VITAL & HEALTH STATISTICS

Health of an Aging America

Issues on Data for Policy Analysis

The papers in this report were background to a study conducted by the Panel on Statistics for an Aging Population, of the Committee on National Statistics, focusing on data needed over the next decade for health policy analysis for an aging America.

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National Center for Health Statistics

Division of Health Care Statistics

Health of an Aging America: Issues on Data for Policy Analysis

Foreword

We are witnessing the "graying" of America. Today one in every eight Americans is 65 years of age or older. By the year 2025, one in every five will be older Americans. This demographic shift is unprecedented in our history and in that of other industrialized nations as well. Life expectancy has increased dramatically. In 1900, life expectancy was 47 years. Today, it is 75 years—an addition on the average of 28 years. This increase forecasts changes that will reshape American society, especially in the health area. We can expect major differences in the health status of older persons, in their use of health care, and in its costs.

The graying of America is challenging our ability to make health policy to meet the changing needs of older persons. What data will be needed in the next decade to develop, evaluate, and modify health policy for an aging America? With this question in mind, the National Center for Health Statistics joined with other Federal agencies that produce data about the health of older persons to commission a study. These agencies are the Health Care Financing Administration, the National Institute on Aging, the National Institute of Mental Health, the Office of the Assistant Secretary for Planning and Evaluation, and the Social Security Administration—all of the Department of Health and Human Services—and the Veterans Administration. The study, commissioned in 1984, was conducted by the Panel on Statistics for an Aging Population of the Committee on National Statistics, which is part of the National Research Council. The charge to the Panel was to focus on data needed over the next decade for health policy analysis for an aging America. Within this context, the Panel was charged with making recommendations in three areas:

- Data requirements and appropriate remedies to major shortcomings
- Actions for refining relevant statistical methodology
- Changes in the decentralized Federal statistical system to facilitate integrating data across components

To address this charge, the Panel divided into three work groups. Each commissioned several papers as background. These papers constitute the content of this report. The papers are categorized here according to the working group that commissioned them:

- Health issues and data requirements
- Methodology issues
- Issues in improving data resources

The work groups used the papers to provide indepth information for their deliberations and development of recommendations. In many instances, the concepts, views, and recommendations from the papers are reflected in the Panel's final report—*The Aging Population in the Twenty-first Century: Statistics for Health Policy* (National Research Council, 1988).

These papers were written in the summer of 1985. They were the focus of the Symposium on Statistics for an Aging Population convened in September 1985 by the National Research Council. Over 100 experts in health policy, data analysis, and statistical policy attended the symposium. Its purpose was to provide a forum for presentation of the papers and their critique by both invited discussants and symposium participants. The papers were subsequently revised to reflect the discussions at the symposium. Final copy was submitted to the work groups at the close of 1985, although minor revisions were made to some papers within the last year. These papers reflect the views of the authors and not those of their employers nor of the Department of Health and Human Services.

These papers are presented here as a companion volume to the Panel's final report. They provide a fuller treatment of some of the issues addressed by the Panel in its development of recommendations. It is important to add the insights of these papers to our growing body of knowledge for strengthening data to meet the challenges of making and modifying health policy for an aging America.

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

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Chapter I
Health issues and data requirements

Measurements of health and disease, a transitional perspective[a, b]

by Kenneth G. Manton, Ph.D., Duke University Center for Demographic Studies and Duke University Medical Center

I. Introduction

The identification of the rate and nature of health transitions at advanced ages is a complex analytic issue that has not been satisfactorily resolved. For example, many studies of the loss of physiological function with age have recently been undergoing revision because they were based upon representative samples of elderly persons which included chronically ill persons. Since the age-specific prevalence of chronic morbidity tends to increase with age (which could be due simply to the greater time of exposure to these diseases), the actual age rate of physiological decline for the individual was confounded in the population with the physiological deficits due to disease; that is, the physical impairments generated by age-related diseases were confounded with functional decreases associated with "general" aging processes. Studies of "healthy" elderly populations suggest very different rates of loss with age, with some functions showing little decline even to very advanced ages (e.g., cardiovascular output can be maintained in healthy persons at least up to the eighth decade of life; Lakatta, 1985).

