
Vital and Health Statistics

Proceedings of the 1991 International Symposium on Data on Aging

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The 1991 International Symposium was convened from September 4 to 6, in Rockville, Maryland, as a follow-on to a 1988 symposium. The 1988 symposium focused on developing a research agenda on measuring health and health care for the elderly in a standard manner to permit valid comparisons across nations. The theme of the 1991 Symposium was "Meeting the Challenges of an Aging World." Its purpose was to share the interim results of the research agenda from the 1988 symposium and to review the goals for the next few years. 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 five topics addressed by the International Symposium: health promotion, vitality, functional disability, outcomes of nursing home care, and common chronic diseases.

Manning Feinleib, M.D., Dr.P.H., Editor

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Chapter 1

Welcome and charge

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

Welcome

Good morning and welcome! I'm Manning Feinleib, Director of the National Center for Health Statistics (NCHS), the sponsor of this 1991 Symposium on the International Collaborative Effort (ICE) on Aging, Measuring Health and Health Care, also known as the ICE on Aging.

Before I explain how ICE on Aging came to be, let me thank two people who were instrumental in seeing that this ICE on Aging symposium came to be—Joan Van Nostrand, the NCHS Coordinator of Data On Aging, and Jacqueline Davis from the Office of International Statistics. I would also like to thank the many other people who helped put this symposium together.

I should make one announcement about the package that you received. The world map is currently being revised. We hope by the next symposium it will be up to date on the latest developments in some of the larger areas of the globe.

We launched the ICE on Aging in 1988 in response to the unprecedented challenge that the world's aging population presented. These challenges are described in the Proceedings of the first symposium held in December 1988 and should be in your conference packet. True to the International Collaborative Effort emphasis, the Proceedings include papers from our international colleagues as well as from the U.S. participants.

NOTE: The affiliations shown in the papers in this report are those in effect at the time of the International Symposium on Data on Aging. The opinions expressed are those of the authors, not of the organizations for which they work.

Theme

The first symposium focused on developing a research agenda on measurement issues, such as how to measure health and health care for the elderly in a standard manner to permit valid comparisons across nations. Although the first symposium focused on aging well, this symposium has been broadened to cover the entire spectrum of health issues of the aging, from healthy aging to disability. That is why we have chosen the theme "Meeting the Challenges of an Aging World"—to review these challenges of an aging world and to share with you the interim results of the ICE on Aging. At this symposium, we will examine where we are, what has been accomplished so far, where we are going, and our goals for the next few years.

International effort and purpose

The international forum provided by the ICE on Aging, including Australia, Canada, France, Hong Kong, Hungary, Israel, Italy, Norway, the Netherlands, the United Kingdom, and the United States, allows us to join with a large cadre of experts around the world who are researching methods to improve measurements of both health and health care for older people. One specific objective of this effort is to apply the research results to NCHS programs in order to strengthen the collection, analysis, and dissemination of data on aging. The international emphasis also permits the exchange of diverse perspectives, approaches, and insights among nations facing similar situations and challenges. The fruits of this collaboration will be

disseminated widely to encourage international applications.

Five main research topics

Among the many research proposals outlined at the first symposium, five broad research areas emerged. These have been reformulated and now consist of

- Health promotion and disease prevention
- Measurement of vitality in older persons
- Comparative analysis of health statistics for selected diseases common in older persons
- Functional disability
- Measuring outcomes of nursing home care

Research teams for each topic were formed, and these included an NCHS staff member or one from the National Institute on Aging as principal investigator and several American and international researchers from government agencies, universities, and research organizations.

Modifications and changes

As is often the case, some changes to the initial concepts of the various research projects and research teams were made along the way. I am sure you are all familiar with the old saying, "the only constant in the universe is change." Even for researchers, or perhaps especially for researchers, this is always the case. Our researchers often discovered that data that they had thought would be readily available were in fact not available at all. Others who plan to use certain data find that the data do exist, but the content limits comparability. ICE on Aging researchers have not been exempt from these obstacles, and I would say these only prove that "Meeting the Challenges of an Aging World" was an apt choice as this year's theme.

In addition to reformulating the topics and schedules, some of our colleagues have changed, and researchers from additional countries have joined the research projects. How data eluded the research teams and why some of the research-

ers have changed will be discussed in special sessions Thursday afternoon.

Discussions

At the concurrent workshop sessions on Thursday afternoon, you will have the opportunity to hear about and discuss many issues, including

- Research plans that had to be modified
- How reality intruded upon research
- How cultural differences that arose during the course of our projects were handled

Questions that arose after the research began. Because there are no question-and-answer periods during the plenary sessions, I ask you to hold your comments, questions, and suggestions for other topics you wish to discuss until tomorrow's working sessions.

Importance

The problems of aging have been with us since men and women were first able to survive beyond the reproductive period. It is safe to say that these problems will be with us as long as mankind continues to survive. We have gathered to talk about contemporary research regarding problems of measurement, but perhaps we should consider at least one other perspective. Aristotle lived from 384 to 322 B.C., dying at the age of 62, a ripe old age in that period. He studied under Plato, he educated Alexander the Great, and he had this to say about time and aging, "Time crumbles things; everything grows older under the power of Time and is forgotten through the lapse of Time." In Aristotle's day, that was quite true; and many of our older people today would agree with the pessimistic implications of Aristotle's statement. But as was said before, things change, and for most of us here, there is considerable optimism that we can solve some of these problems that truly span the ages. The ICE on Aging and this symposium will shed some light on this issue and justify our optimism.

Chapter 2

Crosscutting issues on health and disability: Introduction

by Gene D. Cohen, M.D., Ph.D.,
National Institute on Aging, National Institutes
of Health

It is a pleasure to be here in this very important international meeting on measuring health and health care. I would like to congratulate the National Center for Health Statistics for putting together such a fine conference.

I was reviewing the agenda for the meeting at home while my teenage son was listening to a new rap album by a group called “Vanilla Ice.” When he saw this ICE on Aging, he asked if I were going to an aging rap group meeting. I said, “Perhaps.” To state the obvious, cross-national research is valuable because it identifies universal health trends. At the same time, it suggests the extent to which age-associated changes in health and functioning can be modified. This is probably the true value of international research and comparisons.

The National Institute on Aging (NIA) works in close collaboration with the World Health Organization Program on Aging. In fact, this program is housed in NIA office space—a nice symbol for our effective collaboration.

In all of our research, both domestic and cross-national, NIA has a vision that research on aging offers the best opportunity to reduce risk factors leading to costly long-term care services and promote independent functioning in later life.

Aging research is influenced by many international perspectives. I would like to share two very striking views of old age—striking because they are opposite, yet both are absolutely true. Does this sound like a statement from the sphinx?

Let me illustrate. Here is a quote from Shakespeare in his 16th century masterpiece “As You Like It”:

Last scene of all, that ends this strange eventful history in second childishness and mere oblivion, sans teeth, sans eyes, sans taste, sans everything.

The second is a quote from Cicero’s “De Senectute,” written in the first century B.C.:

Intelligence and reflection and judgment reside in old men, and if there had been none of them, no states could exist at all.

Totally different statements, yet both accurate. Shakespeare describes illness and disability in later life, and Cicero portrays the health and vitality of old age. Both conditions will be better quantified and understood thanks to the contributions of the ICE on Aging.

The second international perspective is a myth from Greek mythology dating back 25 centuries. Its relevance is clear today as we look forward to the extraordinary developments anticipated in research over the next 25 years. It is the myth of Tithonus. In this story, there are three key characters: Tithonus, a mere mortal; Eos, the Goddess of Dawn; and Zeus—known as both mighty and tricky. Tithonus fell in love with Eos. Because she was a goddess and immortal, Eos was concerned that she would outlive her lover Tithonus. She pleaded with almighty Zeus to bestow immortality upon her lover. She asked

this with some trepidation, remembering Zeus' reputation for being unpredictable. To Eos' surprise, Zeus granted her wish and bestowed immortality upon Tithonus. However, because Zeus left out the essential ingredient of eternal youth, Tithonus grows older and older and more and

more frail each day. To avoid the plight of Tithonus, research on aging must ensure that science allows the quality of life to keep pace with its quantity. And with that, I wish you a successful conference.

Chapter 3

Healthy aging

by John Rowe, M.D., Mount Sinai School of Medicine, Mount Sinai Hospital, New York

This paper aims to share with you a perspective from studies I have been coordinating over the past several years under the aegis of the MacArthur Foundation Research Network on Successful Aging. The MacArthur Foundation has a set of networks in various areas of health, primarily in human development and in mental health. The Network on Aging was established 6 years ago as an interdisciplinary, long-term research approach to aging.

The interdisciplinary group includes basic neuroscientists, physiologists, sociologists, physicians, and methodologists. We work together designing research projects in animal and human populations to evaluate the factors that permit older individuals to function successfully. The members of the group are Marilyn Albert, Lisa Berkman, Daniel Blazer, Carl Cotman, David Featherman, Caleb Finch, Norman Garnezy, Robert Kahn, Gerald McClearn, Guy McKhann, Richard Mohs, John Nesselroade, Edward Schneider, and Teresa Seeman.

Although one of our aims has been the establishment of an approach to field studies of characteristics of aging populations, from both a financial and a time point of view, this is not a dominant part of our effort. Much of our work has been basic neuroscience.

In this paper, I would like to describe the conceptual background and the products to date and the current activities related to these field studies of successful aging.

Let me begin with an overview of the rationale for these studies. Our approach basically is

that most research related to aging has focused on, and perhaps has been preoccupied with, disability. We have measured disability in different ways and focus on the losses that occur with advancing age and the various diseases that occur increasingly frequently with advancing age. In the MacArthur studies, we have tried to evaluate what is generally considered to be the normal population of the aged. Therefore, we exclude those disabled individuals who have been the focus of much of the research of most investigators.

The term “normal” is not informative. The population of “normal” individuals included individuals who are in fact at substantial risk, and the term “normal” implies that things are as they were meant to be, that they should not or cannot be changed. We view this “normal,” nondiseased population as including individuals that can be stratified into different groups. The two major groups we identify are “usual” aging and the smaller group of “successfully” aging individuals. The challenge to all of us is to enlarge the proportion of this “normal” aged population that are aging successfully.

We see the usual aging group as having a mix of characteristics that are functions of aging per se, the intrinsic aging process and functions that are the result of the passage of time, exposure to elements, etc. Our basic hypothesis is that there is less to aging than we thought. The intrinsic aspects of aging are less important than previously thought, both from a physiological point of view and from a sociological and behavioral

point of view. The acquired aspects of aging play a very important role in determining the functional capacity of individuals. Usual aging, as we see it, includes factors that vary considerably between individuals with both intrinsic and extrinsic determinants. These usual aging characteristics are associated with significant attributable risk and they are, in many instances, modifiable.

Variability is particularly important in the physiologic aspects of usual aging. Most data sets do not show significant differences between individual increases in variance with advancing age in social and behavioral characteristics. But in physiological characteristics, almost all of the data sets show increasing variability. This is true of most, if not all, physiologic characteristics, including blood pressure, blood sugar response to glucose challenge, bone density, cardiac and lung functions, renal function, immune response, many central nervous system characteristics, and the capacity to metabolize and eliminate many pharmacologic agents.

With regard to the intrinsic and extrinsic determinants, let me review one example from the study by Vestal on antipyrine clearance with age conducted with members of the longitudinal study of the National Institute on Aging based at the Gerontology Research Center. In this cross-sectional study, there is a highly statistically significant effect of age on antipyrine clearance. However, there was marked variance in the data, and detailed analysis demonstrated that an extrinsic lifestyle factor, cigarette smoking, described a greater proportion of the variance in the data set than did age. Much of what initially appeared to be an "aging effect" actually was due to differences in smoking prevalence across different age groups.

Thus, in this case and many others, there might be less to aging than we thought, and more of what we attributed to intrinsic aging might, in fact, be acquired.

Another example relates to blood sugar. There is a remarkable increase with advancing age in post-glucose challenge blood sugar levels. In apparently healthy nondiabetics who are not obese and not on any medicines, it has been found that, in older individuals who did not have an adequate diet and were not very active, 53 percent have abnormal glucose tolerance tests. In a group of older individuals with normal diet but low physical activity, only 33 percent have abnormal glucose tolerance tests. In a group of older individuals with normal diet and normal activity, only one-sixth have abnormal glucose tolerance tests.

An important aspect of "usual" aging factors is the risk attributable to them of subsequent serious illness and functional loss. In a study of usual aging by Zavaroni and colleagues, the relationship between blood sugar and blood insulin levels and age, weight, activity, and medications of workers in an Italian pasta factory was evaluated. On invariate analysis, significant effects were found for age, weight, and medications on the dependent variables of blood glucose and insulin. Insulin levels are particularly important because hyperinsulinemia, common in older persons, is an independent risk factor in the development of coronary disease. However, when partial correlations were calculated with regard to insulin, the effects of age decreased and increases in insulin were found to be related more to other extrinsic factors (that is, obesity, activity, and medications) than to age.

The risk of usual aging characteristics is of prime importance. A study of interest in this regard was conducted by Donahue and colleagues. This 12-year followup of 6,400 nondiabetic men, who were ages 45–70 years at entry from the Honolulu Heart Program, related the 1-hour postprandial glucose to the subsequent risk of coronary disease. In this "normal" population, using the risk of the development of

either a fatal or nonfatal heart attack, they found that increasing glucose level in the normal population was associated with a more than twofold increase in the risk of fatal heart attack and an approximately 50-percent increase in the risk of nonfatal heart attack.

Finally, there are increasing data from a number of sources that show that many of these factors of usual aging are indeed modifiable.

Chapter 4

Models of disability

by Pierre Minaire, M.D., School of Medicine,
University Jean Monnet, Saint-Etienne

For many years now, life expectancy has increased slowly but steadily. Unfortunately, the mortality rate and life expectancy do not provide a sufficient description of the real health status of populations. A growing interest in chronic diseases and chronic conditions (for instance post-traumatic or secondary to genetic abnormalities) has fostered a renewed interest in the concepts of disability and disablement. Medically speaking, consequences of disease are appreciated not only in terms of mortality, but also morbidity. On extended life spans, medical diagnosis tends to become less important than existential problems of daily life, for individuals as well as for institutions, policy makers, or epidemiologists. International comparisons show that a major difficulty resides in the definition of disability and, more particularly, disablement.

Disablement is a process related to an experience of disease. At first sight, health can be defined at least as the absence of disease, but is it only that? What is disease? What is health? The answers to these questions are a prerequisite to the analysis of theoretical models. The models have to be constructed on clear definitions or concepts that will guide the choice and the design of relevant instruments.

Biomedicine, as it is defined in Western cultures, includes a wide array of knowledge, practices, organizations, and social roles dealing

with “diseases.” Disease is what physicians and biologists study. Disease signifies an abstract biological condition, independent of social behavior. It is also a deviation from a narrow range of physiological and biological variables that are common to the human species.

Illness is the clinical situation of the patient suffering from a disease. Little consideration is usually given to the sufferer in this concept, much more is given to the disease itself. This attitude of separation is fostered by longstanding traditions of medicine, and of physicians, and has constituted the basis for an abundant literature, including dramas, comedies, and even tragedies, as well as technical reports.

Health is certainly related to freedom from disease. But this negative, monofactorial definition can be poorly applied to the emerging field of chronic diseases, in which the current distinction between the medical and social aspects of illness appears to be nonoperant. At the present time, health is also defined as a complete state of physical, mental, and social well-being; or the capacity to function optimally in the individual’s environment; or an adaptation to the environment (or to the milieu). Thus, the development of a disease “does not simply eliminate or incapacitate an individual in some mechanical sense, but rather affects the individual’s capacity and performance as a participating member of a highly interdependent group” (1).

Initially, these definitions were supposed to be unmeasurable. The recent focus of interest on disablement (conceived as a process leading

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to disability and handicap) has fostered the development of techniques to measure health such as it is defined above (2).

In summary, the shift over the past 30 years from:

1. "survival" to
2. "freedom from disease" to
3. "the individual's ability to perform his daily activities" and to
4. the positive themes of "well-being" and "quality of life"

explains and supports the four theoretical models that can be currently identified: the biomedical model, the ICIDH (WHO) model, the situation handicap model, and the Quality of Life model.

The biomedical model

It can be defined as the following sequence, based on the concept of disease:

etiology —> pathology —> manifestation

This model has been criticized by many researchers, who state that biomedical diseases are usually and inadequately considered to be "common" to humans and to social groups. Conversely, it has been observed that biomedical diseases are not only defined by negative anatomical, biochemical, and physiological variables, but also particular physical, cultural, and social factors. Diseases are therefore neither invariable nor universal (3).

In reality, this accurate observation should not overlook the fact that some variables related to disease are of some prospective value for the assessment of the disablement process, at least as key elements of the introduction of the individual into the process.

Three groups of useful biomedical variables can thus be identified: diagnosis and lesions, symptoms, and other related indicators, particularly physiological and economic.

- Diagnosis and lesions: it was observed long ago that certain diagnoses and lesions are associated with a high probability of disablement. Diagnostic labeling is certainly not enough to characterize the quality and the severity of the disability and handicap, but it may constitute a relevant and even valid portal of entry into the disablement process and can be used as such in demographical and epidemiological surveys. However, it must be remembered:

1. that there is no "linearity" between the type and severity of the diagnosis and lesions and the consequences of the "disease"; and
2. that the indication of the degree of dependence expressed by the diagnosis remains unreliable when compared to the valuable information it provides for the management of the disease.

- Symptoms are also important for determining the acute medical management (4). Nevertheless, it has been shown that symptoms such as exertional chest pain, chronic productive cough, breathlessness, and exertional pain in the calves (intermittent claudication), have a consistent rank order in the daily-life activities that people are unable to perform. This order is modified with increasing severity and multiplicity of symptoms.

- Other related indicators, such as:

1. blood glucose levels, respiratory, or cardiac parameters; or
2. consulting rates, number of days in hospital, and number of days in incapacitation

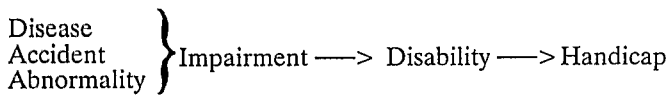
constitute obvious potential indicators of possible disabling consequences. Their real value in this respect has to be precisely assessed.

