented at professional meetings, in journal articles, and in a *Vital and Health Statistics* series report. Findings also will be available for the development of major NCHS data collection efforts.

Work on tier II research will begin midway through the development of tier I research on the context of LTC. Activities can start at the point when data on populations served and service levels of nursing homes have been analyzed and decisions on appropriate classes for international comparison have been made. Research activity will continue throughout the project. It will begin with the first component on variables to measure and predict outcome. When that has been established, work on the second component—comparisons across LTC settings—can be initiated. Once that is well under way, the third component—comparisons between actual versus expected outcomes—can begin. Research will then proceed simultaneously on all three components.

Tier III addresses developmental research in measuring expected well-being after discharge as an outcome. This research activity focuses on the early stages of measurement research. It is conceptualized as "developmental" research because our knowledge and experience in measuring this concept are rudimentary in comparison to our knowledge and experience about outcomes. While national data are the focus of much of the research proposed in tiers I and II, some subnational sources rich in data on this topic could serve as important resources. The goal for tier III research is to operationalize and develop preliminary approaches to measuring expected well-being after discharge. These approaches can be shared cross-nationally. Collaborating (and other) countries can then test and refine the approaches in the context of developmental research for their data systems.

Expected well-being after discharge as an outcome of nursing home care was conceptualized by the work group as multidimensional. The dimensions include expectations about the patients' functioning after discharge in terms of:

- Autonomy and discretion of the patient at discharge.
- Economic and financial concerns.
- Satisfaction with care received and its outcome.
- Social status and function.
- Psychological status and function.

The concept of expected well-being after discharge must be operationalized, and a variety of measurement issues particular to the nursing home setting must be addressed. (For example, nursing home staff may report a patient as "satisfied" with care when the patient is withdrawn and depressed.) Dealing with expected functioning after discharge based on measures made prior to or at the point of discharge is a particular challenge of this developmental measurement research.

There are several proposed outputs for tier III research. Presentations at professional meetings and conferences as well as journal articles can raise the measurement issues and report on approaches to solving them. As the work progresses, there is potential that a *Vital and Health Statistics* series report on data methodology can summarize the findings so that the collaborating countries can build into their data systems the testing and refining of measures of expected well-being after discharge.

The work group noted that the potential exists to establish linkages between this research and other International Collaborative Effort (ICE) projects. Because activities of daily living (ADL's) have been identified as an important patient characteristic for predicting outcomes, an appropriate linkage is to the ICE project on functional ability. Information from the functional ability project on approaches to measuring severe disability can feed into tier II research on measuring and predicting outcomes. Because of the transitions of the LTC population between the community and the nursing home, comparable measurement of ADL's between these two settings can provide important information for approaches not only to improve outcomes but ultimately to prevent nursing home stays.

Tier III developmental research on measuring expected well-being after discharge could be strengthened by a linkage to the ICE project on measuring vitality in older persons. The social and psychological dimensions of expected well-being are similar to major components of the vitality research. Approaches and findings from both projects can be shared. While this linkage will not necessarily ensure that similar concepts will be measured identically, it will increase the potential of comparability.

Once the research on comparability of common diagnoses is developed more fully, the possibility exists of linkages to that project. Causes of negative outcomes in nursing homes may be the same as those under study in the project on common diseases. Hip fracture is a good example.

We are still in the stages of casting our net to capture other data bases that would be relevant to tiers II and III of the proposed research. Additional collaborators are welcome. This research presents some formidable problems in making international comparisons, but I believe that the experts working on the project are more than able to meet the challenge.

Chapter 35
Assessment of vitality and aging

by Richard J. Havlik, M.D., Office of Planning and Extramural Programs, National Center for Health Statistics

Because, as you heard earlier, there are some linkages between health promotion and disease prevention and vitality, some of the same people attended both sessions. There is clear overlap. I liked the analogy that was used of the two-sided coin. On one side you have health promotion, and on the other side, you have vitality. It does not hold up completely, but one is a predictor and the other is an outcome. Exercise can be on both sides.

Our group generally acquiesced to the construct of physical, social, and mental vitality. We will get into that next, but a couple of interesting ideas were presented. One actually overlaps with Joan Van Nostrand's suggestion about use of the nursing home in studies of vitality and quality of life. The concept of vitality and quality of life is relative. For example, individuals who can climb mountains, such as the 92-year-old woman who does these things, have finally in their older age reached their full potential. In the nursing home situation, obviously, we are moving in a much narrower context. Whether we can really measure such concepts across nations is the question.

The next interesting idea, and this is a subjective one, is the whole concept of biological age and vitality. This is where one uses health-risk assessment. Dr. Ronald Blankenbaker has been working with the people in the Society of Prospective Medicine for a number of years. They use estimates of risk profiles and can calculate a biological age, which is compared to an actual age. If we really had enough information about vitality, we might be able to have a vitality age that one could use as an objective measure.