Frequently, epidemiological studies have not included populations at very old ages, so we currently lack the same amount of evidence about risk factor change and disease-risk factor associations that we possess for persons in late middle age. The available evidence suggests that risk factors may have different effects at different ages. Demographic studies have often assumed that mortality at advanced ages follows a Gompertz-type hazard function, which many studies indicate predicts too rapid an increase in the hazard rate (Perks, 1932; Spiegelman, 1968; Wilkin, 1982; Manton, Stallard, and Vaupel, 1986), or have assumed a risk-homogeneous population—despite extensive epidemiological evidence documenting major differentials in chronic disease risk factor exposures and the effects of systematic mortality selection.

Another major problem in analyzing health changes at advanced ages is the fact that chronic diseases evolve over a lengthy period of time, have complex natural histories, interact with other chronic diseases, and are related to physiological aging changes in a multidimensional fashion. This suggests that the study of health changes at advanced ages must be a study of interrelated *processes;* that is, the conceptualization of disease as an event or fixed state will be inadequate. In order to conceptualize health changes at advanced ages, the World Health Organization (1984) has proposed a model that describes such health changes in terms of three age-directed and interacting processes—morbidity, disability, and mortality. Researchers at the World Health Organization were able to describe the linkage (though not the detailed interaction) of these processes according to figure 1, which is based upon standard life table concepts.

The outermost curve in the figure represents the survival probability to age x from a standard life table model. The life tables may be formulated on either a cohort or period basis, where the period life table is a synthetic rendition of what current prevalence and mortality rates would imply free of the effects of differences in birth cohort size and prior survival. The innermost line represents the probability of survival to age x free of disease. The middle line represents survival to age x with disease but free of disability. The positioning of the morbidity and disability curves represents the assumption that chronic diseases, as they progress, generate disability. Though disability is generated by chronic disease, this does not require that chronic disease map one-to-one on disability (Manton, 1985). Both advanced cancer and a severe stroke can produce a bedridden incontinent patient with total dependence in activities of daily living. Thus, the mapping of disease processes to disability outcomes is a probabilistic many-to-one mapping.

The prime advantage of the curves in figure 1 is that they describe health changes in duration (i.e., person-year) terms and show how those duration effects are correlated with age. The concepts represented in figure 1 have been used by Wilkins and Adams (1983) to describe various aspects of health changes in Canada. For example, in table 1 we see a decomposition of life expectancy based upon institutionalization or degree of activity restriction. We see that a significant portion of life (5.4 years for males, 8.7 years for females) is expected to be spent with restriction in a major activity. Because the portion of life spent with restriction of major activity is based upon life table measures, it is possible also to portray this decomposition on an age-specific basis.

In table 2 we present (a) life expectancy remaining at age x; (b) quality-adjusted life expectancy based upon a weighting of person-years of survival by certain qualitative health characteristics (i.e., each year of survival in an institution is counted only as 0.4 year in quality-adjusted terms; a person with no disability contributes 1.0 quality-adjusted year for

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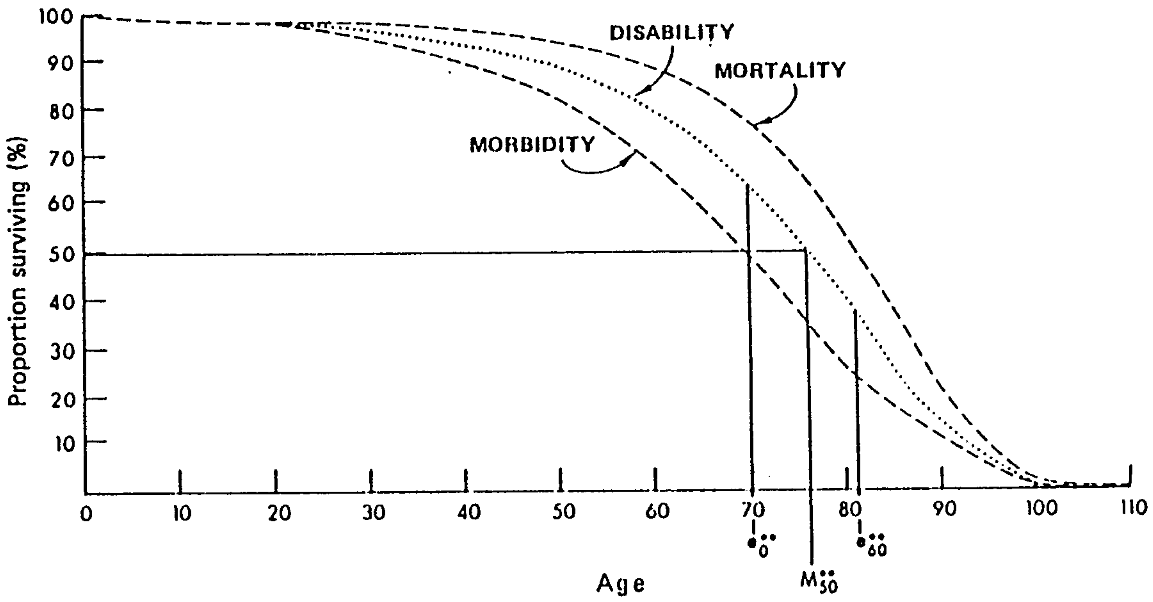
[a] Contents are the opinions of the author and not those of the Department of Health and Human Services or the organization he works for.