The ICIDH model

In 1980, the World Health Organization (WHO) presented the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) to support the identification of the consequences of diseases (5). The construction of the conceptual model is based on four principal events:

- “something abnormal occurs within the individual.
- someone becomes aware of such an occurrence.
- the performance or behavior of the individual may be altered as a result.
- the awareness itself, or the altered performance or behavior to which this gives rise, may place the individual at a disadvantage relative to others.” (5)

This succession of events goes from an interiorized to an exteriorized experience, and to a socialization of the experience. This has been clarified by the proposal of three dimensions, which can be represented in the following sequence:



The meaning of the different terms may be summarized as follows:

Impairment—Any disturbance to the body’s mental or physical structure or functioning. The impairment is characterized by a permanent or temporary loss or abnormality of psychological, physiological, or anatomical structure or function in a tissue, organ, limb, functional system, or mechanism in the body.

Disability—A reduction or loss of functional capacity or activity resulting from an impairment. Disability is characterized by excesses or deficiencies of customarily expected behavior or functions, and represents the objectification of

impairments through their effects on everyday activities.

Handicap—The social disadvantage resulting from an impairment and/or a disability, entailing a divergence between the individual’s performance or status and that expected of him by his social group. Handicap therefore represents the social and environmental consequences of impairments and disabilities.

These three dimensions constitute an original conceptual framework largely discussed, if not yet universally accepted. These dimensions are highly recognized as a tool for analysis and a sound basis for the design of relevant instruments for the assessment of the disablement process. The development of measurements of physical functioning has followed this framework: from impairment scales toward measuring disability (functional limitations and activity restrictions) (6,7) and subsequently handicap (fulfillment of social roles, mobility, physical independence, occupational abilities).

The main advantage of the ICIDH model is that it provides a common “language” for the numerous and various actors of handicap. This is probably due to the resolute shift away from the biomedical model. It is also incidentally an efficient teaching instrument. The model is applicable to individual assessment, as well as to population surveys and samples (8). It is useful for prevention and planning. Finally, it avoids the usual partitioning between the medical and social consequences of disease (9,10).

The main criticism formulated against the ICIDH model is the excessive emphasis placed on the individual experience as a source and support of the disablement process to the prejudice of the role of the environment. Secondly, the concept of temporal or causal sequence cannot be applied as a fully developed description of disablement experience because it remains difficult to draw a clear dividing line between each of the conceptual elements.

The situational handicap model

Disablement is a process which unfolds with time. More precisely, disablement is a variable depending on life situations. These situations take place at different moments of the life process and may vary with time. Life is a combination of macro-situations (school, housing, professional activities, sports, family life, etc.), composed of micro-situations (driving, moving in and out, opening doors, windows, cans, etc.), which all constitute a particular environment.

Handicap is the result of the encounter between disability and the situations of the environment. The disability process thus includes many aspects of the environment analyzed in terms of situations. Disablement constitutes a social system functioning in a given environment. The description of the system corresponds to a description of its structure at a given time. It is an "open" system, exchanging permanently and regularly with both the cultural and biophysical components of the environment (11).

The analysis of the situational disablement involves separate analysis of:

1. the individual biomedical, psychological, and social process;
2. the disabling situations experienced by the person or the group;
3. the environment of the system, assembling cultural, ecological, physical, economic, legal, religious, administrative, and other aspects (12).

This implies an internal and an external equilibrium of the system. Situational disablement tends toward a balance between individual, situational, and environmental inputs and outputs. This balance is necessarily readjusted from time to time, sometimes frequently.

The model also implies the *integration* of the individual into an environment and of the environment into the personal experience, but, through the concept of situation, it allows a

differentiation of the individual experiences or systems. Conversely, it would be inaccurate and even dangerous to reduce the process of disablement exclusively to a situational experience by erasing or ignoring the biomedical and psychological history of the individual. If such a danger remains theoretical in population surveys, for instance, it might acquire practical importance when action is implied, particularly by well-meaning and over-enthusiastic institutions or agencies concerned with the social treatment of handicap.

The quality of life model

The term "quality of life" means different things to different people, reflecting a wide array of knowledge, experiences, perceptions, and values. Quality of life has been an implicit component of medical care since ancient times. More recently, the increasing participation of patients in health care has moved the center of determination of quality of life from the physician to the person concerned.

Quality of life has often been a "catch" expression not based on a precise definition. It is usually admitted that quality of life is a multi-dimensional concept that covers several domains, motivations, or social indicators: functional status (self-care activities, mobility, physical and role activities); disease and treatment-related symptoms; psychological functioning; social functioning; spiritual or existential concerns; safety of the environment; adequate housing; decent and guaranteed income; love, respect, freedom, etc. It is usual to single out health-related quality of life (HRQOL), which can be defined as "the value assigned to the duration of life as modified by the social opportunities, perceptions, functional states, and impairments that are influenced by disease, injuries, treatments, or policies" (4).

Two conceptual frameworks apply to the quality of life model:

- One is the ICIDH model, in which quality of life appears to be closely related to the dimension of handicap.
- The other is a concentric series of circles determining successive boxes going from disease in the center, to personal functioning, psychological status, general health perception, and social or role functioning.

The difficulty in this model lies in the inter-relationship between the global assessment of quality of life (for example, “How are you?”) and the separate assessments of the components of quality of life. This has led to the design of composite batteries of measurements including generic and disease- or condition-specific measures. Whatever the choice, the composite measures should be submitted to analysis by components in order to consider the contribution of each concept or category to an overall score.

Some objective and synthetic measurements of fitness (defined as the positive nature of physical activity), impairments, or functional limitations or activity restrictions are claimed to approach or even to be representative of the individual’s quality of life. In reality, the term “quality of life” should be reserved to the subjective assessments by individuals, which have been proved to be quite reliable. Quality comes from the Latin “qualis” (translated “such”) and means: that which makes or helps to make anything such as it is. The life of a person is such as to be defined, assessed, evaluated, by this person first. This represents the particular operational difficulty of the quality of life model.

Operational considerations for the assessment of disability and handicap

The four models of the disablement process identified above are in fact complementary to each other. It is possible to distribute and combine them along a unifying model (figures 1–4) of the disablement process.

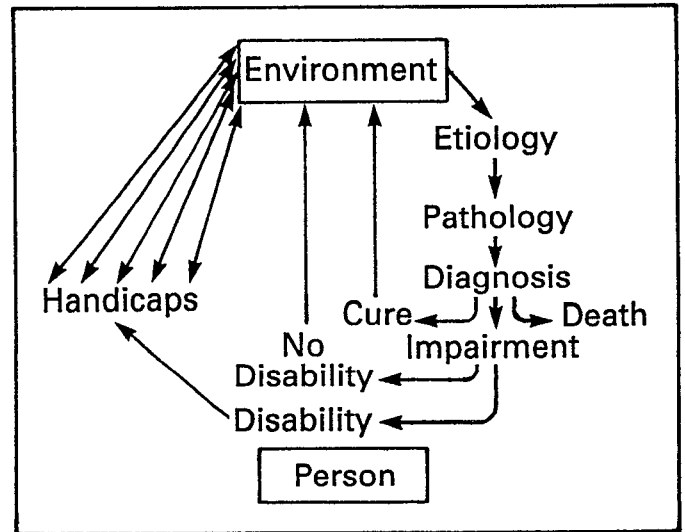


Figure 1. A unifying conceptual scheme of the disablement process

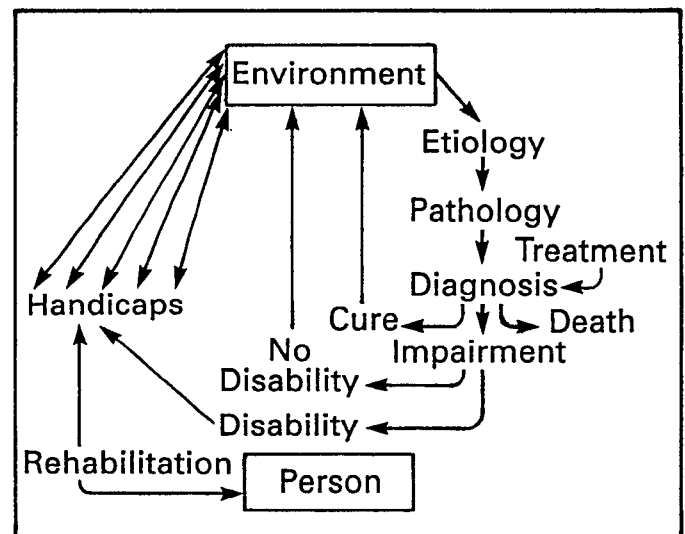


Figure 2. The place of the treatment and of the rehabilitation in the global scheme of disablement

In such a modeled construction, the role of the environment specific to the person or to the group, in its broadest meaning, appears to be fundamental. It will be also noted that handicaps are multiple and that they may result from one or several situations of everyday life, as well as from one or several biomedical problems. The medical or psychosocial rehabilitation procedures may alter the process in a positive way. This scheme applies to developed, as well as to developing, countries.

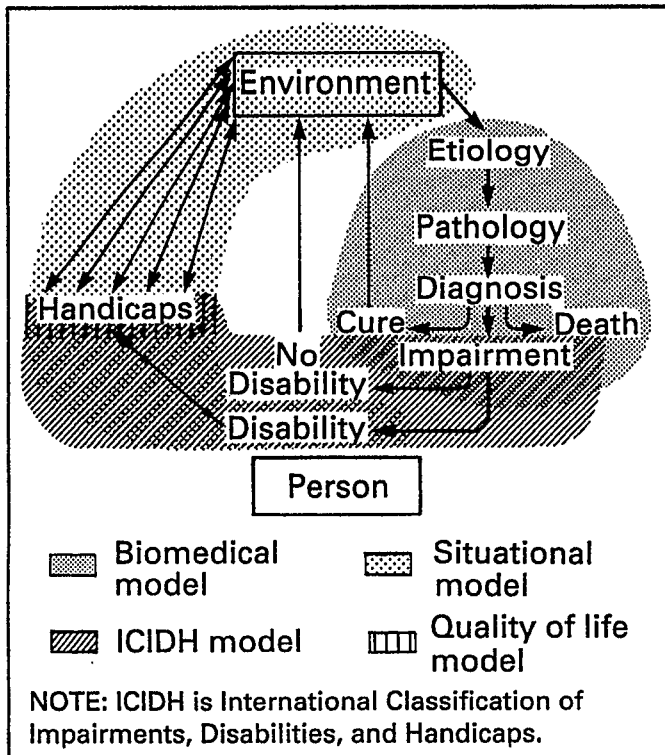


Figure 3. The four theoretical models of the disablement process along the conceptual scheme

Some operational guidelines can be established from these conceptual models:

- The ICIDH concept constitutes the clearest, most consistent, and cross-disciplinary conceptual framework, a basis for common definitions and language, and a tool for the

analysis of disablement, whatever the objectives of the analysis (population surveys or censuses, consequences of diseases, elaboration of policies, etc.).

- The three-dimensional ICIDH concept is a model for surveys of prevalence of disablement. Its usefulness for surveys of incidence of disabling chronic conditions remains questionable: the linearity of the chain of causality along the three dimensions has to be demonstrated, and the types of inter-dimensional transitions have to be defined.
- Disease and impairment are primarily the concern of medical services. Disability and handicap, which are the fundamental components of the process of disablement, are the concern not only of rehabilitation clinicians, but also of those professionals dealing with education, transport, housing, or employment of disabled persons and above all of the persons with difficulties themselves.
- Diagnosis, biomedical parameters, and health economy indicators are useful but not sufficient for the analysis and design of measuring instruments of the disablement process.
- Disease and disability have very different definitions. The existence of a particular

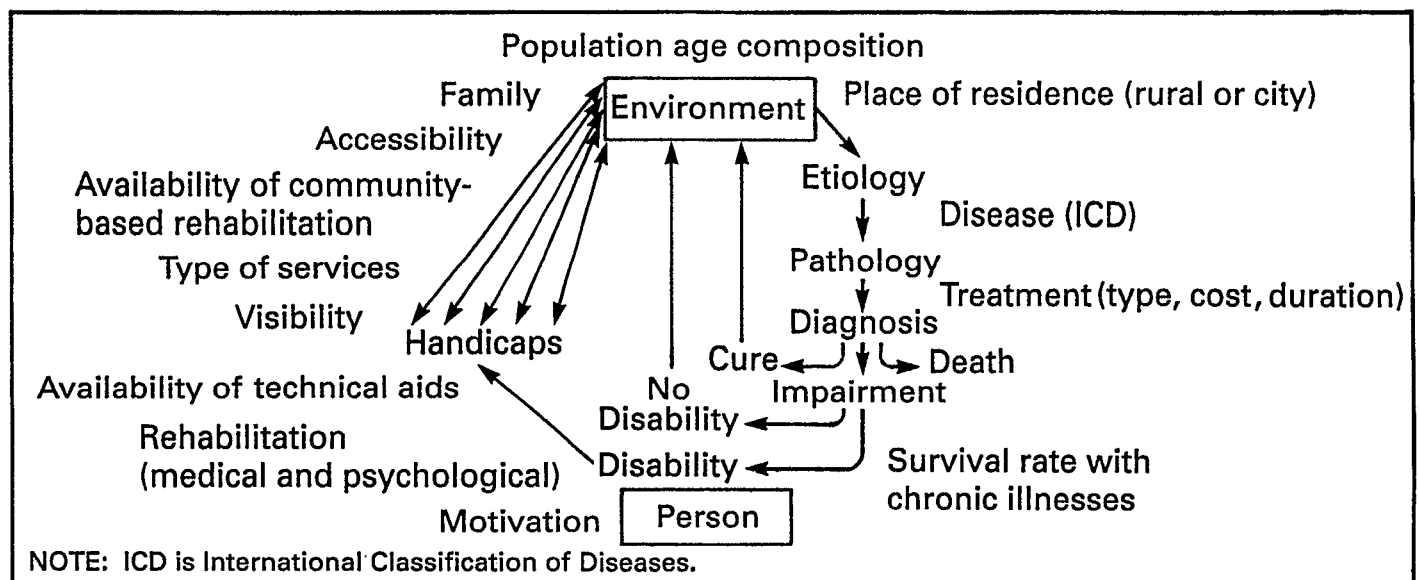


Figure 4. Factors likely to modify the process of disablement

disease, whatever its potential severity, is not always associated with a corresponding disability. The same remark applies to the comparison of the definitions of impairment and disability.

- It should be recommended to classify or define the Healthy Life Expectancy measuring instruments and surveys according to the most suitable model to which they refer (biomedical=class I or type I, for instance, etc.). This would facilitate the comparability of existing materials and the interpretation of collected data.

Disability is measurable. Specific measuring instruments exist, which give a score and a profile of disability for each individual. It is possible to determine function-related groups of individuals. Handicap adds a degree of dependence, severity, and disadvantage to disability. Disability is a predictor of the adjustment to social life. Handicap is a component of the adjustment to social life. Thus, the most reliable indicators of disability at the present time (7) are the activities of daily living and locomotion; the most reliable indicators of handicap are physical independence (to be distinguished from autonomy) and mobility. Neither disability nor handicap is value free, but handicap and quality of life depend very closely and singularly on cultural factors.

Handicap, and the self-assessed quality of life related to it, are the combination of three distinct elements:

- The consequences of diseases, impairments, and disabilities
- The history (medical and social) of the person
- The relationship to the broadly defined environment

Two of these elements are intrinsic to the person, one is extrinsic. The permanent inter-relationship between extrinsic and intrinsic elements is complex, and probably varies with

situations, tasks, places, etc.

It is of utmost importance to consider what can modify the sequence of events and factors which constitute the disablement process. Some of the modifying factors can be identified (figure 4):

- The *disease* itself, as it is classified for instance in the International Classification of Diseases (ICD). Each etiology, each pathology, has obviously its own handicapping potential. However, the age, the type of aging, and some particular frailty have also an influence on the disablement process, beyond merely initiating it.
- The *treatment*: the type, amount, availability, and side effects of treatments can alter the course of the disablement process.
- The *survival* rate with chronic illnesses or impairments.
- The *motivation* to live with an impairment and/or to reduce the disability and the resulting handicaps. Motivation is certainly individual but may have sometimes collective aspects.
- The *rehabilitation* work is aimed at preventing and reducing disability. It includes medical and psychosocial rehabilitation. Its availability and type should be considered, with particular attention given to the necessity and availability of technical aids. Considerable differences may exist between and within countries. Developed countries try usually to rely more heavily on technical aids, which are theoretically cheaper than human assistance, but with limited success so far.
- *Visibility* of disabilities and handicaps modifies substantially the whole process. This has led to a general underestimation of the handicapping consequences of visceral disorders. In less-developed countries, and for historical reasons in western countries, attention is only or primarily devoted to blind or deaf persons, amputees, or those with atrophies of limbs, for instance.

- The *types of services* available, run by state or local government, or nongovernmental organizations.
- *Community-based rehabilitation*, proposed by the WHO for the developing countries, is applicable to developed countries, and particularly to elderly people. It relies on the social interactions, within a geographic area, of persons with various ties, and not only on professional medical and psycho-social rehabilitation. The presence of such a structured supporting network allows continuous rehabilitation work, sticking to the individual needs and likely to modify positively the disablement process.
- *Accessibility*: physical access to the environment, but also to services, benefits, etc. Accessibility is an important factor of adjustment with handicaps, if they are considered as the results of the encounters of persons and environments. As such, it is a fundamental component of the disablement process.
- *Family*: marital status, age, size, cohesion of the family, composition of the family, degree of acceptance of the family, the role assigned to the family by the professionals and the community: all these constitute a prime factor of integration at the outcome of the disablement process (see, for instance, the classical problem of families having to cope with cases of dementia or stroke).
- Demographical indicators, such as the *population age-composition*, or *geographical* factors (rural areas versus cities, for instance): the handicap resulting from urinary incontinence is somehow reduced in villages in comparison with big cities.