The group was appropriately cautious about cross-national comparisons. Although the other groups have become excited about cross-national comparisons and publishing, the feeling was that we had to be somewhat more cautious about this with vitality. In the vitality area, it may very well be that we are all more alike than we are different. There was not a clear indication that cross-national hypotheses were evident in the vitality area, but this may really be because we do not have enough information to see the differences in how vitality is conceptualized across countries.

Additionally, we are limited by culturally bound factors, things that we just cannot completely eliminate. One of the examples used is that, in a social sense, it would be nice to be able to compare individuals who are taking a course in the University of the Third Age with other individuals. However, in Italy it would be unusual for someone in the cohort of older women to venture out to participate in such activity. One could thus get the false impression that older Italian women are not interested in education. When we do these comparisons, we are going to need an interpretation to go along with them.

Another issue to consider is that the indicators of a certain type of vitality may vary among countries. For example, in the analogy of social interaction, one person may play cards and one person may go to a club. If we do not ask the right question for the right country, we may miss part of the social interaction that occurs. We need a broad span of questioning so that if we are really talking about social interaction, we have enough of the potential components. We will go into some of the details.

After all is said and done, we concluded that cross-national comparisons were still worth it. In fact, we are enthusiastic about doing this and would like to forge ahead in this collaborative effort.

Let us talk, then, about physical vitality. Because of the universality of walking, we felt that it should be part of vitality. We do have a problem of capturing the different types of walking. For example, it was noted that in analyzing some U.S. data, we should specifically ask about walking to and from work or walking to and from the store. If we ask only about general walking, we might miss these other contexts, so the comparison of prevalence would be misleading.

Since we are building on some of the other discussions, we were able to go into slightly more detail about what these questions ought to include. The feeling was that we should think in terms of what is measurable and that one-quarter mile or 400 meters is truly very difficult for people to estimate. Perhaps time is the more usual way of thinking about the amount of walking done. However, then one gets into specifying time for a specific unit—per day or per week. Thus there is still a very major problem in the questions that we will use or attempt to compare between countries. Information on intensity, although it is important at this older age, might not have to be collected other than for the very, very highly functioning group.

Another common activity reported in countries is work around the house and garden. This was another aspect of physical vitality. Whether we should ask about this activity in terms of frequency compared to others or other details was not discussed.

Flexibility is not flexibility in attitudes or scheduling but in movement. Stooping and bending may be work-related activities, but they are very important and merit as much attention as the other aspects of physical activity such as endurance.

All of us are aware of actual behaviors versus the capacity for behaviors: "I would walk," or "I could do it, but we have somebody else do it," or "My wife has always done that." This is an underlying problem that we may not be able to address.

Finally, there are exercise and sports. If data are available, we should try to collect them. Because these activities are uncommon at older ages and may vary from area to area, it may be very difficult to collect data, but we should try to do it.

The next area of the troika is social vitality. One of the questions was, How do you define social vitality, what it is and is not? An overarching theme could be participation in social networks, such as frequency of seeing family members, and, separately, of seeing friends, but social vitality also involves organizations, amusements, and other kinds of social networks. However, we are also interested in finding out about a more benevolent and activist kind of role, such as volunteerism. Attending an organization or participating in a group session is one issue. If you reach out and help somebody or do something for somebody, this is another component of vitality that might be measurable. There have been some questions and various countries have addressed it.

The issue that I mentioned in my introductory remarks comes up again: That is, there are different types of social interaction within the same construct. We have to make sure that we cover as many of these as we can in any comparisons.

We did not really spend much time on mental vitality. The Center for Epidemiological Studies–Depression (CES–D) scale scores, which were discussed in the plenary session, seemed to be worth comparing. Someone raised the concept of locus of control. That is an old concept, but actually control over your environment—over what is going on in a nursing home situation or a workshop or in anything that we do—may be a good indicator of vitality. We tried to differentiate between autonomy and control. Autonomy is doing what you want to do and controlling yourself. Locus of control refers to outward control, and it might be the more appropriate aspect to measure. Sets of questions on locus of control exist, including a set developed by J.B. Rotter.

What is our plan for vitality? It is interesting that great minds move in the same direction in that we want to get our information together. We want to collaborate. That is the only way to go. We will have to get the questionnaires from the various studies, including the schedules, protocols, guidelines, and any other information that we can accumulate.

There are small studies on the issues of validity and reliability. Some of them hinge on national and subnational data, but others are purely directed at one small topic or another. Maybe we can get some information on the validity and reliability of the measures that we can actually use for vitality.

There are other considerations. I have already said that our group was cautious about the interpretation of cross-national data. We are going to have a country-vitality matrix that will include at the onset three indicators of vitality—walking, social interaction, and CES–D. We will try to have some results, at least preliminary ones, 18 months from now. The matrix should be the basis of further thinking and refinement, not conclusions. We are then going to have to expand and interpret the data. A number of work groups had the idea that we should get information together. A "minimum data set" or "uniform data set" could be used to provide comparable information. Some information that all of us would be interested in seeing could be put in one place for descriptive purposes. Data on health, functional ability, and vitality should be put together so that they will be available for interpretation in one place.

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