[b]

FIGURE 1

The observed mortality and hypothetical morbidity and disability survival curves for females in the United States of America in 1980



e_0** and e_{60}** are the number of years of autonomous life expected at birth and at age 60, respectively. M_{50}** is the age to which 50% of females could expect to survive without loss of autonomy.

SOURCE: World Health Organization, 1984.

each actual year lived); and (c) the number of years expected to be lived after age *x* free of disability. We can see that, with advancing age, the proportion of remaining life expectancy that will be disability free declines (e.g., for males from 85 percent at birth to 57 percent at age 65).

Such, measures can also be used to represent temporal trends. This is exemplified in table 3, for the period 1951–78. This table addresses the question that has frequently emerged in the debate over whether the improvement in health status on an age-specific basis has paralleled recent life expectancy gains. We see, from 1951 to 1978, that Canadian life expectancy increased 6.0 years. We also see that this gain was a function both of increases in disability-free years (1.3 years) and in disabled years (4.7 years). Thus some improvement is evident, though not as much as might be expected. The gain in quality-adjusted life years is larger (3.7 years) than for disability-free years (1.3), indicating that much of the disability was at low levels. These figures serve to emphasize the need to develop health policy to increase active life expectancy as one increases total life expectancy (i.e., to minimize the area between the two outside curves in figure 1). Such policies would seem consistent with the goals of geriatric medicine to maintain function at advanced age to the degree possible (Minaker and Rowe, 1985).

Construction of these tables requires the synthesis of data from multiple sources (i.e., population survey data of various types). Though this has been done for several other countries such as Japan (Nihon University, 1982), a similar comprehensive exercise has not been conducted in the United States (Luce, Liu, and Manton, 1984).

Though the above concepts are useful to describe health changes at advanced ages in the population, they do not describe the physiological mechanisms underlying the interacting processes at the individual level. It is the individual-level mechanisms that are important clinically for the appropriate management of the geriatric patients with multiple, interacting chronic diseases, and for the investigation of the basic physiology of aging mechanisms—especially in terms of a complex multidimensional process and the discrimination of "aging" from "morbid" physiological changes. This manuscript is designed to explore health transitions in terms of these individual-level processes.

II. Health transitions at advanced ages: Population data

A major issue in describing health transitions at later ages is to distinguish between the evidence provided on these transitions at the aggregate level and the actual transitions of the individual. Typically, in survival studies, it is assumed that the survival curve generated in the population is representative of the failure process at the individual level. A consequence of this argument is that the population survival curve is also representative of the age-related loss of physiological homeostasis and thus represents the basic dynamics of physiological aging processes, e.g., Gompertzian aging dynamics (Fries, 1980). In fact, the population hazard function is representative of the age increase in mortality risks only if the population is completely risk homogeneous. Clearly a large body of epidemiological evidence tells us that it is not. Consequently, the population hazard rate represents only the *average* risk among survivors to a given age. Since the survivors to a given age are systematically determined by mortality, the population hazard rate is not representative of the physiological process in any given individual. Of course, one can statistically "reduce" the risk heterogeneity of any population by stratifying (or by using other means of statistical control) for risk factor level. In general, many factors (e.g., genetic endowment) will not be measured, so that this reduces the problem only in degree.