Synthesis and conclusion

The end results of the disablement process can be analyzed in terms of disability and/or handicaps. The best indicators are summarized in the following table:

<i>Disability</i>	<i>Handicap</i>
Locomotion	Mobility
Activities-of-daily-living abilities	Physical independence
Communication/cognitive	Social interaction

Among the dimensions of handicap, mobility is certainly the least culture-bound, but nevertheless remains culture-bound to a certain degree. Compare, for instance, the mobility required and expected from an old lady in Minnesota, Florida, or New York City; or Denmark and Sicily, two distant parts of the European Economic Community. Physical independence and above all social interaction are more subordinate to the behaviors, knowledge, know-how, and abilities, which constitute the culture of a human group or of a society.

Differences between countries in the field of disablement are based not only on economical development, but also on biophysical and cultural features, which determine for instance the ratio between human and technical solutions. International comparability goes with simplicity of questionnaires (for example, four items, four questions). Comparability within a country needs more comprehensive, precise, and specific questionnaires.

Scores or their equivalent, although simple to use and versatile, are less meaningful than profiles. Disability and handicaps are in fact a set of several components. The whole model of the disablement process should be applied to any disease, diagnosis, or symptom, with use of each of its components. At each level of the process, the interacting factors should be taken into account, and the corresponding prevalence rates calculated. This exercise applies to any type of economical development, and constitutes a set of tools for policymakers, as well as economists, clinicians, statisticians, or demographers. Some research is being conducted in this direction, with fruitful results so far.

The disablement process is finally a synthesis of medical, sociological, and anthropological

analyses made in the reality of human projects and activities.

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Chapter 5

Crosscutting issues on long-term care: Introduction

by Diane Rowland, Sc.D., Department of Health Policy and Management, Johns Hopkins University School of Hygiene and Public Health

I am most pleased to be here with you this morning and to moderate this panel on international studies of long-term care. My new responsibilities with the Kaiser Commission on the Future of Medicaid will direct my work toward analysis of the Medicaid program and the problems of the low-income population. As a result, many people think that my work is primarily with low-income families. Yet, next to Medicare, Medicaid is our most important program for the elderly population in the health care area, both as the program that fills Medicare's acute care gaps and as the only program in the United States that provides for long-term care coverage. During the next 5 years with this new commission, I envision devoting a substantial effort to looking at the way we cover long-term care services for the elderly under our Medicaid Program. I hope the Commission's agenda will build on the efforts of the Commonwealth Fund Commission on Elderly People Living Alone, whose work is now drawing to a close.

In the policy world in the United States today, we have a growing interest in looking at an international perspective and learning from the experiences of other countries. It is with great interest that I watch us looking at the Canadian health system, the German health system, and other international experiences as we try and shape our acute care policy. Recently, we have also begun to recognize that our long-term care problems are not unique in the world and that we can learn much from the programs

of other countries. During the last 6 years, the Commonwealth Fund Commission on Elderly People Living Alone has tried to learn as much as it could about the U.S. elderly population, especially those who live alone, and has tried to identify ways to improve their economic well-being and their health status.

In working with the Commission, we identified through many of the reports, studies, and data tapes from the National Center for Health Statistics the 9 million elderly people who live alone within our 29 million noninstitutionalized elderly population. We looked at the typical elderly person living alone and found that she was a widowed woman, often in her eighties, generally struggling to make ends meet on a meager income. We found that she was five times as likely as her married counterparts to live in poverty; and yet she only had a one in five chance of getting cash assistance from the Supplemental Security Income Program, which is the Federal cash assistance program designed to help get the elderly out of poverty. We found that being poor brought other problems as well. The poor were twice as likely as those with higher incomes to have serious health problems; and yet, in the United States, the elderly poor were those most often with the most inadequate health insurance coverage. A third of the elderly poor people are assisted by the Medicaid program to cover additional services and cost sharing under Medicare, a third have to buy private health insurance supplementary coverage to help

with Medicare, and a third rely solely on Medicare. As a result, many of our elderly people are driven into poverty by their medical expenses. Studies by the Commonwealth Commission showed that nearly one-third of those with incomes between 100 and 150 percent of poverty were actually impoverished when their medical expenses were taken into account. Being alone also often meant being without family or friends to whom one could turn for assistance with long-term care needs. Without formal support, those living alone were at high risk of losing an independent lifestyle and having to go to an institution.

Since its inception 6 years ago, the Commonwealth Commission has sought to document and heighten public awareness of these serious problems and to develop recommendations to improve the economic well-being, insurance protection, and at-home assistance with long-term care needs of the elderly population. As we struggled to find innovative approaches to improve the life and economic and social well-being of elderly people, we have looked abroad for options and answers to some of the dilemmas facing the United States.

We have just completed an international survey of elderly people living in the United States, Canada, Great Britain, West Germany,

and Japan. Nine hundred elderly people were interviewed in each of those countries to provide a snapshot of the differences between the five countries. We sought to learn whether the phenomenon of living alone that we saw in the United States and its association with poverty and the greater risk of health needs would hold among the other countries. We asked about life satisfaction, quality of life, and perceptions of the adequacy of health systems, social security, insurance, and long-term care systems.

The survey was in the field during the summer. We are now in the process of analyzing the results. We hope they will give us some new insights into the problems facing elderly people in the United States and help us learn how common these problems are across some of our comparison countries. In conducting this survey and now in trying to analyze it, we have become increasingly concerned with the difficulties of cross-cultural comparisons. The work of this group and the work of this meeting are most timely and important. Discussions such as this will help to lay the groundwork for all of us to be able to gain better insights into how to address our health and social problems with regard to the elderly population, as we work toward more common definitions and a better understanding of cultural differences among countries.

Chapter 6

Cognitive function and the elderly

by Barry Gurland, M.D., Sidney Katz, M.D.,
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For most patients, and for their caregivers, the meaning of dementia, like any other disease, lies in its impact on quality of life. Insofar as it applies to problems of mental health, quality of life has received detailed attention elsewhere (1). Some of the quantitative methods presently available for study of health-related impairments in qualities of life will be applied in this paper to the resolution of conflicts between reports of rates of dementia (Alzheimer's disease and related disorders) in the general elderly population.

Although the emphasis in this paper will be on quantitative analysis, a few qualitative statements from clinical descriptions of the course of dementia can help bring the issues into focus. With specific reference to Alzheimer's disease and related dementias, threats to quality of life are seen in the progressive loss of abilities required for self-direction and independence. Fear, anguish, and despair may accompany the recognition of relentless deterioration. As the disease advances, persons afflicted lose authority over personal decisions and are exposed to a growing risk of being wrenched from their accustomed environment. There may be repeated blows to the person's self-esteem, aggravated by an undermining of respect and affection from others. A heavy burden may be placed upon the caregivers. For all concerned, there is a drain upon emotional and material resources that normally would go to fulfilling more desirable needs.

This picture of the impaired quality of life inflicted by dementia is bad enough for the

sufferer and caregiver, but it also looms large in the minds of those who are not yet afflicted but are growing older, and in the concerns of those who must plan for the provision of formal care for the victims of this condition. Policymakers and planners are accordingly influenced to give priority for research and service investment to illnesses such as Alzheimer's disease and related dementias "that make life miserable for the elderly" (2).

The size and distribution of the problem posed to society and its members by impairments in quality of life associated with dementia are usually estimated by turning to prevalence and incidence rates of dementia. These estimates are often extended to the projected rates of dementia over the next few decades. Whatever the magnitude of impact on quality of life that is presently attributed to dementia, the position is likely to be aggravated by the steep rise in rates of dementia that is anticipated in the next few decades. Nevertheless, considerable uncertainties exist about the true rates of dementia that should constitute the multiplier effect in drawing inferences about the impact of dementia on quality of life, either now or in the foreseeable future.

Data on rates of dementia for the elderly population residing in the community are conflicting; for example, there is substantial variation in the results (3) from 27 published epidemiological studies that yield prevalence rates for moderate and severe dementia in the

population 65 years of age and over. The rates range from 1.1 percent to 7.8 percent, with a median of about 4 percent. In a more recent report (4), Evans, Funkenstein, and Albert reported a prevalence rate of 10 percent for dementia among the general elderly population 65 years of age and over. Among those 85 years of age and over, the rate is usually about 20 percent. But here again, there is a range of rates with a high of 47 percent in the report just cited. Furthermore, discrepancies in reported rates for dementia have recently been shown to occur when different screening techniques are applied even to the same population (5). Probable dementia was determined by conventional cut-points on five widely used screening scales. The absolute and culturally relative rates varied widely, depending on the scale applied.

Most projections of future rates for dementia have been extrapolated from current age-specific rates that are only half as high as some that have been reported (that is, the projections may be grossly underestimated, if certain reports are taken as the current benchmark). To make matters worse, rates for persons 85 years of age and over, which are less than half those recently reported, contribute particularly heavily to projections into the future.

Breadth of concepts of dementia

A parsimonious explanation for differences in reported rates for dementia is that different concepts are at play: Some are narrow (more stringent) and some broader (more inclusive) in demarcating groups of persons with dementia. Moreover, these various concepts of dementia might carry very different implications for impairments in quality of life. Thus, there remains great ambiguity about what it means for quality of life that there may be, for example, twice as many dementias among persons in the older age group than previously accepted. It cannot be assumed that twice as many is twice as bad. Yet a perspective on the relationship between rates

for dementia and levels of quality of life should (and does) influence the way aging is viewed and services are planned.

These issues also have a bearing on diagnosis of dementia in individual cases. The implications carried by a diagnosis of dementia for the quality of life of a particular patient may vary with the concept of dementia used by the physician who makes the diagnosis.

These and similar questions about the meaning conveyed by the diagnosis of dementia at an individual and population level can be addressed by operationalizing and applying to epidemiological data on dementia the concepts and language of health-related impairments in quality of life. This process will be demonstrated in the strategies for data analysis presented in this paper.

Data from a community survey

Narrow, broad, and marginal concepts of dementia were examined in a large study of the general elderly community population (6) ($N=445$ in New York City; $N=396$ in London; samples combined in these analyses). The narrow group fitted operational criteria (7) for a clinically significant diagnosis (that is, having relevance to prognosis and management). The broad group was abnormal according to statistical classification (latent class analysis); this group designates cases additional to the narrow group but also includes nearly all those falling within the narrow definition. The marginal group was defined as those who were classified as broad but not narrow. It is notable that the broad group of dementias ($N=54$) was about twice as frequent as the narrow ($N=31$), replicating the problem of choosing between the previously mentioned conflicting reports of prevalence rates in dementia.

In examining the relationship between the concepts of dementia on the one hand and quality of life on the other, the marginal group can represent that which is peculiar to the broad as opposed to the narrow group.

Relationship to domains of quality of life

The first domain in quality of life considered here is the subjective sense of being able to gain access to one's memory store. The frequency with which this quality of life domain is impaired in the narrow and marginal concept groups of dementia and in normal (that is, neither demented nor depressed) elderly persons is shown in table 1, part A. The narrow-concept dementia group tends to be uniformly worse off than the marginals and significantly worse than the normals; the marginals are only variably worse than the normals.

The next domain of quality of life examined is performance in the activities of daily living (table 1, part B). The narrow-concept dementia group again tends to be consistently worse than the marginals and significantly worse than normals. The marginal dementias are closer to the normals than to the narrow-concept dementias with respect to several dependency items (for example, preparing own meals, dressing) and intermediate between normals and narrow-concept dementias for other items (for example, shopping, business); the marginals are significantly different from normals in only 2 of 11 items. This dimension affects the quality of life

Table 1. Comparison of narrow and marginal concept dementias in some quality of life indicators: United States/United Kingdom community study

Quality of life indicator	Percent with problem			Significance ¹	
	(a) Narrow-concept dementia (N=31)	(b) Marginal-concept dementia (N=23)	(c) Normals (N=614)	a versus c	b versus c
A. Subjective memory					
Is impaired.....	61	44	22	+	+
Impairment is a problem.....	13	4	4	(.061)	-
Impairment is embarrassing.....	13	4	4	(.061)	-
B. Dependency					
Does almost no chores.....	52	9	9	+	-
Can't prepare own meals.....	48	9	9	+	-
Difficulty putting on shoes.....	13	4	5	-	-
Difficulty dressing self.....	32	9	4	+	-
Difficulty grooming self.....	23	9	4	+	-
Problems using bath or shower.....	36	17	7	+	-
Others help with chores.....	65	35	26	+	-
Others do shopping.....	84	61	44	+	-
Problems handling personal business...	55	30	5	+	+
Needs help walking outside.....	39	22	4	+	+
Needs help with toileting.....	7	4	1	(.064)	-
C. Subjective distress					
Often feels lonely.....	13	0	7	-	-
Not enough energy.....	29	9	17	-	-
Sad or depressed.....	39	13	15	+	-
Almost nothing enjoyed.....	23	9	3	+	-
Lies awake due to pain.....	13	9	5	-	-
Life not worth living.....	6	0	1	-	-
D. Disturbing behavior					
Irritable, argues.....	16	0	11	-	-
Not eating well.....	13	4	5	-	-
Forgets safety precautions.....	16	9	2	+	-
Sits around listlessly.....	45	35	24	+	-
Sleeps 2 or more hours during the day..	3	4	2	-	-
Medicine at night to sleep.....	10	17	12	-	-

¹Chi-square (2-tailed) with Yates correction has probability of <0.05.

NOTES: Combined sample N=841 (New York City N=445, London N=396). Excluded here are persons with clinical levels of depression.

of the caregiver as well. Cases fitting the different concepts of dementia will likely affect the caregiver in different ways and to a different degree.

As can be seen in table 1, part C (subjective distress), the narrow-concept dementias also tend to be the most depressed. Two of the key mood items (that is, concerning depression and enjoyment) are significantly more frequent in the narrow-concept dementias than in the normals. It is evident from this that dementias *can* talk about their feelings. Overall, and perhaps surprisingly, the marginal dementias tend *not* to be more depressed than the normals. Not a single item of depression is more frequent in the marginals than in the normals. This runs counter to the expectation that early or mild dementias are more likely (than more advanced dementias) to be aware of their declining abilities and thus to be more depressed.

A selection of those behaviors characteristic of dementia that might disturb the quality of life of a caregiver is shown in table 1, part D. There are different frequencies of these behaviors in the two concepts of dementia: Mostly these behaviors tend to predominate in the narrow-concept dementias. Two behaviors that can be very troubling to caregivers (that is, regarding safety and apathy) are significantly more common in the narrow-concept dementias than in

normals. There is no consistency, and no statistically significant differences, in the relative frequencies of disturbing behaviors between marginal dementias and the normals.

Data from primary medical care (table 2)

The relation between breadth of concept of dementia and dimensions of quality of life was further examined in a sample of 205 Hispanic patients in a primary medical care group practice (8). This study provides supportive evidence of systematic differences between concepts of dementia of varying breadth. Four levels of severity of dementia scores were selected on the basis of a scale of cognitive impairment. Level 4 corresponds to the narrow-concept dementias, and level 3 (again based on latent-class analysis) corresponds to the marginals. Level 2 comprises normals with poor cognitive function.

As seen in table 2, the narrow-concept group of dementias tends to be more impaired than the marginal group (as well as the normals with poor cognitive function) in basic and instrumental activities of daily living and also tends to be worse off in three (subjective) dimensions: depression, sense of stress, and self-perceived health. However, the only significant difference between marginal dementias and normals is in the activities of daily living. Severity of pain is at

Table 2. Comparisons of narrow and marginal-concept dementias in some quality of life indicators: Hispanic cohort study

Quality of life indicator	Percent with problem				Significance ¹		
	(a) Narrow- concept dementia (N=11)	(b) Marginal- concept dementia (N=32)	(c) Poor cognitive function (N=60)	(d) Normals (N=101)	a versus d	b versus d	c versus d
ADL or IADL impaired	45	33	25	8	+	+	+
Depressed	45	24	30	16	+	-	(.054)
Sense of stress	54	27	18	13	+	-	-
Self-perceived health	63	36	35	29	+	-	-
Severity of pain	36	42	38	38	-	-	-

¹Chi-square (2-tailed) with Yates correction has probability of <0.05. None of the a versus b or a versus c or b versus c comparisons are significant.

NOTES: ADL is activity of daily living. IADL is instrumental activity of daily living.

about the same level of frequency for all the groups. This latter finding might be expected and thus may increase confidence in the other findings.

Conclusions

The findings of epidemiological studies of dementia should be interpreted in the light of the concepts of dementia employed and their implications for the quality of life of the patient and caregivers. Data analyzed in this paper consistently indicate that a narrow (stringent, conservative) concept of dementia carries with it more serious consequences for quality of life than does a broader (more inclusive) concept. This contrast is seen more sharply where the nonoverlapping group of (marginal) dementias is delineated for comparison with the narrow concept.

Prevalence studies of dementia in the general elderly population, using the narrow concept described here, have produced rates in the usual ranges found in the literature. It is reasonable to assume, therefore, that reports of higher age-adjusted rates are a reflection of a broader concept of dementia.

Thus the recent reports of an unexpectedly high rate for dementias in the elderly population give no cause for new and exaggerated apprehensions about the damage to quality of life caused by this set of conditions. There need be no change as yet in the current and future projected rates of dementia, *at least as it applies to the concept of dementia that has conventionally formed the empiric foundation* for policy and planning of services, for caregiver concerns, and for lay attitudes toward aging. This assertion is intended to maintain that the current and projected magnitude of the problems imposed by dementia on quality of life is great, but not outside the challenge that society has already accepted as feasible.

Documentation of the impacts on quality of life inflicted by defined concepts of dementia

allows an informed selection to be made of specific concepts for specific purposes. Reports of exceptionally high rates of dementia can be understood in terms of the quality of life implications and accepted or rejected in that light. Similarly, differences between screening techniques in rates of classification of probable dementias can be interpreted and resolved in terms of the breadth of concept of dementia entailed and the quality-of-life impairments attached to the particular concepts of dementia reflected by the screening technique. Ambiguities surrounding the diagnosis of the borderline case of dementia can be correspondingly clarified. The meaning behind these classificatory alternatives can be seen through the application of quality-of-life indicators. The value of each alternative can be portrayed, and a reasoned choice among the alternatives can be made. *Each concept may have a unique usefulness.*

Quality-of-life issues should be a main reference point in the consideration of planning of policy, service programs or clinical management for the care and relief of persons with dementia and for support of their caregivers. Such planning will be more accurate and realistic where groups of persons with dementia or its subtypes are described in terms of quality-of-life consequences. An illustrative presentation of quality-of-life profiles in dementia groups reflecting varying breadth of concept has been offered in this paper. In order to allow due consideration of quality-of-life issues in policy, planning, and service, it should be ensured that the information on dementia generated in the health care system by administrative, clinical, and research reports includes state-of-the-art quality-of-life indicators.