Given the confounding effect of risk heterogeneity, it is reasonable to ask if there are analytic tools which can resolve our problem. One mode of resolving the problem is to construct a model of population risk heterogeneity, on either theoretical or empirical grounds, and unconfound the effects of selectivity analytically. In the development of such techniques, we can utilize the fact that the effects of heterogeneity can be shown mathematically to bias the relation of the individual to population heterogeneity in a given direction (Manton and Stallard, 1984). Specifically, regardless of the actual shape of the distribution of risk differentials in the population, we find that the relation of the population ($\bar{\mu}$) to individual (μ) hazard functions involves the following type of function:

$$\bar{\mu}(a) = \frac{\partial}{\partial a} \{-\ell n[\mathrm{MGF}[-\int_x^a \mu\ (w|z = 1)dw]]\},$$

$$\text{where } \mu(a|z) = z \cdot \mu(a|z = 1), \tag{1}$$

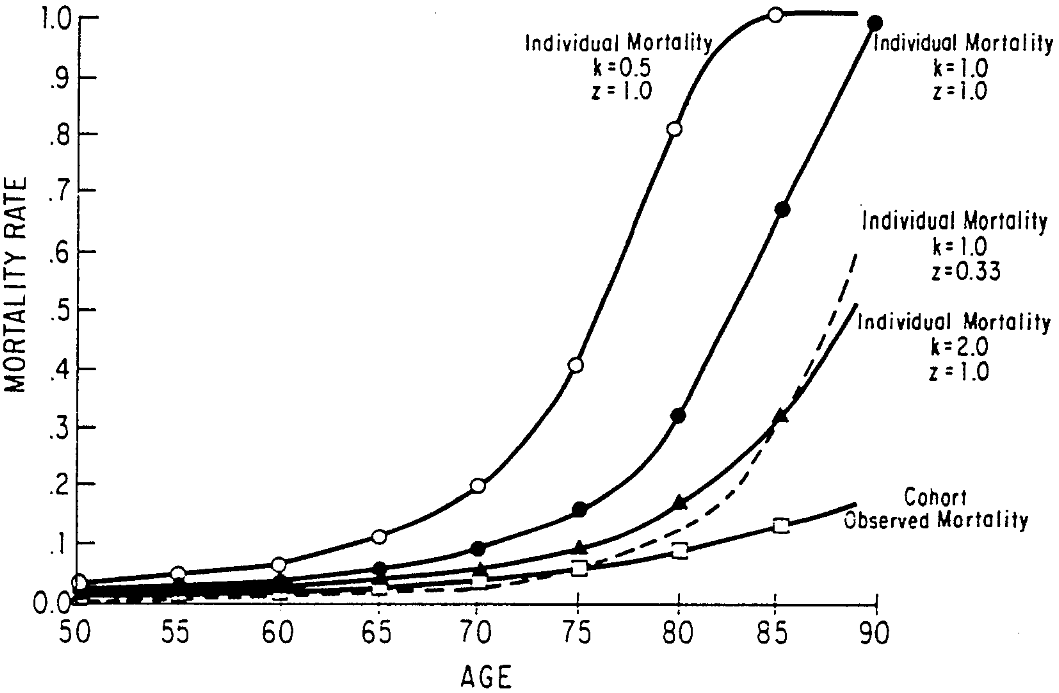
which expresses the average force of mortality at age *a* as a function of (a) the distribution of frailty (i.e., the fixed level of susceptibility to death) at a prior age x and (b) the cumulative mortality hazard for individuals at the frailty value $z = 1$. This relation holds for any distribution with a moment generating function (MGF), i.e., a distribution with finite moments. The implications of this relation can be illustrated by examining the relation of individual to population mortality rates, ${}_1q_x(z)$'s, in figure 2, i.e., where ${}_1q_x(z) \simeq 1 - \exp[-\mu(x + \frac{1}{2}|z)]$.

In this figure we have plotted the theoretical mortality rate for four types of individuals (i.e., at frailty level $z = 1.0$ for frailty distributed as a gamma distribution with shape parameter, k, of 0.5, 1.0, and 2.0 and for frailty level 0.33 in a population with gamma parameter 1.0) and for the observed cohort.

We see that the relative rate of increase with age of the individual mortality rate is greater than in the population.

FIGURE 2

Observed and individual age-specific mortality rates after adjustment for population heterogeneity, white females in the U.S., 1875 birth cohort.



Equation (1) tells us this is the case for any distribution with an MGF, i.e., for most distributions we are likely to encounter in nature.

To illustrate this relation quantitatively, we present the parameter describing the age rate of increase in risk for the Weibull hazard function (i.e., the hazard rate increases as the $m-1$ power of age, or t^{m-1}) for a series of elderly female Medicare cohorts aged 65–84 in 1968 (i.e., the birth cohort of 1883–1902) and followed to 1978.

The first column in table 4 presents the values of $m-1 = \beta$ in the Weibull function if one assumes the population to be homogeneous. The second column presents the values of β estimated from the data using a model which adjusts for risk heterogeneity (by assuming that the individual hazard curves are proportional and that the proportionality factors for individuals follow the gamma distribution). In the third and fourth columns, we present the exponents for a Gompertz function (i.e., θ in $e^{\theta t}$) with and without a similar gamma adjustment for individual differences in risk.

The Weibull function was found to explain the cohort risks better than the Gompertz (Manton, Stallard, and Vaupel, 1986). The Gompertz parameters are included because of their general use and because the exponent θ can be simply interpreted as the annual percentage increase in the mortality rate.

We can see that, for both the Gompertz and Weibull hazard functions, the shape parameters (i.e., β and θ) are larger for the functions adjusted for heterogeneity than for the functions which assume the population to be homogeneous. The larger parameter values mean a more sharply curved function. Since the Gompertz and Weibull parameters estimated for the population have often been used to signify the rate of aging changes (e.g., Sacher, 1977; Fries, 1980), this suggests that the estimates of the "aging rate" from the population are not truly descriptive of the aging rates for individuals. Most particularly, since the β (and θ) coefficients are larger for the adjusted hazard function, this suggests that these risks rise relatively more rapidly than the hazard function assuming heterogeneity. Consequently, the period during which a person is at high risk of death is shorter than would be suggested by the population estimates. This simply reflects the fact that the hazard function parameters in the population are confounded with interindividual differences in risk and so do not directly describe individual aging changes. The more rapid increase in risks for individuals seems consistent with evidence on the "terminal decline" often noted for persons in longitudinally followed populations and with concepts of mortality resulting from a loss of physiological homeostasis at advanced ages.

A second important insight resulting from the estimates provided in table 4 is that there is a decline in the curvature parameters for individuals over cohorts, i.e., the age rate of increase of mortality declines for the younger cohorts. This is not evident in the Gompertz hazard function estimated assuming risk homogeneity, where there is actually a slight tendency to increase (i.e., from 5.86 percent for the 1883 cohort to 6.26 percent for the 1902 cohort), suggesting an *acceleration* of age-related risks. In the case of the Gompertz function adjusted for heterogeneity, we see a sharp decline in the θ parameter from 10.37 (1883 birth cohort) to 7.34 (1902 birth cohort). Thus, there are apparent changes in the aging process for the individual when we statistically adjust for heterogeneity. This may be a result of clinical innovation over the 20-year span of cohorts that allows the younger cohorts to maintain homeostasis in the face of greater physiological challenge. For example, improved management of chronic diseases such as diabetes or hypertension may have helped younger cohorts to maintain physiological homeostasis in a more impaired condition and thus altered the form of the hazard function. Alternatively, improved health at later ages may have led to greater homeostatic reserve due to a lessened prevalence of chronic diseases. Regardless of its possible sources, none of this effect is evident in the Gompertz hazard function assuming homogeneity because of confounding of the trajectory of the hazard function with interindividual differences. (For example, risk heterogeneity may have increased for younger cohorts because of the greater survival of diabetics due to the reduction of stroke mortality.)