Acknowledgment

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Chapter 7

Long-term care policy in international perspective

by Patrick Hennessy, M.Sc., Organization for Economic Cooperation and Development, Paris, France

Why the interest from the Organization for Economic Cooperation and Development (OECD)? The theme of this symposium, “Meeting the challenges of an aging world,” is central to many of the social policy concerns of OECD. For a number of years, OECD has been exploring and setting out the policy consequences of aging populations (1).

We are approaching the midpoint of a century of change, from 1950 to 2050, during which the proportion of the population 65 years of age and over in the 24 countries of OECD will increase from less than 10 percent to more than 20 percent. During the next 40 years, this aging process is particularly marked by increases in the numbers of the elderly 80 years of age and over, in what has been termed the “fourth age.”

This is bound to have profound consequences for the programs that OECD countries have introduced to improve the social conditions and health care of the elderly. Relevant studies that have been carried out by OECD in this area include studies of the financing and delivery of health care (2), of the reform of public pension schemes (3), and of retirement-age policies and practices (4). These are now being complemented by a comparative study of the long-term care of frail elderly people.

What are the policy issues? It is remarkable, given the considerable variation of the organization of welfare in OECD countries, that there appears to be such a degree of consensus about the central policy issue. Most countries are concerned about the extent to which publicly financed long-term care is provided mainly within

institutionalized settings. Care in an institutionalized setting is now generally seen as unsatisfactory in personal, social, and financial terms:

- In *personal* terms, both because of the evidence that elderly people prefer to stay in their own homes and because they frequently become more rather than less dependent in institutions.
- In *social* terms, because this type of care isolates many of the most elderly members from the rest of society.
- In *financial* terms, because of the high cost of institutional care to both the public purse and to elderly persons themselves.

At the same time, there is a recognition that for elderly people with high levels of disability and personal dependency, the degree of personal care required can frequently not be provided, either by their family or by formal care services, outside of a controlled setting. The overall policy objective, therefore, is to limit the need for admittance to such institutionalized settings to a necessary minimum.

This raises a number of related policy issues that the OECD project will address:

- What is the extent of informal care by families for their elderly members? Can its extent be influenced by public policy? And, given the need, within an aging population, to maximize the potential of the younger population, should the policy goal be to encourage or to replace family care?
- Many countries have invested in an extension of formal home care services. To what extent

do these services, in addition to their undoubted effect in improving the quality of life, have a substantial quantifiable effect on the number of elderly people entering institutional care?

- Is the home environment in which many elderly people live part of the problem rather than part of the solution? Could home improvements at limited cost help to reduce the need for institutionalized care?
- What are the implications for the institutionalized sector of a policy bias to home care? If those entering such settings are the most dependent elderly, is it likely that the frequently expressed hope of making care institutions more “home like” can be realized?
- Finally, the OECD study will be particularly concerned to explore the methods of funding of care programs, both within institutional settings and in community settings. In most countries long-term care is primarily a public cost, through direct provision, through government-run health insurance, through income-related compensation for poorer elderly people, or, more usually, some combination of these methods. Can private funding of care, either through an extension of long-term care insurance or the release of housing equity, help to reduce public costs and add to individual choice? And can public policy objectives for long-term care be achieved if the funding of care is largely through private means?

Three examples of policy development

The timing of the OECD study is not coincidental. It reflects the extent to which this is a live policy issue in many countries. Following the initial establishment of welfare institutions in the 1930's and 1940's, the development of long-term care has been largely incremental. Public-funding mechanisms have similarly developed in what has frequently been an ad hoc fashion to meeting the needs of the moment.

In recent years, a number of countries have embarked on fundamental reviews of this policy area, with the aim of establishing greater overall coherence. This has often been sparked by a realization that current funding structures represented a perverse incentive by supporting institutional care more generously than home care alternatives. It is an important role of OECD studies to act as a kind of mutual learning process through which countries can exchange new ideas and the results of putting those new ideas into practice. It will be a central goal of this study to show what alternatives to institutional care have been introduced, and with what success, and how countries have adapted existing service structures to meet new objectives.

As an indication of the value of such a learning process, let me briefly describe examples of policy development of three quite different countries that have recently reviewed the direction of their long-term care policies and arrived at surprisingly similar conclusions. The three countries are Australia, Denmark, and Great Britain.

Australia

Australia is an extremely large country with a federal political system and a liberal market economy. Its population, while growing, is relatively small in relation to the size of the country. It is in comparative terms a young population, in which, however, the proportion of elderly people is growing considerably more rapidly than the average. There was little government direction of the development of long-term care, and a large private nursing home sector grew up. It was encouraged by federal funding, which fully reimbursed nursing home costs.

From 1985 Australia saw the introduction of a new policy on care of the aged, with the aim of limiting the nursing home sector and encouraging the growth of both home care services and of congregate housing for the elderly as an alternative. Within the first 5 years of this policy, the

proportion of federal funding going to these two alternative sectors has doubled, and the growth in nursing home expenditures has been well below the rate of growth of the elderly population.

Two important policy tools in achieving this have been the establishment and monitoring of overall planning totals for the number of nursing home beds and the strengthening of pre-admission assessment procedures (5).

Denmark

Denmark is, by contrast, one of the smaller countries and characteristically for Scandinavia, has a population in which the aging process is far advanced and an integrated welfare system in which government plays a major role as both provider and funder. A policy review, which was initiated in 1979, suggested that policy should now pursue three goals: greater continuity in the life of the elderly person, avoiding the disruptions caused by moving in pursuit of appropriate care; greater self-determination in the outcome; and a better framework for the application of individual resources.

Again, a combination of restricting nursing home entry and extending home care was pursued. From January 1988, no more nursing homes will be opened. Many older nursing homes have been demolished or rebuilt as apartments for the elderly or as specialized units for small numbers of demented elderly people. In many local authorities, the basis of payment for care is also undergoing change, with elderly people retaining their pension (previously largely withdrawn on admission) and paying rent for the board and lodging aspects of the home. Personal and nursing care are directly funded by government.

There has been a considerable expansion of community care, with the objective of having the home of every elderly person at risk connected

to a 24-hour emergency call system. This is linked to a home help service that is increasingly organized in groups of 10 to 15 home helpers, who work as a team looking after the elderly in their neighborhood.

Again, two important policy tools have been the use of overall planning controls on nursing homes and strengthened assessment teams able to use funding in a flexible way.

Great Britain

Great Britain is a relatively small country, but with a long history of urbanization and a population approximately 3 times that of Australia and 10 times that of Denmark. It also has a long history of providing public institutions for the care of elderly people.

With the extension of the welfare state in the 1940's, this tradition of institutional care was continued, with the provisions of long-term care in hospitals under the National Health Service and in residential homes provided by local authorities. However, during the next 30 years, there was a considerable expansion of alternative home nursing and home help services from the same two public authorities. By 1981, Great Britain had a fairly low proportion of its elderly people in institutional care.

The pattern of predominantly public provisions was altered in the 1980's by the extension of public funding for private nursing and residential homes. Public funding for private care expanded by a factor of 10, while the public providers sought to reduce further their relatively expensive commitments to long-term institutional care.

Great Britain now had a mixed economy of care, but the public funding of private care extended only to institutional care and with limited assessment requirements. There was concern that funding was now too heavily loaded on

the institutional option, and a report on community care by a prime ministerial advisor in 1988 was followed by a government white paper in 1990 setting out the principles of a new system to be in place from 1993.

Under these new arrangements, elderly people entering a home will be responsible, as in the new Danish scheme, only for paying, via their pension, for the board and lodging element of care. Local government social services departments will be responsible for the assessment of needs and have discretion to fund either home care services or the care element of institutional care. The demand for nursing or residential home places and, therefore, the size of the sector will be largely set by the extent to which assessment teams seek to make use of them.

In each of these three cases, from widely different beginnings, we see the same policy objectives of establishing a limit, based on essential need, for nursing home places; of an increased emphasis on imaginative home care alternatives; and of a central role of assessment teams in managing a more diverse system.

The future of the project

Preliminary results will be available for a meeting of OECD social policy ministers at the end of 1992, and a final report will be published early in 1994. I would be delighted if you would invite OECD to share the full results of this project with you at your next symposium.

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Chapter 8

Crosscutting issues on other international research on aging: Introduction

by Gwendolyn S. King, Social Security Administration

It is my pleasure to welcome you to this third day of the conference, and it is my pleasure to be a part of this final plenary session of the International Symposium on Aging.

When Dr. Feinleib invited me to participate in today's session, it struck me what a great opportunity this symposium presents. Even though virtually everyone of us, we citizens of the world, will grow old and, therefore, have a personal vested interest in knowing as much as we can about the aging process, our collective desire and quest for that knowledge have not yet matched our actual need for it.

This is particularly true in the public policy arena, where I spend my waking hours. We spend a great deal of time in government, in politics, talking about aging and the aged, debating what policies need to be established, what programs need to be created, and what regulations need to be implemented in order to provide the best possible benefits for the people who have reached retirement age. We debate these issues. We propose solutions. We devise programs and regulations, and we do so without being as careful and meticulous and as curious as we should be about the data that we use to reach some of these important decisions.

As Commissioner of Social Security, I am very sensitive to the misconceptions that exist about the elderly and the aging process and the potential ramifications that can result from those misconceptions. That is why I value so greatly the work that you perform at your respective institutions and that you have been sharing here this week.

My work, of course, leads me into the economic and financial aspects of the aging process. Virtually every older American receives Social Security benefits. Ninety-five percent of the American public takes part in the Social Security System—those who are paying into the system as taxpayers as well as those who are currently receiving benefits from it. There are over 40 million people on our rolls, and that number is going to be growing by 600,000 per year.

You may not be discussing in specific terms social insurance programs for the elderly, but I nonetheless have a very strong interest in the ideas that you are discussing and developing in areas such as health promotion, vitality, and the overall well-being of the elderly. I believe there is a very strong link, particularly among the elderly, between financial security and physical and emotional well-being.

One of the leading misconceptions, at least in this country, about the elderly is that they are generally well off. There is a widespread belief that the elderly are more financially comfortable than their sons and daughters, who may be struggling to make ends meet. Those who harbor that misconception generally fall into two schools.

One group takes a benign pleasure in the fact that there are programs like Social Security that take care of senior citizens and, therefore, they do not have to worry about them. Then there is a group that is more aggressive in its belief that every dollar you spend on a senior citizen is a dollar you take away from somewhere else, and we ought to start pulling back some of those resources.

And both of them have this notion that senior citizens are very well off. But if it were not for benefits from the Social Security program, benefits that are not making anyone wealthy, the poverty rate among older Americans in this country would escalate anywhere from between 10 and 15 percent to over 50 percent. That illustrates the economic vulnerability of our older citizens.

I found out very quickly, as Commissioner of Social Security, how dangerous it is to believe that everyone who is elderly in this country is already receiving Social Security. There are thousands and thousands of older men and women in the United States who are eligible for supplemental security income, a program that pays benefits to people who are elderly, blind, and disabled, with little income or assets.

There are people who are not receiving these benefits because they have not applied for them. They are doing without benefits that could provide them the basics of food, clothing, and shelter. At Social Security, we are making a concentrated, aggressive effort to find those senior citizens, people who are disabled and who have very low income, and get them the benefits to which they are entitled.

We are succeeding to some degree, but the relative invisibility of some of these citizens tells us just how difficult our job is. Many of these people may have lived their entire lives in the United States and may not be able to speak English. So it does not do us any good to publish fancy pamphlets in English to send out to people who do not speak English. Many of our senior citizens who are in this category have never learned to read and, therefore, fancy pamphlets again do not do the job. We have a very extensive outreach effort using people to carry our message, the message that if you are elderly and low income, you may be eligible for our program.

Then there is an issue that is of great concern to me, an issue you can help me address. That is the plight of elderly women in this country. By the year 2000, there will be an estimated 19 million older women in the United States, and they will make up a majority of this Nation's elderly population. There is also the strong likelihood that they will have a very difficult time in their old age because of factors like low-paying jobs, lack of pensions, widowhood, and the time they take away from a career in order to raise a family or give care to an elderly person.

The financially poorest demographic group we serve at the Social Security Administration is older women living alone. I would be interested in seeing greater study and attention given to these women and how strong a connection exists between their financial plight and what they experience in terms of chronic illness and decreased lifespan.

As our nations continue to age, there is so much more we need to know about aging and the aging process. As we debate public policy about economic security programs like Social Security, about health care assistance programs, long-term care, and the types of medical assistance most suited for and needed by the elderly, we need to be guided by more than feelings and political pressures. We need to be guided by knowledge and information. As one who has the responsibility to implement public policy, I respect and value very greatly the guidance you will be providing.

With the knowledge you develop and disseminate, we can begin to do away with the myths and misconceptions we have about the elderly. We can begin to better understand the real needs that exist among older Americans, and we can do a better job of anticipating the needs that will arise in the remainder of this decade and in the next century.

Chapter 9

International research on healthy life expectancy

by George C. Myers, Ph.D., Center for Demographic Studies, Duke University

My presentation on this, the third day of the symposium, provides an opportunity to reflect on earlier presentations and to discuss some points that reflect both prior thought and knowledge acquired at this meeting. It also enables me to present information about several international programs that are in process that complement in important ways the ICE program. I will specifically discuss the activities of the International Network on Health Expectancy and the Disability Process (known by the French acronym REVES), the series of 13 studies conducted in three World Health Organization (WHO) regions, and the WHO Program for Research on Aging (PRA) plans for studies on the Determinants of Healthy Aging. Dr. Maggi, in the next presentation, will present other information about the overall PRA research program. And finally, I will discuss how I see research evolving on health and health care of the aging in the decade before the next millennium.

The REVES International Network was organized in 1989 by representatives from the French National Institute on Health and Medical Research (INSERM); the Conseil des Affaires Sociales, Quebec, Canada; the headquarters of WHO; and the Center for Demographic Studies of Duke University. Jean-Marie Robine of INSERM has been the coordinator of the Network. It consists of more than 108 researchers representing 73 research and statistical offices in 17 countries and 4 international organizations. Joan Van Nostrand has been the National Center for Health Statistics (NCHS) representative.

The main activities of the Network are organized around twice-yearly workshops that have been held in Quebec City; Geneva; Durham, North Carolina; and most recently in Leiden, The Netherlands. Future workshops are planned for Ottawa and Montpellier, France, in 1992. Proceedings of these workshops are in process and, in addition, two bibliographies and Statistical World Yearbooks have been published.

From the outset, the Network has been bonded by a desire to coordinate and standardize actuarially based measures of healthy life expectancy (variously termed "active" or "disability-free" life expectancy). The guiding principle behind these efforts is that such measures provide an important means of assessing aggregate levels of individual functioning over time and among important subcategories of the population. As such, measures of this type may be viewed as important indicators of one of the main components of health status and one that can complement aggregate measures based on morbidity or mortality. Recognition of this fact can be seen in the introduction of such measures in the 1991 WHO 3-year monitoring report on the "Health for All by the Year 2000" strategy, in which Target 4 notes that "the average number of years that people live free from major disease and disability should be increased by 10 percent" (1). Whether this is a meaningful target remains to be seen, but it does indicate the growing use of such measures. A like objective using healthy life expectancy is also included in the U.S. national health promotion and disease

prevention goals for the year 2000, as we were informed the other day.

The goals of the Network set forth before the first Workshop were the following:

- To consider conditions necessary for comparing various measures of Health Life Expectancy (HLE), with a particular view to international geographic comparisons
- To consider means of interpreting chronological series of HLE measures
- To examine uses of HLE in sociohealth planning and organizations
- To examine the possibilities of procedural standardization of data collection and calculation of HLE

These are goals that are shared by many activities in the ICE project.

Each of the workshops has been designed to emphasize different themes, such as time-series research, geographic variations, measurement concerns, and policy implications. From these workshops has come a growing body of data on measures of healthy life expectancy from an increasing number of countries and across many time points. The last meeting included presentations of such data for Taiwan, China, Sweden, Switzerland, and Myanmar to mention only a few countries. Such data are compiled by INSERM and are now available in a Statistical World Yearbook (2). Most of these measures reported to date have been calculated using the so-called "Sullivan method," named for a former staff person of NCHS, who first proposed such measures (3). However, a major priority of REVES, as noted earlier, has been the assessment of alternate procedures for calculating healthy life expectancy.

As is true of most international collaborative activities, there have been organizational and thematic modifications that have evolved over the past few years. Most importantly, discussions have led toward the creation of subcommittees to address underlying issues related to the

measurement of healthy life expectancy. These now include groups dealing with the following:

- *Conceptual harmonization*—especially concerning the use of the WHO International Classification of Impairments, Disabilities, and Handicaps as a conceptual framework and classification device. Dr. Minaire's earlier presentation reflects upon some of these efforts, which also include activities related to measurement instruments.
- *Mental deterioration*—assessment of appropriate measures of cognitive functioning, dementia, and behavior disorders
- *Use of national health surveys*—for both temporal and comparative analysis
- *Research designs*—particularly the use of longitudinal and panel studies
- *Policy relevance*—how results may be translated for policymakers

In my view, the major accomplishments of REVES to date have been threefold:

1. It has emphasized the importance of various measures of healthy life expectancy as aggregate *indicators* that are appealing to researchers and meaningful for policymakers in tracking developments within countries over time and among subgroups of populations. Moreover, comparisons among countries allow us to assess whether improvements in life expectancy are accompanied by increases in healthy life expectancy, the dimensions of which were laid out in the survival curve presentations made earlier. This can lead to important theoretical insights into societal disability transitions that may be associated with demographic and epidemiologic transitions. These efforts should be seen as highly complementary to those of the United Nations Statistical Office in developing and disseminating international statistics on disability—the so-called DISTAT program (4).

2. REVES from the outset has been concerned with international standardization of concepts, measurements, and calculations that can enable us to make comparative analyses.
3. Not the least of these efforts has been the evolving attention given to national and regional *longitudinal* studies that permit us to improve the calculations of HLE and examine more fully the processes that underlie changes in health statuses during the course of life, especially in later life.

Indonesia
Sri Lanka
Thailand

The fact that these studies were deemed sufficiently important to be undertaken and their successful completion indicates the growing attention that aging concerns are receiving in *developing* countries. Preliminary analyses from the studies reveal that health and related issues are of major importance for older persons even in countries in which the percents of such persons in the total populations are relatively low compared with those in more developed countries. The rapidly growing numbers of older persons in developing countries, produced in large measures by large entry cohorts and improved survival to older ages, presage significant emerging problems in health care demands and pressures on traditional family support systems for older persons. These demands are particularly onerous for countries facing strong competing demands for scarce resources. Of paramount importance are issues arising from changes in family and household structures and population redistributions within these developing countries.

Levels of HLEs for these countries are shown by the data presented in figures 1–4. They reflect the proportion of years of life expectancy free of six personal (Katz-type) activities of daily living (ADL's), based on prevalence rates for persons who cannot perform the task or who need assistance in the task. In the absence of up-to-date life tables for many of these countries, life expectancies at age 65 were derived from contemporaneous life tables supplied by the Center for International Research of the U.S. Bureau of the Census. Sullivan-type calculations were employed. The analyses were jointly prepared with Vicki L. Lamb.

Life expectancies of males at 65 years of age range from a low of 9.4 years for Fiji to a high of 14.6 years for Sri Lanka (figure 1). The proportions of remaining lifetime at age 65 consisting

WHO regional studies

Next, I would like to turn our attention to a series of country studies sponsored by the WHO regional offices. These Epidemiological Surveys of Health and Aging have been coordinated by Dr. Gary R. Andrews, Centre for Ageing Studies, Flinders University, South Australia. The Duke University Center for Demographic Studies has been involved in some comparative studies of data from these studies. A major feature of these studies, which have been conducted in 13 countries, is the use of comparable research designs in terms of age range, questionnaire content, field procedures, and data processing. The surveys have been completed in the following countries:

Western Pacific Region (WPRO)

Fiji
Republic of Korea
Malaysia
Philippines

Eastern Mediterranean Region (EMRO)

Bahrain
Egypt
Jordan
Tunisia

South East Asia Region (SEARO)

Myanmar (formerly Burma)
Democratic People's Republic of Korea

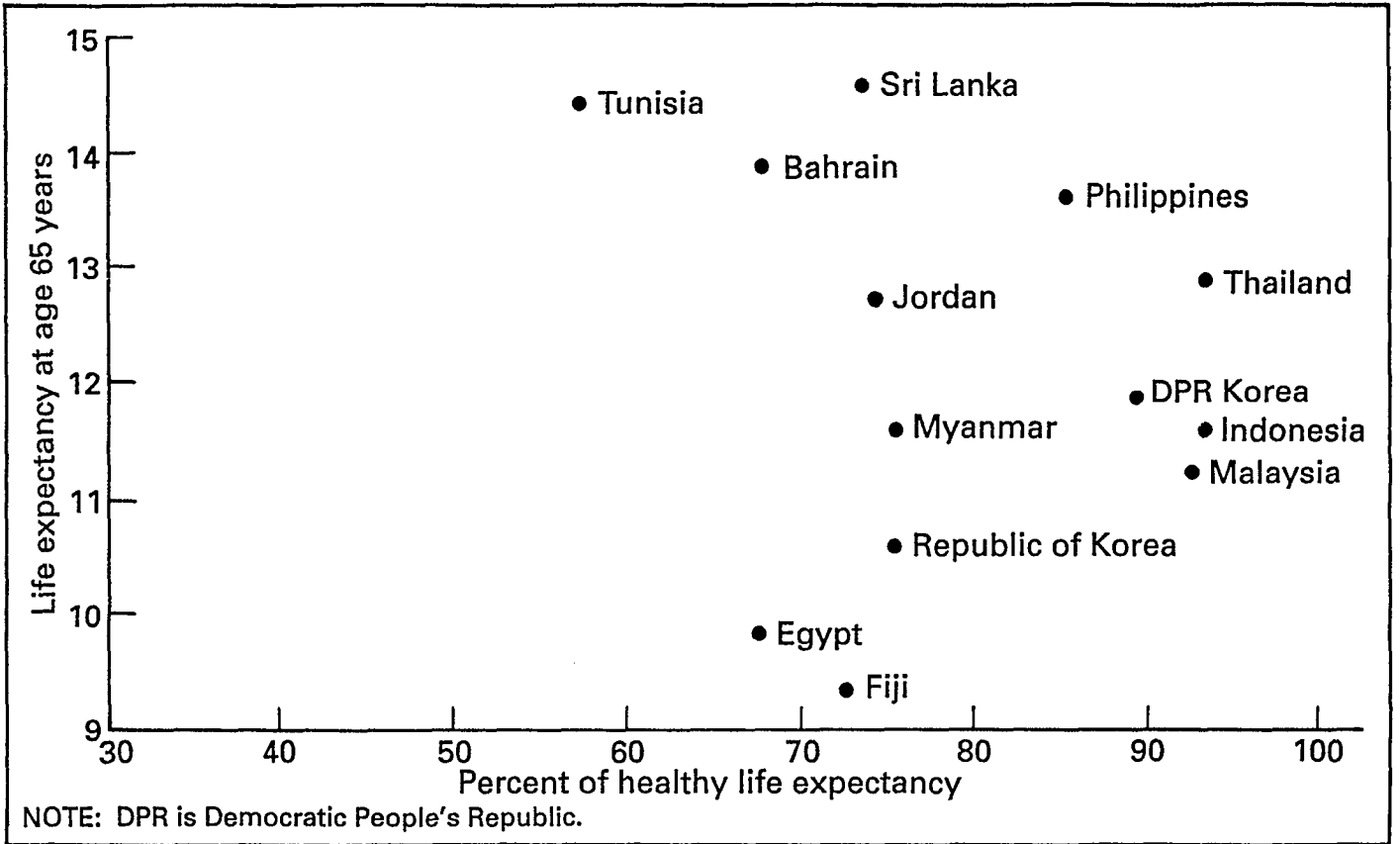


Figure 1. Life expectancy of males at age 65 years and percent of healthy life expectancy.

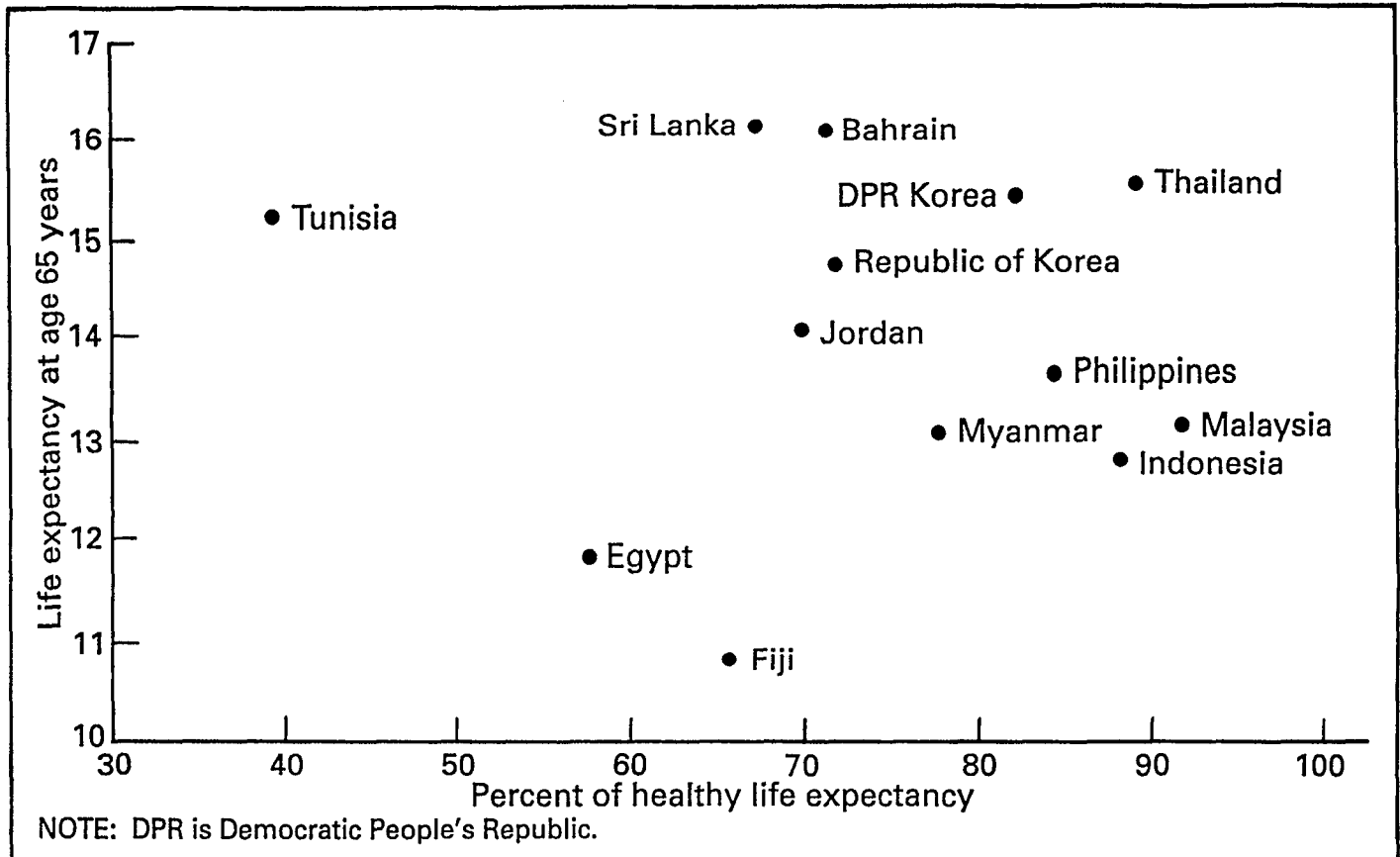


Figure 2. Life expectancy of females at age 65 years and percent of healthy life expectancy.

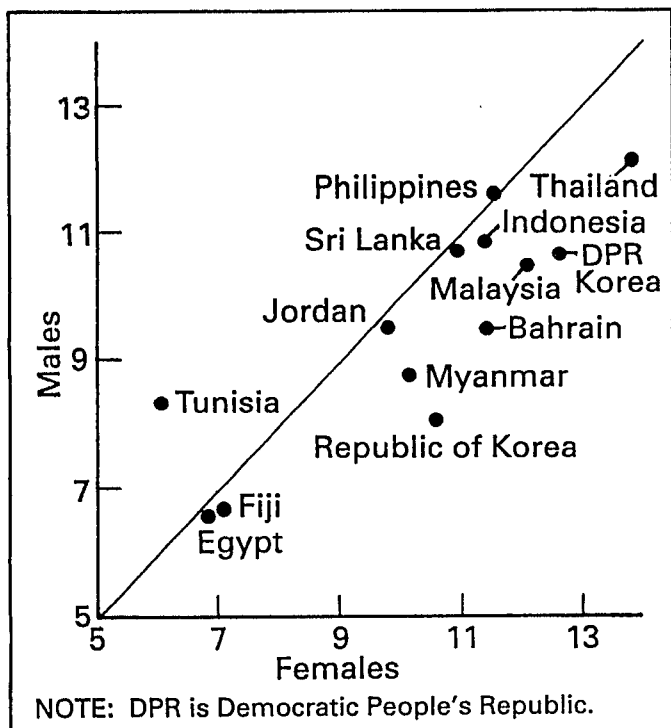


Figure 3. Healthy life expectancy of males and females at age 65 years

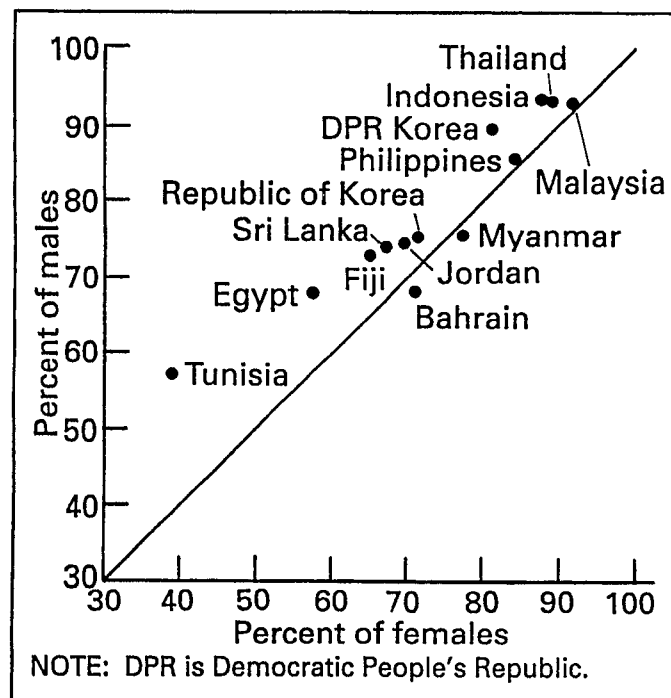


Figure 4. Percent of healthy life expectancy of males and females at age 65 years

of healthy life expectancy reveal considerably more variation among countries. The Eastern Mediterranean countries show lower proportions of life expectancy free of disability, whereas

many of the Asian countries have very high ratios. Indeed, the latter figures are considerably higher than those that have been reported previously for more developed countries. Figure 2 shows even more variation in ratios of healthy life expectancy for females than for males, along with higher life expectancy as expected, but the relative ordering of countries is much the same as that for males (figure 1).

Comparing male and female healthy life expectancy (figure 3), the distributions show slightly higher levels for males than for females in Tunisia and the Philippines, but lower levels in the other countries. *The ratios of life expectancy free of disability, in contrast, show male superiority for all but two countries* (figure 4). Thus, females tend to live longer, but a higher proportion of these years are spent in disability states. These findings are quite comparable to those reported in more developed countries.

These analyses provide only initial findings from the set of country studies. Further research that is ongoing will treat instrumental activity of daily living (IADL) measures, where appropriate, as well as ADL measures and the existence of co-disabilities. An interesting feature of the studies in three Southeast Asian countries was the use of performance tests, based on procedures used in the Establishment of Populations for Epidemiologic Studies of the Elderly (EPESE). Comparisons of the results from such measures with ADL measures should prove quite instructive. In addition, separate analyses of various ADL and IADL measures are being made, covariate analyses with important characteristics of the population, along with multivariate studies of relationships with related health conditions, physical, and mental statuses. Preliminary results indicate relatively high levels of physical impairments; sensory problems, especially sight and hearing; and considerably high levels of dental prosthesis that affect satisfactory eating behavior. The prevalence of some of these

problems appears to exceed those that have been found in developed countries, although interestingly, self-assessed health levels appear to be comparable to those found in more developed countries. The existence of considerable variations between countries and regions in age-distributed patterns of disabilities and associated health states suggests that there are characteristic disability transitions. The modeling of these cross-sectionally determined national patterns will be a first step toward developing temporal patterns that are linked to overall demographic transitions in the process of socioeconomic development.

This program of cross-sectional national studies has demonstrated, as noted previously, the wide national interest and feasibility of conducting such studies in developing as well as developed countries. These studies also provide evidence that the means for measuring important epidemiological and socially based dimensions of health status and functioning can be reasonably applied in such countries, with due consideration to cultural differences that require certain modified procedures. Finally, the data from studies of this type can yield both cross-nationally valid indicators of healthy life expectancy and, through multivariate analyses, greater understanding of the correlated factors involved in these states.

WHO determinants of healthy aging studies

Since the creation of the WHO Program for Research on Aging in 1987, with a unit attached to the U.S. National Institute on Aging, there has been an interest in conducting a series of studies of the health status of older persons as one of its three main programs. A steering committee meeting was convened in 1988 in Hawaii to formulate such a program. In spite of some difficulties encountered initially in this

particular project, plans are moving ahead to complete a research plan. I can relate some points of agreement from previous meetings and my own personal feelings about these developments.

There was earlier consensus that it would be desirable to have the studies conducted in both less and more developed countries, that the design should be *longitudinal*, and that the studies should lead toward greater understanding of the relative health and functioning status of older persons, of changes over time in these statuses, and of factors determining these states. To assess the states and their transitions, it was agreed, would require standardized procedures for obtaining assessment of individuals in the multidimensional aspects of their health, social, and economic well-being. Another aspect of the research design that was given support was the desirability of obtaining biomedical data through limited clinical examinations, even in the developing countries. Finally, serious consideration was given to the idea of obtaining information from other family members, especially of a primary caregiver in situations in which long-term care is being provided.

Although not an explicit feature of the PRA program, it was noted that a registry of cross-national research would be maintained. This could be an important aspect of the activities of PRA in following the development of longitudinal studies of older persons being conducted or planned in other countries and in offering assistance for some coordination of these studies. Indeed, one could envision a two-tier series of coordinated research activities, one that would involve more centrally designed national studies and another that would include community or regional studies that are not intended to be nationally representative. In this regard, I would note that longitudinal studies are being conducted or planned in Canada, Australia, Japan,

Taiwan, China, Israel, and several European countries; and many of these are being funded in part by the National Institute on Aging.

Such a research program can represent an evolution in the way age-related changes in healthy life expectancy are conceptualized and studied. The PRA project distinctly builds on prior efforts but offers an opportunity to integrate features of them in important new ways. In the remainder of my presentation, I would like to present my views on these developments.

Conceptualization

A new paradigm is emerging in how aging processes are conceptualized within the framework of longitudinal investigations, especially cross-nationally. Note that I already am positing that prospective research designs are crucial for furthering understanding of these processes. There have been two perspectives that have dominated our thinking on these matters. One, that probably owes its origin to a biological viewpoint, can be termed the “normative,” in which it is believed that individuals are programmed in certain ways and experience gradual deficits with advanced age. Interestingly, this view also has been embedded in most psychologically oriented longitudinal research, from programmed childhood maturation to senescence later in life. A second perspective, closely associated with a medical or epidemiological view, has an “outcome” orientation, in which risk factors are assessed that may eventually lead to certain endpoints, such as manifestations of specific diseases or death. Both perspectives may be quite broadly conceived in terms of considering the varied elements that may be involved in the aging process. However, both view the underlying processes in a deterministic way and the mechanisms are generally regarded as universal.

Rowe and Kahn (5) introduced a distinction between successful and usual aging, which would lead researchers to forego the search for simple effects of the aging process and to give explicit

consideration to heterogeneity and the role of possible interventions. However, from their formulation it is difficult to see how successful or even usual aging can be assessed, except in some subjective or residual manner. Moreover, it is clear that such efforts measure trajectories that may change over time as interventions and changes in risk behavior are modified. Another recent effort to clarify what is involved in the process of aging has been made by Fozard, Metter, and Brant (6). They stress the importance of diseases themselves in modifying the aging process and, thus, the need to consider the interactions between pathological and nonpathological processes. Both of these formulations are of considerable merit, but they still are wed to the belief that there exist some universal, but as yet unmeasurable, dimensions of the so-called aging process.

A new paradigm appears to be emerging that emphasizes the importance of examining the transitions between various states of health and ill-health, as well as disabilities, that may or may not lead to death, the absorbing state. Such a view does not neglect the importance of ascertaining the determinants and correlates of relatively healthy life states, but it does acknowledge the complex processes involved in alterations to these states as people age. The factors involved in the changes include the role of comorbidities; nondisease events; non-life-threatening health problems; environmental and situational conditions; and the role of interventions, such as behavioral modifications, medical care, and other formal and informal caregiving. In short, in this perspective, attention is directed to states of health and ill-health (including disabilities), events that may modify these states, and the age and duration-dependent nature of these complex processes.

Methodological considerations

Longitudinal studies that focus on these aspects of the new research paradigm must be

designed to determine not only static-state conditions but also the precise timing of events that may have brought about any changes in status. To do so does not mean the abandonment of fixed interviewing schedules at specified points in time but the implementation of modules that would enable the researcher to investigate the determining factors within waves that have led toward changes. Although this perspective might be considered to be longitudinal in the long term, there also is explicit attention to interwave alterations, their determinants, and consequences. A focus on these interval events would reduce problems of recall error that have limited purely retrospective studies. Other information derived from linkages with administrative or physician records could also provide important additions to establishing changes in states and their determinants.

There are a number of technical issues that could contribute in innovative ways to the design and conduct of longitudinal studies. I will summarize some of these points.

- There has been widespread development toward a focus on the context of family and household dynamics in affecting individual states and behavior. For example, one can note joint husband-wife effects on retirement decisions and the interactive aspects of other life course decisions. By analogy, it can be suggested that greater attention should be devoted to the family context as it affects health behaviors, states, and outcomes. A shift of focus from the individual to broader contexts of the family would lead to greater use of multiple respondents within families in surveys, especially longitudinal studies. Far too little attention has been given to the ways in which multiple risk factors of family members affect individual outcomes (nutrition, smoking, etc.); the interactive aspects of joint decision-making on health care-seeking behavior and compliances; and long-term care

decisions, arrangements, and outcomes. Interviewing of multiple persons in a household provides additional information that can be used for more precise assessment, cross-validation, and determining more fully the situations facing individuals in which decisions are made. It also can be used for establishing a sound basis for obtaining information from proxies in subsequent waves and, indeed, information about fatal episodes. In these regards, the flexible use of alternative schedules permits us to obtain data from individuals (for example, frail persons) who may be unable to participate fully in the interviewing process.

- A major issue that has bedeviled surveys of older persons generally has been the high levels of nonresponse. It is clear that maximizing response rates has to be given higher priority than it has been traditionally. The New England Research Institute (7) has suggested several steps that can assure this objective. They include using experienced field staff to foster respondent identification with the project, use of mixed-mode techniques in data collection, employment of comprehensive field-tracking procedures, home-based collection of physiologic data, and careful selection of proxies when appropriate.
- The appealing use of computer-assisted interviews in data collection and entry of data also has received considerable attention of late. Noteworthy in this respect has been the use of computer-assisted personal interviewing (CAPI), which makes use of laptop computers. These procedures have proved effective in improving the burdens of intricate interviewing (for example, skip patterns), ensuring that valid data entry occurs, and in the virtual elimination of coding errors. The interactive capacity of CAPI makes it possible to call up previous information from earlier interviews. These technical developments

could prove to be particularly effective in field studies conducted in developing countries, where inexperienced and inadequate infrastructures often exist.

Analytic aspects

It should be clear that many of these features of a new perspective on longitudinal studies of the process of aging rest on analytic developments that make it possible to analyze such data.

Event history analyses, multistate life tables, and other multivariate procedures, such as the grade-of-membership approach, provide analytic strategies that are particularly effective in examining both the dynamics of changes in discrete and continuous-state and time-continuous models and in covariate structural models. These more fine-grain models of transitions, as Manton (8) points out, enable us to simulate the effects of interventions on life expectancy and various levels of healthy life expectancy. Without appropriate data, such modeling is limited, and, thereby, our capacity to evaluate the kinetics of the multidimensional aging process that involves risk factors, immediate states of disease and disability, the effects of interventions and, eventually, death. The survival models implied by calculations of various aspects of healthy life expectancy provide a readily understandable means of comparing countries at varying stages of epidemiologic transitions. Focusing on transitions and the crucial components of these transitions and their covariates permits us to disentangle the underly-

ing changes and allows more valid forecasts to be made of future levels and their consequences.

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Chapter 10

World Health Organization Program for Research on Aging

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The World Health Organization's (WHO) efforts to address the health problems of the aged began in 1979 with the adoption by the WHO Assembly of its first resolution targeted to health care of the elderly, which resulted in the establishment of the Global Program for Health of the Elderly (1). Since then, many activities have been developed in collaboration with the member governments to address the problems associated with aging. The goal is to promote health and well-being throughout the entire life of the individual and to find meaningful solutions to secure comprehensive care services for the elderly. Cross-national research has been shown to be a powerful method of identifying special, as well as universal, risk factors in disease and disability as well as protective factors that lead to healthy and productive aging. A major challenge to social and behavioral investigators is how to employ their results to optimize the potential of older persons to perform rewarding roles in society. Such research can benefit older persons in developed and in developing countries of the world (2).

An important step to promote the cooperation of scientists to the accomplishment of the objectives of the Global Program was the agreement (signed in June 1987) between WHO and the U.S. National Institute on Aging to host the research component of the Global Program on the campus of the U.S. National Institutes of Health. An extensive presentation of the WHO Program for Research on Aging (PRA) has been

published (3), so it will be reviewed only briefly in this presentation.

The four priority areas selected by the Global Advisory Committee for Health Research are:

- Age-associated dementia
- Osteoporosis
- Determinants of healthy aging
- Immunological changes with aging

For each project there is a coordinating center responsible for tasks such as translation of the protocol, preparation of manuals for quality control, training, and data management and analysis.

Participating countries are chosen to ensure a wide range of cross-national variation in the variables of interest. In addition, academic infrastructures, experienced investigators, governmental support, and stability are necessary to carry out the studies.

Parallel studies are encouraged by PRA based on the following criteria agreed to by the steering committees:

- The proposal for the parallel study has to undergo a peer review and be approved.
- The Centers carrying on the parallel study must be financially self-supported and must have all infrastructures needed for the successful completion of the project.
- The instruments adopted should be the same as those used in the WHO participating centers.

- The clinical investigators should exchange documentation on clinical cases and participate in exercises to ensure agreement on diagnosis of specific conditions.
- The investigators should participate in a common training session, organized by the coordinating center and the PRA office.
- The investigators should be willing to share the data collected with the coordinating center.

Project on age-associated dementia

Population-based data on age-associated dementia are not yet available from developing countries, nor are the risk factors well identified (4).

The principal research goals of the study can be summarized as follows:

- Standardization and validation of research instruments for cross-national diagnosis of dementia and dementia subtypes
- Comparison of age- and sex-specific prevalence ratios and incidence rates of dementia across developed and developing countries
- Assessment of prevalence and distribution of risk factors across countries

The research project is envisioned in three parts:

- Preliminary phase
- Pilot study
- Field study

The preliminary phase consists of the standardization of the clinical diagnosis of dementia across centers, training of clinicians and epidemiologists, and validation of the screening instruments. The first step in the validation of the screening instruments is their harmonization, now ongoing in each participating country. The protocols have been translated and adapted to the local cultural conditions. These will be pre-tested in the local populations early in 1992 (in Canada, Chile, Malta, Nigeria, Spain, and the United States).

A 100-subject pilot study will be carried out in each participating country to test the feasibility of the study procedure and to validate the screening instrument in terms of sensitivity and specificity using the clinical diagnosis as the gold standard. Two screening tests, the Mini-Mental State Examination (5) and the Information-Memory-Concentration Test (6), will be used. Only one will be selected for the field study on the basis of the best accuracy. The cutoff scores will be selected according to the definite balance between sensitivity and specificity that might lead to different cutoff points among the participating countries and age groups.

The field study will be conducted as follows:

Time one—to screen for cognitive impairment and to identify dementia cases that will yield the prevalence ratio and the assessment of risk factors. The target population is a random sample of individuals 65 years of age and over, both free-dwelling and institutionalized. The sample size for each center is 5,000 subjects (2,500 in rural areas and 2,500 in urban areas.)

Time two (1–2 years after Time one)—to reassess the same population in order to identify incident cases of dementia.

A multiphase procedure will be used for case identification and diagnosis, as shown in figure 1:

Phase one—the screening test for cognitive impairment, the Instrumental Activity of Daily Living Scale (7), and a risk-factor questionnaire will be administered by trained interviewers to 5,000 subjects. The risk-factor interview includes putative risk factors for Alzheimer's disease (dementia or Down's syndrome in relatives, parental age at subjects' birth, head trauma); sociodemographic features (age, sex, race, ethnicity, marital status, residence, living in institutions, education, occupation); and risk factors relevant to vascular and other dementia syndromes (smoking, alcohol consumption, hypertension, diabetes).

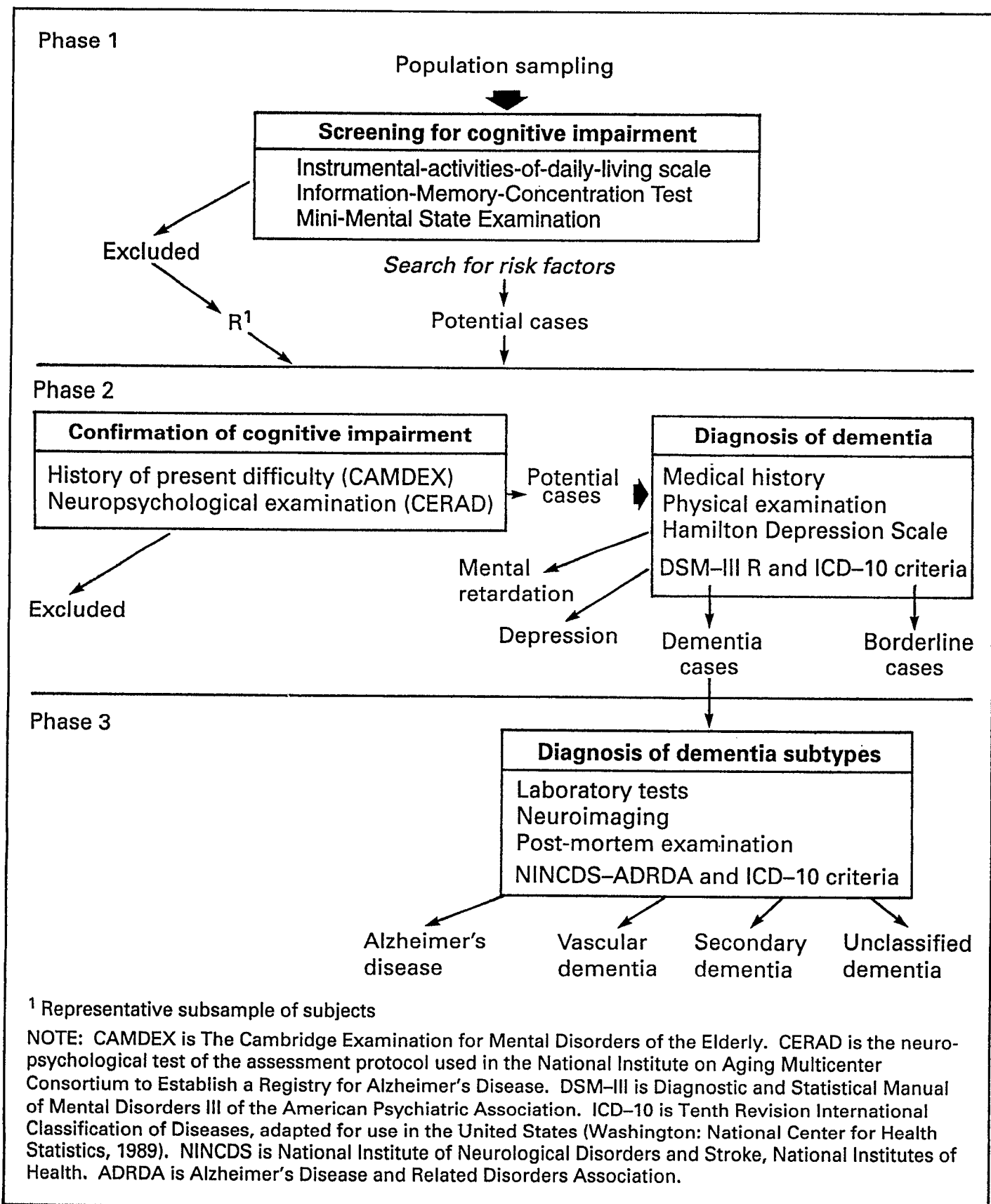


Figure 1. Multiphase procedure

Phases two and three—those who screen positive will undergo extensive clinical, neuropsychological, and laboratory workups (6,8) to confirm the cognitive impairment and to reach the final diagnosis of dementia syndrome and dementing diseases. Dementia cases will be followed after 1 year to draw up the natural history of the disease. Depressed patients (9), borderline or doubtful cases, will be followed with a 6-month reassessment until the diagnosis is confirmed.

The diagnosis of dementia and dementia subtypes is primarily a clinical decision. In order to reach a reliable consensus, a standardization exercise is ongoing in the participating centers. Records of 51 patients have been collected from all 6 participating countries and from the coordinating center, University of Florence, Italy. The patients have been consecutively admitted to the neurological departments for cognitive difficulties and have completed a diagnostic assessment. The final diagnosis was confirmed by means of either a minimum 2-year followup or a postmortem examination.

The records have been organized in a standard format and distributed to each of the 12 investigators involved in the research, together with structured diagnostic forms, to be completed according to the diagnostic criteria used in this study for dementia syndrome (DSM-III-R (10) and ICD-10 (11)), depression (DSM-III-R), and dementia subtypes (ICD-10 and DSM and NINCDS-ADRDA(12)).

The investigators are now reassessing the records. The level of agreement will be estimated on the following diagnoses:

No cognitive impairment, cognitive impairment without dementia, depression, other psychiatric disorders, dementia syndrome, probable or possible Alzheimer's disease, vascular dementia, Creutzfeldt Jacob's disease, and dementia in other diseases.

The agreement analysis is carried out by means of the Kappa index (13). The consider-

ations of disagreement will lead to suggestions for guide manuals and training sessions and to possible reiterations of the standardization exercise until a suitable level of agreement is reached. Preliminary results show that the agreement goes from fair to good for Alzheimer's disease, vascular, and other dementia.

Project on osteoporosis

The osteoporosis project is a cross-national study, with cross-sectional, case-control, and longitudinal components. It is designed to:

- a. ascertain the incidence of hip fracture in participating countries,
- b. identify risk factors for hip fracture and for the decrease of bone mass in postmenopausal women, and
- c. determine the age of peak bone mass and the distribution of bone mass in different populations by race, age, and sex.

The cross-national exploration of differences in incidence of hip fracture and in risk and protective factors will advance the development of etiological hypotheses and identify specific preventive and therapeutic interventions.

The principal research goals are the following:

- Validation of cross-national data on osteoporotic fractures
- Determination of age- and sex-specific prevalence ratios and incidence rates of osteoporotic fractures in each participating country
- Cross-national assessment of risk factors for bone loss and fractures

A cross-national analysis of hip fracture incidence rates may be useful in developing etiological hypotheses that can be tested by analytic epidemiologic studies and clinical investigations (14). The comparisons of incidence rates for hip fractures in different countries show higher rates for white than for black, Asian, and Hispanic populations. The rates are higher for white fe-

Table 1. Age-adjusted incidence rates of hip fractures per 100,000 population 50 years of age and over, by sex

Geographic area and years of survey	Age-adjusted rates		Age-and-sex-adjusted rates
	Women	Men	
Norway, 1983–84.....	1,293	551	968
Sweden, 1972–81.....	622	291	477
New Zealand (white), 1973–76.....	620	151	414
United States (white), 1983–84.....	559	207	402
United States (Asian), 1983–84.....	338	104	235
United Kingdom, 1973–77.....	275	96	196
United States (black), 1983–84.....	219	144	185
Finland, 1968.....	100	249	183
United States (Hispanic), 1983–84.....	197	90	151
New Zealand (Maori), 1973–76.....	107	182	149
Singapore, 1955–62.....	75	100	86
Africa, Bantu, 1950–64...	26	38	31

Source: Modified from: Maggi et al., Osteoporosis, International 1:232, 1991.

males than for white males, but for Asians, black persons, and Maoris, the sex ratios are often reversed (table 1).

Unfortunately, there are several shortcomings that may affect the comparison of existing data, such as:

- Difference in definition of fracture
- Difference in case ascertainment
- Difference in selection of study population
- Difference in the period of ascertainment
- Difference in sample size

A cross-national study, using the same definitions, instruments, and sampling criteria may help in overcoming most of these problems.

The research components for the WHO project are:

- Descriptive
- Etiologic
- Quantitative
- Preventive interventions

Five components are envisioned for this project:

- The cross-national annual incidence of fracture of the hip in the population 50 years of age and over will be estimated from *hospital discharge data analysis* and from other sources of health information specific to each country (for example, bonesetters in Africa).
- A *population survey* will be undertaken to validate the data available from these sources, with the goal of providing comparable incidence rates from one country to another, corrected for possible underreporting in some countries.
- A *case-control study* will be used to compare cross-cultural risk factors for fracture of the hip, such as family history (15,16), dietary habits (17–26), physical activity (27–33), medication use (34,35), sensory impairments (36,37), smoking habit (38–40), etc.
- A *study on peak bone mass*, using Dual Photon X-ray (DPX), will assess the age of peak bone mass in each country, the factors affecting the peak bone mass and the bone mass distribution in each age group (after the peak bone mass).
- A *longitudinal study* is planned in two age groups:

A group at the age of peak bone mass. The bone mass loss will be measured at a 4-year followup in individuals chosen by a probability sampling method, stratified by gender.

A group of women in perimenopause and early postmenopause (50–59 years of age). Individuals identified during the population survey will be followed for 5 years in order to study the association between the occurrence of hip fracture and bone loss, calcium intake, physical activity, and gender.

The results of these studies will constitute the background information for promoting preventive interventions.

Project on Determinants of Healthy Aging

The Project on Determinants of Healthy Aging has reached the stage of finalizing the research proposal. It is envisioned as a cross-national longitudinal study, designed to identify factors affecting the full realization of physical, mental, emotional, social, and economic well-being of individuals as they age. It is intended to provide the basis to plan for interventions aimed at promoting health and autonomy in aging populations and maintaining the well-being and productivity of older persons in all societies. It should also facilitate the assessment of the impact of the aging of the populations on the social and economic situation in developed and, particularly, developing countries (41–48).

Study design

Six countries, two developed and four developing, will be chosen by the steering committee to participate in this longitudinal study. A cohort of 3,000–4,000 subjects per country is likely to be the maximum manageable size for a longitudinal study of this nature.

Baseline data collection will include an interview on demographic, health, social, behavioral, and economic factors; a functional assessment; and laboratory tests.

Contact will be made with each study subject on at least an annual basis to determine whether functional status has changed, whether cognitive function has been altered, whether any significant life events have occurred, and the extent of supportive services used or needed. The mechanisms of maintaining contact should maximize response rate and accuracy of responses. Because it may be too costly conducting a followup home interview, alternative methods may be

employed, where feasible (telephone interview and mailed questionnaire). In the event that the subject has died or been institutionalized, independent verifications will be required.

At the second and fourth years of followup, a home interview will be conducted, similar to the baseline interview. Performance-based measures of function and venipuncture will also be repeated. The exact content and form of the interview and examination may be modified, based on previous results. All such changes will be comparable across sites and subject to the approval of the secretariat, steering committee, coordinating center, and participating countries.

The baseline examination will include:

- Performance-based measures of physical function
- Vision and hearing assessment
- Pulmonary function
- Grip strength
- Anthropometry
- Blood pressure measurement
- Venipuncture

The development of the instruments will be substantially aided by the efforts of the working group of the International Research Network on Healthy Life Expectancy who is charged with development and validity testing in various cultural contexts of instruments to measure:

- Physical function
- Mental function
- Performance in activities of daily living
- Mobility and community contact

This working group met last in July 1991 to explore appropriate measures for the instrument (49). It is their plan to commence cross-national validation studies in the centers selected by the steering committee for participation in the WHO Determinants of Healthy Aging Project.

Instruments will be selected and harmonized into local cultural conditions and pretested in the local populations.

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Chapter 11

Health promotion and disease prevention workshop

by Gerry E. Hendershot, Ph.D., Division of Health Interview Statistics, National Center for Health Statistics

Our interest in doing comparative international studies of health promotion and disease prevention among the elderly arose from the need, using the U.S. National Health Interview Survey, to track progress toward, first, the 1990 Health Objectives for the Nation and, now, the Year 2000 Health Objectives for the Nation. As part of that tracking effort, the Division of Health Interview Statistics, by means of the Health Interview Survey, did surveys of health promotion and disease prevention in 1985 and 1990 and is presently conducting a similar survey for 1991. We expect to do future surveys in 1995 and the year 2000 and possibly beyond if there is another set of objectives.

Thus, we have a major commitment to measuring health promotion and disease prevention in the U.S. population. It has been noted by authoritative bodies looking at measurements of health promotion in the United States that they were not designed especially well for measuring health promotion and disease prevention among the elderly. It was our hope in participating in this international collaborative effort that we could improve measures of health promotion and disease prevention among the elderly in the United States. As part of that effort, we have been collaborating with the Netherlands Health Interview Survey staff. The Netherlands Health Interview Survey is similar in many respects to the U.S. National Health Interview Survey, which makes the possibility of comparison between the two realistic. We have a good working relationship now with the staff, Yaap Van Den Berg,

Henk Swinkels, and their colleagues in the Netherlands.

Our general approach in that collaboration is to, first, estimate the prevalence of health-related behaviors in the elderly population in the two countries, using the respective health interview surveys. Then, once those prevalence estimates have been made and compared, we would investigate the possible methodological causes for the differences we find in the prevalence estimates. Then, when we have resolved some of those methodological differences, we would move on to consider some of the societal and cultural differences between the two countries that could explain differences in the prevalence estimates.

During this conference, we have further specified the list of topics on which we want to focus in this international comparison. In addition to mental health, smoking, and alcohol, about which some results were presented earlier in the meeting, we are adding overweight, blood pressure, and preventive services, specifically Pap tests and mammograms for elderly women. We decided at yesterday's workshop that we would approach those serially rather than all at once, beginning with smoking and alcohol, and then move on to mental health as the data from the U.S. Survey become available.

Other ideas that came out of yesterday's meeting were that we should focus more in a substantive way on the purposes of the international comparison, which will make a difference in how we approach the analysis of the data.

What was meant here I think is that we should have some hypotheses in mind when comparing estimates of prevalence of health-related behaviors in the elderly in the Netherlands and the United States. For instance, are we interested in differences in the health care financing and health care delivery systems in the two countries that might affect health promotion and disease prevention behaviors in the elderly? It was pointed out, for instance, that in the Netherlands there is virtual universal health care coverage, whereas in the United States, as you know, 13 or 14 percent of the population is reported not to have any health care coverage. Does that difference in health care coverage affect access to preventive services among the elderly in the two countries, which could then affect the prevalence of health-related behaviors? If that were the focus of our comparing estimates from the two countries, our approach to the analysis of the data might be different than it would be, say, if we were looking at the epidemiology of health conditions in the two countries. I do not know what our substantive focus will be, but we were grateful for the suggestion that we focus more in forming hypotheses for the comparison of the data from the two countries.

It was also suggested that, instead of taking an ad hoc approach to the investigation of methodological differences between the two surveys, which might affect our measures, we should be more focused in that regard as well. That is, we should identify potential methodological differences and problems and focus some of the research specifically on those problems. For example, one difference between the two surveys that I think we should investigate is the much higher nonresponse rate in the Dutch National Health Interview Survey—I'm not sure, but I think that rate is about 40 percent.

Forty percent is much higher than the U.S. National Health Interview Survey nonresponse rate, which, depending on what survey we are

talking about, is anywhere from 5 to 15 percent. That is an important difference between the two surveys, one that we should keep in mind when comparing the results of the two countries.

We have only two countries, the United States and the Netherlands, currently involved in this study of health promotion and disease prevention among the elderly. And it was suggested again yesterday that we should include, if we can find them, other countries. Specifically, the United Kingdom was suggested. The United Kingdom does a general household survey that includes some health questions, such as smoking on a regular basis, and has recently begun a national health survey that is similar in some respects to our National Health Interview Survey. So there is the possibility that we can get the United Kingdom involved in this study. Also, David Williams made a presentation here based on a survey of health-related behaviors of Moscow residents that was not focused specifically on the elderly but did include them, and I am hopeful that we can make some comparisons with that data set, perhaps focusing on some comparable large city in the United States for which we can make estimates from the National Health Interview Survey.

A related activity in which our Dutch colleagues have been involved is the World Health Organization's consultations on health interview surveys in European countries related to the Health for All Objectives, an attempt to standardize some of the measures that are tracking progress toward those objectives using health interview surveys. The U.S. Health Interview Survey staff has participated in one of those consultations and plans to continue to participate in future consultations as part of that effort.

Finally, it was not discussed at the workshop yesterday, but I would like to say again that our staff in the Division of Health Interview Statistics has a developing interest in the role of the family in various issues of health status and use

of medical care services, including the elderly population as it is affected by family conditions. That is an area I hope we will be able to include in our collaboration with our Dutch and (potentially) English and Soviet collaborators.

I want to thank those who participated in the workshop yesterday. It was very helpful, and it has been a good meeting for us. I think we are moving ahead and will expect to see some hard results in a year or two.

Chapter 12

Vitality workshop

by Richard Havlik, M.D., M.P.H. National Institute on Aging, National Institutes of Health

The goal of this cross-national research project is to understand the meaning of any similarities or differences in measures of physical, social, and mental vitality among populations in the United States, Italy, and Israel. Before interpreting preliminary findings, such as the similarity in frequency of those able to do heavy housework in the three countries, issues of methods, definitions, and other related factors must be addressed. These issues were the focus of the workshop deliberations.

Under “Methods,” the following topics were discussed by team members and other participants:

- Details of comparisons: Questions and statistics
- Validity of exercise questions—MONICA (Monitoring Cardiovascular Disease Project)
- Variability
- Longitudinal studies
- Replicates: Cohort effects
- Calibrate questions on younger group (50 years versus 65–74 years)
- Use continuous measures with standard deviations

The team members were properly cautioned about the need to make sure that any comparisons are valid, and that includes both the questions themselves and the statistics used, for example, age adjustment. Actually, to carefully dissect any results, we know that this has to be done. The validity of the exercise questions came up in discussion. Originally, it was hoped

that the validity of some of the exercise questions could be addressed by the health promotion group as part of the activities of the questionnaire design lab at the National Center for Health Statistics (NCHS). Because this was not possible, we still lack some very basic validity measures of the questions. For example, the results for walking a half a mile were comparable to analyses using walking a quarter of a mile. So, clearly, there will have to be some comparisons to other studies, such as the World Health Organization project called MONICA (Monitoring Cardiovascular Disease Project), even though the age range is predominantly 65 years and under and the study has a small older subgroup. In some of the countries, they are doing detailed exercise validations, and we might be able to use them to understand the validity of some of the exercise questions.

Variability in measures can be both short term and long term. This is an ongoing problem for any questionnaire-driven analysis. And, of course, we do not know what the short-term variability is of these various states or traits, but, hopefully, we will try to get some information. Whether it can be done in the context of the existing studies or would require separate studies is to be determined.

In addition to the issue of variability is the plea that Dr. George Myers and others have made for longitudinal studies. Such studies allow for better predictions of outcomes. In these areas, there are plans for followup, certainly in the Established Populations for Epidemiologic

Studies of the Elderly (EPESE) and the Longitudinal Study of Aging. This also then will give us some idea of whether the vitality measures that we have been using are stable or how they do change. Also, it is important to replicate results both within the country and among other countries. The issue of quality of life of the elderly in the Veneto (Italy) study, as Dr. Mara Pavan said during the plenary session, is that, although she is confident that the questions asked and responses given in the Veneto study are representative of at least Northern Italy, this is probably not the case for Southern Italy. So, a replicate that not only duplicates those questions asked in Northern Italy but also does them elsewhere is necessary. In fact, there are plans to use many of these same questions in longitudinal studies at 6 or 10 different sites in Italy. Israel is also doing a replicate and a longitudinal study.

A possible cohort effect must be considered. This issue came up during the discussion as the question: Are we becoming more vital and aging better? In the model of Dr. Alvar Svanborg in Sweden, where he had replicates of similar groups 70–79 years of age that were asked the same set of questions, in fact the investigator appeared to be seeing better cognitive function over time. Such findings suggest that the earlier and later cohorts might differ in certain fundamental ways.

We addressed the issue of whether these vitality questions are “culturally bound” or being interpreted differently by subgroups because of variable life experiences. One of the strategies for addressing this would be to determine how the questions perform in a slightly younger group. Now, interestingly, some people felt the most vital age was about 50 years of age, the “great halfway point.” This age would be used as the standard of comparison. Another possibility is to try to dichotomize the analysis so that we basically look at the age group 65–74 years, which is

really quite “young/old” and might be an indicator of a goal for the older age groups. Of course, at NCHS and in other work, we have used, for example, the age group 20–29 years for ideal weight; and there is certainly some argument as to whether one should go to a very young age to set standards for an older age group.

A very good point was made about heterogeneity in older persons. Dr. T. Franklin Williams, the former director of the National Institute on Aging, has talked on other occasions about the inappropriateness of only presenting means without the distribution. Also, the idea was emphasized that we should show in our analyses at least three or four subdivisions, such as “much,” “some,” “many.” This need developed in our discussion of the mental vitality measures of enjoying life or being happy during the past week. When we looked at the distribution, it appeared that the difference between Italy and the United States was really in the “very much” category of five to seven times per week, whereas the rest of the distribution was very similar.

These comments summarize necessary improvements in methods, and the team members thought that we got some good suggestions. It is a challenge and, in fact, we are going to move ahead with these ideas, at least where we can, and initiate these analyses.

Perhaps the most interesting part of the discussion involved definitions of vitality. Topics included:

- Mental vitality—Cognitive and emotional components
- Read newspapers—Social and mental vitality
- Physical aspect of occupation
- Quality of life, for example, *no* loneliness, *no* tiredness
- General vitality measure (World Health Organization)

- Crosscutting measures, for example, voting, driving, peak expiratory flow rate, and sexuality (frequency versus satisfaction)

Fortunately, nobody said that our paradigm was completely inoperative or inappropriate, but there were some subtle suggestions that maybe there could be improvements. For example, in studies in the Netherlands, there is a tendency not to use the term “mental vitality” but to get at the issue of cognition versus the emotional side. It may be that we can keep mental vitality but begin dividing up, or getting at, subdomains that are more specific.

There was a question about reading newspapers. Is this an indication of mental vitality, or is it really quite social? Certainly these questions can be moved around to other categories. The same issue appears with occupation. Is occupation really an indicator of social productivity or, even better, does it have exercise components? Certainly in the Iowa subgroup of EPESE it does, and what it suggests is that there is probably no simple classification. In fact, in thinking about it now, maybe it will be most important to identify a number of these crosscutting issues that address more than one domain. Maybe, we do need to have some categories that are more general, that address all three: the physical, social, and mental.

The quality-of-life issue was raised again, and I think it comes up periodically. Are we maybe setting our sights too high and trying to be too objective where, in fact, the issue is the subjective quality of life; that is, no loneliness, no tiredness, no depression? We should really make sure that this aspect is covered. One of the workshop participants, just from personal experiences, felt that this was really the area of most importance. In support of this view, in an issue of *Controlled Clinical Trials*, there was a discussion of the use of quality of life as an outcome measure in clinical trials. It is a nice summary of

all the problems in trying to use this kind of an indicator.

We were also told that, like most things, there is nothing new under the sun and that the World Health Organization had tried to develop general vitality measures many years ago and had identified some relevant questions. It was suggested that we go back to the literature and do a little more homework in trying to find those definitions of general vitality.

Crosscutting measures have been alluded to, but there are things that really are summary measures. For example, peak expiratory flow rate or vital capacity may be a better indicator of what we have been discussing than some of the subjective measures.

Certainly, driving a car has a physical component, a social component (where you want to go, why you have to go), and a mental component, as well. Voting is another one, and we may be able to develop a whole other list. However, whether we have enough data in the existing sites is not known.

Finally, on a popular topic, the group got into a lively discussion about male–female differences in sexual activity. The issue of whether the question should be frequency or satisfaction was raised, and it seemed to have a gender effect that was different. This topic merits further consideration.

There are some miscellaneous issues that were discussed. The topics were as follows:

- Heterogeneity: Male–female differences
- Volunteerism as substitute for family in the United States
- Comorbidity
- Use of psychotropic drugs

With special emphasis, the group again identified male–female differences in measures of vitality as important. Such comparisons were mentioned during Dr. Myers’ presentation, that

is, to look at differences for men and women in various indicators of vitality among countries. Obviously, vitality measures are the complement to or the opposite side of disability, and there may be some gender comparisons that would be worthwhile.

We talked about why volunteerism might be more common in the United States than in other countries. It was pointed out, incidently, that actually the Supplement on Aging Survey does have a question on volunteerism. So, we will be able to compare what was obtained in the study "Americans' Changing Lives" with the 1984 Supplement on Aging. One of the ideas that was presented was that somehow volunteerism is a substitute for the general United States' lack of an extended family. One is helping other people and, presumably, then getting some reward. This is a cultural difference that we have in the United States, where nuclear families are more common.

There is the major issue of covariables and how they can affect our vitality measure. Various

categories of diseases will have different effects. Also, psychotropic drugs can affect vitality assessment, not in the positive sense of being tranquilized and happy but in the negative sense of perhaps discouraging vitality by the overuse of medications.

Also, because someone is identifying somebody at a specific point in time, a disease, medication, cold, fall, family problem, loss of a loved one, or any of these kinds of things can occur simultaneously and will obviously affect any measurements.

Replicates were mentioned earlier. We keep open the possibility of incorporating data from other sources, for example, from Asia. There are some population-based studies in Japan and in Taiwan that have used exactly the same questions as Americans' Changing Lives. I am aware that the Hong Kong group has some similar questions, so we might be able to expand this into another area.

The workshop was a very good one, and the team members appreciate everyone's input.

Chapter 13

Functional disability workshop

by Mary Grace Kovar, Dr.P.H., Office of Vital and Health Statistics Systems, National Center for Health Statistics

Given our work group, I do not think they will have questions, they will probably have corrections. All of the members of the work group contributed to the discussions, and what I have to say owes much to their generous willingness to contribute their intellectual and data resources. Although I am presenting the results, we are all authors. Those were the opening sentences of my report on Functional Disability Workshop at the first ICE on Aging. They were true then and they are true now. I want to add that we were extraordinarily fortunate to have the people who attended and participated in the workshop yesterday. Their intellectual input was really impressive.

We had two additional advantages. The group certainly had more experience with international collaboration that included data on disability. You heard a bit the other day about the two projects that are underway, so I do not need to elaborate on that. The group also had the advantage of including people involved in the work of the World Health Organization, Dr. Van Den Berg from the Netherlands and George Myers whom you heard this morning.

We also had two members with responsibility for major projects on disability in the United States: Dr. Winn, who is Deputy Director of the Division of Health Interview Statistics, told us of the plans for a Disability Supplement to the National Health Interview Survey in 1993–94, and Dr. Seltser, who is Chair of a Public Health Service Task Force on the Medical Criteria for

Disability, told us of the plans for that task force.

I wanted to tell you who was in the workshop because that combination of people has a great deal of knowledge about what is going on in the international field and has responsibility for major happenings in the United States. Their knowledge certainly informed and enriched our discussion. It also influenced the summary and the recommendations that I will be telling you about and definitely influenced them for the better. I hope that the recommendations are the consensus of the group. The editorial comments obviously are my own.

There was general agreement that the two collaborative efforts that are already underway should be completed and published within the year so that everyone can have access to the data. That should be taken as a given. The people who are responsible are in this room; we have to get it done. There needs to be more emphasis on involving more people in collaborative analysis. We must build on what we have. That conforms to a basic tenant of ICE on Aging: Use the data we have. And without any direction from anybody, it was reiterated yesterday. We need more comparable analyses.

One suggestion was that we need to write a paper on what is available, invite others to respond, and then perhaps be able to create an inventory of disability data for international comparisons. No one really took responsibility for

writing that paper, but I think it is something that we need to get going.

The issue of collecting comparable data on the prevalence of disability has to be a top priority. Such data are needed for many purposes—ranging from the estimates of intrinsic variability in populations to estimates of how well we are doing with our different health care systems. In the near future at least, coordination is probably best accomplished through working with the international organization, using questions that they are recommending, and also having input into the kinds of questions they are recommending. In every country, the people who have the responsibility for collecting the basic data on disability should work with such organizations as the World Health Organization, the Organization for Economic Cooperation and Development, and the International Network on Health Expectancy and the Disability Process network. My editorial comment on that is that we probably need to take care that the international meetings are attended both by university representatives—the people who are doing the thinking about some of the policy issues—and by the people who are responsible for collecting the basic information so that we can better coordinate what actually gets done.

If we are ever to measure the prevalence of functional disability, we must include cognitive functioning. We must also learn more about the interaction between physical functioning, which is now measured by activities of daily living (ADL's), for example, and cognitive functioning. I do not want to belabor this point, but it is obvious to everyone who has ever worked with ADL's, and even more so for the instrumental activities of daily living, that, although they are often viewed as measures of physical functioning, they incorporate measures of cognitive functioning, which are seldom measured directly.

When we are collecting the outcome data, the physical disability data, we must also be

certain that we collect the information on the correlates. We need the measures of socioeconomic status, we need the measures of differences of the population, we need the measures of the conditions that probably lead to disability, we need to make a separation between illnesses and injuries, and we need the measures of the things that help alleviate disability, such as community services, family support, and assistive devices.

A relatively minor point is that quite probably one way of dealing with the differences in socioeconomic status in the different countries is to switch to the use of quintiles so that we have comparable proportions of the population.

Returning to major points, information about the people in institutions is critical if we are going to understand what is happening with disability of older people. The three surveys that were used for the data that we presented the other day all rely on data on community-dwelling noninstitutionalized populations. We do not really know very much about the differences between the people who were in institutions and the ones who were not, the proportion of people in institutions, or even what it means to be institutionalized in different countries. We do not know whether our definitions are even comparable, partially because we are under different health care systems. The Canadian data that Dr. Forbes presented provided a tantalizing glimpse of what we could learn if the total population of older people, regardless of where they reside, were included in surveys. If we cannot include them, and there are sometimes reasons why we cannot, we should at least learn where they are, how many of them there are, and what institutionalization means in the different countries. If we cannot include the total aging population, let us at least know more about whom we are excluding.

There was, as usual, discussion of the International Classification of Disability and Handi-

caps (ICDH) and whether we should be using it. There was, also as usual, a lack of consensus. However, the ICDH is being revised, and the United States should be involved in that revision. We should be involved, just as we are with the International Classification of Diseases (ICD). There was a very strong recommendation for our involvement.

In addition to the international comparisons of cross-sectional data, we need evidence about the processes from longitudinal data. As we all know, longitudinal data might lead to different conclusions about the correlates and consequences than cross-national comparisons from cross-sectional data. Finally, we need to work for comparability within as well as among countries.

I think there was a strong sense from the group that this is a very, very high-priority area. The population of the world is aging; if we do not learn how to prevent or postpone functional disability, we are going to have major problems.

We are going to have problems with the burden on resources. I'm not just talking about the public resources, it's the burden on people who either are suffering themselves or whose families have to provide their care. If we are going to reach the goal of successful aging and high vitality that Dr. Havlik talked about, this is one of the things we must do to get there. We have to learn and do something, because people who are disabled are not going to be vital, active people.

We need to learn more because, as I said, the population of the world is aging, and there is going to be a major burden on the health care systems of the world. George Myers talked about the status of people at age 65 and said that women in particular all over the world are not as healthy as they should be. We need to learn more about the variability among the countries and the variability among people so that both men and women that age will be healthier in the future.

Chapter 14

Outcomes of nursing home care workshop

by Joan F. Van Nostrand, M.P.A., Office of Vital and Health Statistics Systems, National Center for Health Statistics

Introduction

The plenary sessions of this International Symposium have highlighted several issues about long-term care (LTC) in general and nursing home care in particular. Dr. Cohen, in his Introduction to the Symposium, said that a major focus of research on aging was eventually to eliminate the need for LTC. Dr. Hennessy, in his presentation about the LTC project of the Organization for Economic Cooperation and Development (OECD), spoke about different systems of providing LTC in OECD countries and about common problems: how to fund the increasing demand for LTC and how to keep the elderly out of nursing homes through the use of home health and community-based LTC. These issues are germane to the efforts of the ICE AGE research team analyzing outcomes of nursing home care and surfaced at yesterday's workshop. At the workshop, the research team concentrated discussion on several analytic topics:

- Implications of preliminary data comparisons
- Quality of nursing home care and quality of life
- Comparisons of outcomes between nursing homes and home health care
- Patient careers and transitions
- Measures of dementia

Although other topics were raised, the team focused the discussion on these issues. Each member of the team was the discussion leader for a particular topic. This report on the workshop will summarize the issues, insights, and conclusions of the discussion.

Implications of preliminary data comparisons

Wim van den Heuvel from the Netherlands led this discussion. It was based on issues raised after examining some preliminary data from Australia, the Netherlands, and the United States. Data were only for comparable classes of nursing homes. These classes were selected based on considerable deliberation by the research team after the first International Symposium in 1988. They were: nursing homes in Australia, somatic and psycho-geriatric nursing homes in the Netherlands, and nursing homes certified for Medicare and Medicaid in the United States.

The purpose of the preliminary data comparisons was to identify methodological issues and to select a subset of outcomes to analyze. One methodological issue was whether the nursing home populations are similar across countries. The existence of similar populations is a validity check on the classes of nursing homes chosen for comparison among the countries. Preliminary comparisons showed the existence of similar populations between Australia and the Netherlands. The percent of nursing home residents needing help with specific activities of daily living showed only a 1–4 percent difference between these countries. Comparison was made among Australia, the Netherlands, and the United States in the percent of discharges who had long stays (that is, 1 year or more). The percents were similar when live discharges were compared and also when dead discharges were compared. However, there were major differences in the percent

of those staying less than a year; the rate for live discharges in the Netherlands was higher by 22 percent. A possible reason may be the heavy emphasis on rehabilitation in the nursing homes in the Netherlands. This issue is one for further methodological examination.

The primary diagnosis of dementia, made at admission and also at discharge, raised some critical methodological issues. In both the United States and the Netherlands, there was a decrease between the percent of dementia cases at admission and at discharge. This was the case whether the person was discharged alive or dead. Workshop participants discussed several methodological issues, including what would be reported as the primary diagnosis at discharge for residents with both dementia and serious physical problems. The main conclusion of this discussion was to disaggregate the data, that is, conduct a separate analysis for those with dementia versus those without. The rationale behind this conclusion was that the diagnosis of dementia has certain implications for outcome measures. For example, persons with dementia tend to have longer lengths of stay because discharge to the community may not be feasible. Because of the longer lengths of stay, persons with dementia are more likely to be discharged dead. Further analysis of outcomes for residents with dementia should examine the role of the mental hospital and the acute care hospital vis-à-vis the role of the nursing home in providing care.

Quality of nursing home care and quality of life

Anna Howe from Australia led this discussion. The discussion began with the issue of how to conceptualize quality of care and quality of life and how to establish expected outcomes. One issue that generated much discussion was situations when death was a positive outcome. Another issue was the conceptualization of quality in relation to the level of analysis. Should

quality be conceptualized and analyzed on the basis of individual assessments of residents or of aggregated assessments of groups of residents, such as the percent who were discharged to an acute care hospital? How would the concept of quality based on the characteristics and policies of the nursing home (for example, visiting hours, meal selection) mesh with a concept based on the patient?

One conclusion of the discussion was that a fruitful approach to examining the quality of outcomes was to disaggregate the residents by the goal of care: rehabilitation, management of specific chronic disease, management of cancer, management of dementia.

Some existing frameworks for conceptualizing quality were identified as potentially useful to future analysis. They included:

- The standards for nursing home care of the U.S. Department of Veterans Affairs
- The questions on opportunities for social contacts in a study of board and care homes planned by the U.S. Department of Health and Human Services
- The concept of excess disability. Given a resident's chronic health problems, are there other problems that are treatable but cause unnecessary (that is, excess) disability because they are untreated? One example of excess disability is the resident with Alzheimer's disease who has treatable depression that is untreated. Treatment of the depression can improve the resident's quality of life. Another example is the bedfast resident who has excess disability caused by decubitus ulcers.

Workshop participants recommended a "pragmatic" approach for analyzing quality: analyze only one or two items about quality of care commonly available in all the countries. Examples of possible items were decubitus ulcer and measures of social contacts.

Comparisons of outcomes between nursing homes and home health care

Leaders for this discussion were Betty Havens of Canada and Robert Clark of the United States. The discussion focused on what measures of outcome could be used to compare nursing home care with home health care. One measure proposed was death, but the issue was raised as to whether it could be judged as a positive outcome. Another measure proposed was the satisfaction of the patient. It was noted, however, that patients generally exhibit a positive bias toward home health care because, in comparison to nursing home care, home health care fosters patient autonomy and independence.

Betty Havens described an approach for comparing outcomes in the two settings according to the structure of the LTC system. In Manitoba, Canada, nursing homes and home health care have the same types of clients. For this reason, the rate of persons discharged dead should be similar for the two care settings. Hence, examination of rates would provide a comparison of outcomes for these two care settings. Workshop participants felt that this structure did not exist in the LTC system in the United States. Client characteristics in the two care settings were not the same, and, therefore, rates for dead discharges would not be similar. Hence, the structure of the LTC system was not judged as a useful approach for comparing outcomes among countries.

Workshop participants concluded that the satisfaction of the family, rather than of the patient, with the quality of care might provide a strong basis for comparing outcomes between settings. Another conclusion was that outcomes could be compared at a systemwide level. In such a comparison, the outcome of a discharge from home health care could be measured as an admission to a nursing home. Analysis of outcomes would then concentrate on admission rates to nursing homes and on transitions back

and forth between the community, where home health care is received, and the nursing home.

Patient careers and transitions

Tor Romoren from Norway led this discussion. He described his LTC data set for a local area in Norway. He had recorded the experience of all elderly in the area over a long period of time, describing their careers of service use and their careers of family assistance. He identified a group of about 20 percent of his cases who died after the age of 80. He examined their careers of service use beginning 5 years before death. He found that, of those who used nursing home care, the stay was short (generally less than 30 days). In some cases, there was no nursing home use at all.

This group is in contrast with another group that had several hospital stays and one to two nursing home stays before death.

One conclusion drawn from these examples was that patient careers of prior service use are important to an analysis of nursing home outcomes. Another conclusion was that outcomes should be examined separately:

- a. for heavy versus light service users,
- b. for those with and without hospital stays, and
- c. for those with and without previous nursing home stays. Such comparisons might also provide information about the quality of care in these different settings.

Measures of dementia

I led the discussion on this topic. Dr. Gurland's presentation on cognitive function and the elderly provided a focus for the discussion. Of particular interest to the discussion were his comments about various approaches to measuring dementia: how different approaches provided different types of information and how important it is to examine these multiple dimensions rather than to select one approach as the "best" way to measure dementia. The members

of the research team identified several measures of dementia in their data sets:

- Orientation to time and place
- Actual assessments like the mental-status questionnaire
- Diagnoses that were recorded in each country according to the International Classification of Diseases (ICD)
- Behavior problems and whether or not these behavior problems required extra care

One conclusion of the research team was to use the term “impaired mental functioning” instead of “dementia.” This recommendation was made by workshop participants from the U.S. National Institute of Mental Health because this label was more apt for the elderly than was the term “dementia.” Another conclusion was to follow Dr. Gurland’s recommendation of using multiple dimensions to measure impaired mental functioning. Several dimensions for comparison were proposed:

- Length of stay
- Proportion discharged dead
- Different ICD diagnoses of impaired mental functioning
- Orientation
- Patient assessment of mental status (considering the impact of medication)

These comparisons should help the research team identify the most appropriate measures of outcomes for discharges with impaired mental functioning.

A third conclusion was on the approach for comparing outcomes for discharges with behavior problems. This discharge group should be disaggregated into those with and without transitions to other nursing homes and mental hospitals. This should be done because those with transitions were a special group. They are people with such severe behavior problems that they are discharged elsewhere because the staff has great difficulty in dealing with them when providing care.

This discussion ended with a prediction about the type of patients who would be receiving nursing home care in the future. Central to the discussion were the comments of Dr. Hennessy about the shift in LTC policy of many OECD countries. The shift is toward the use of home health care over nursing home care because costs are assumed to be less and because the elderly prefer the independence that home care offers. If that policy shift occurs, nursing homes would have fewer patients with physical problems because they would be treated in the community. Instead, it is predicted that nursing homes would have more patients with impaired mental functioning. Chief among these would be patients with such severe mental and behavioral problems that they could not be maintained in the community even with the assistance of home health care. Thus, the future for nursing homes may be one in which most of the patients have severely impaired mental functioning. If these are the nursing home patients of the future, it is important for the research team to focus on measuring the outcomes of this particular group.

Chapter 15

Chronic disease common in the elderly workshop

by Tamara Harris, M.D., Office of Analysis and Epidemiology, National Center for Health Statistics

I would like to thank my collaborators, particularly Suzanne Ho from Hong Kong and Ed Bacon, who have been very giving of their time and their energy in allowing us to actually come to this meeting with a product. I would also like to thank Anne Looker and Jennifer Kelsey who have contributed in a major way to this project.

In our session, we reviewed the progress of this project thus far with regard to our original and our revised goals. We decided on a product for the project, which is a manuscript that will compare data on hip fracture incidence between the United States and Hong Kong for submission to an appropriate journal. This manuscript is now in final stages of preparation, and our

discussion at the workshop will help us to complete it.

We said that we would continue to work on a small series of analytic projects related to hip fracture but not to expand the focus of this group beyond this particular outcome. For instance, Dr. Baruch Modan, who has been spending time at the National Center for Health Statistics, has been obtaining data on hip fracture incidence from Israel; and we will use that data to explore the importance of transfer rates on overall rates that might be obtained from more general sources of information from country to country. In addition, we will recontact our original respondents regarding hip fracture rates to expand the countries for comparison.

Chapter 16

Closing comments: Next steps for the ICE on Aging

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

I would like to thank everyone who participated in this symposium, especially Joan Van Nostrand and Jacqueline Davis for producing such a wonderful program.

In the introductory session, Dr. Cohen used the image of the classical myth of Tithonus to highlight some of the points about growing old without being able to maintain vigor and youthfulness. I would like to continue with that aphorism. There are two versions of the final fate of Tithonus. One claims he spent eternity with only the ability to chatter away endlessly. The other version states that he aged into a cicada, a cricket also chattering away forever. I do not want this to be the fate of this symposium—eternal chattering without meaning or utility. I hope the products of our deliberations do not result in endless, uninformed discussions. I want to see meaningful outcomes that will guide public policy and be useful to all people interested in the aging phenomenon. Toward that end, we hope to produce a proceedings of this symposium within a year that will guide us in our future investigations.

I am encouraged by the meetings I have attended, the papers I have heard, and by the international efforts reported from the World Health Organization and George Myers' network.

The world is beginning to realize that many of the issues we face with a growing aging population are the result of the tremendous

progress mankind has made scientifically, technically, socially, and economically. Although the increased longevity is a benefit, it has introduced many other problems that rank on par with, if not greater than, such issues as global overpopulation, environmental damage, and arms control. It is, therefore, very significant that we have embarked on this issue, and it is important that we persevere in this effort.

Many other progress reports and research papers will emerge in addition to the proceedings. Some are already underway and even in process for the scientific literature. I encourage you in your efforts to document what we have been doing. Both the public and the research community need to receive the message that these issues are important. Others may then want to join us in this effort.

It has been nearly 3 years since the first symposium, and it will likely be another 3 years until we convene again. I am looking forward to that 1994 meeting. There will be many problems that will not be resolved and many issues that will be even more difficult once we get into the "nitty-gritty" of deciding some of the actual data to be obtained. However, we should be able to document a lot of progress, and I personally look forward to that meeting and to welcoming each and every one of you back and greeting new faces. Thank you very much for your participation. It has been a pleasure working with you.

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For answers to questions about this report or for a list of reports published in these series, contact:

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