The basic conclusion is that, in contrast to analyses of the population mortality data with the Gompertz function assuming homogeneity, where it was often concluded that there was little change in the rate of aging changes (e.g., Gavrilov, 1983), the hazard function adjusted for risk heterogeneity suggests that there has been considerable change in the rate of aging processes. Furthermore, even for the unadjusted Gompertz hazard functions, our estimates of θ (the basic aging parameter) differ (being much smaller) from values cited in the literature (typically on the order of 0.08) because we employed cohort data rather than cross-sectional data. The estimates of about 8 percent per year in the increase in population mortality risks are confounded with intercohort differences in risk.

The effects of heterogeneity on our ability to make inferences about basic individual aging changes from population data also have important implications for cross-population comparisons. One well studied comparison is that of the age-specific differentials in mortality rates for U.S. black and white persons. After being much elevated in middle age, black mortality rates at advanced ages first approach and then drop below white mortality rates. This has been referred to as the "black-white" mortality crossover (Manton, 1982a). Indeed, even if there is not an actual crossover, there is a convergence of the hazard rate trajectories beginning in midlife. One possible explanation for this crossover (or convergence) is the differential rate of mortality selection between black and white persons, i.e., the fact that higher black mortality rates at earlier ages tend to remove more rapidly black persons with chronic morbid conditions so that the smaller proportion of black persons surviving to advanced ages are relatively healthier than white persons surviving to those ages. Manton and Stallard (1981) show how a model of mortality selection could explain the crossover. Clearly, if the differences in mortality rates at later ages were due to mortality selection, then one would not need to posit different physiological aging processes to explain the different trajectory of age-specific mortality rates between black and white persons.

It is interesting that this black-white crossover can also be demonstrated in a number of longitudinal studies. For example, we see that black persons who survive to later ages in the Duke Longitudinal Study have greater residual life expectancies than white persons who survive to advanced ages (Manton, Siegler, and Woodbury, 1986). A black-white mortality crossover has also been demonstrated in the Evans County study population (Wing, Tyroler, and Manton, 1985). In addition, preliminary analyses (Wing et al., 1987) have also shown a clear black-white mortality crossover in the Charlestown Heart Study—a crossover which is present even after socioeconomic factors are controlled.

One point of confusion that often emerges in discussions of heterogeneity and selection is the effect of "debilitation," i.e., the fact that early adverse mortality conditions may reflect environmental exposure which "damages" the physiology of those persons who do survive. For example, systematic differences in cause-specific mortality patterns, some of which are clearly environmentally generated, exist for middle-aged black and white persons (Manton, 1982a). What is not always recognized is that this damage, or "debilitation," behaves just like risk heterogeneity *after* the age at which it occurs. Thus, if black persons have higher alcohol consumption rates than white persons, and consequently greater risks of deaths from cirrhosis, we would observe a systematic selection (and earlier age at death) of black persons after the ages at which the physiological damage from alcohol consumption occurred. We will illustrate this effect below for lung cancer.

To this point we have examined the effects of population heterogeneity on the trajectory of population-level hazard functions only for total mortality. There is a second, critically important source of heterogeneity that we have not yet controlled for. This is the heterogeneity due to the multiple chronic disease processes that are operational in an elderly population. The tendency has been for mortality and aging at advanced ages to be viewed as due to a unidimensional process. One theoretical justification for this view is that a single factor can become overriding and dominant in the homeostatic control mechanisms that determine age-specific mortality risks. Sacher (1977) showed, in a model of human aging and mortality, that such a dominant factor could produce the Gompertzian type of aging model that has often been applied in the analysis of unadjusted population mortality rates. The emergence of a single dominant mortality function seems not to be supported by the evidence (Schneider and Brody, 1983). Instead, it appears that multiple aging processes, each associated with different chronic disease processes, continue to operate into very advanced ages. Clearly the progression of these processes is time related. Furthermore, there may be interaction among the different chronic disease processes. Nonetheless, the effects of discrete disease processes can be identified and tracked—even at advanced ages (e.g., Howell, 1963a, 1963b, 1981). To illustrate this, consider the cases of lung and breast cancer.

In the case of lung cancer, we can see in figures 3 and 4 that there are strong cohort differentials in risk, probably due to changes in the smoking history of birth cohorts. Further-

FIGURE 3
WHITE MALES
Lung Cancer Mortality

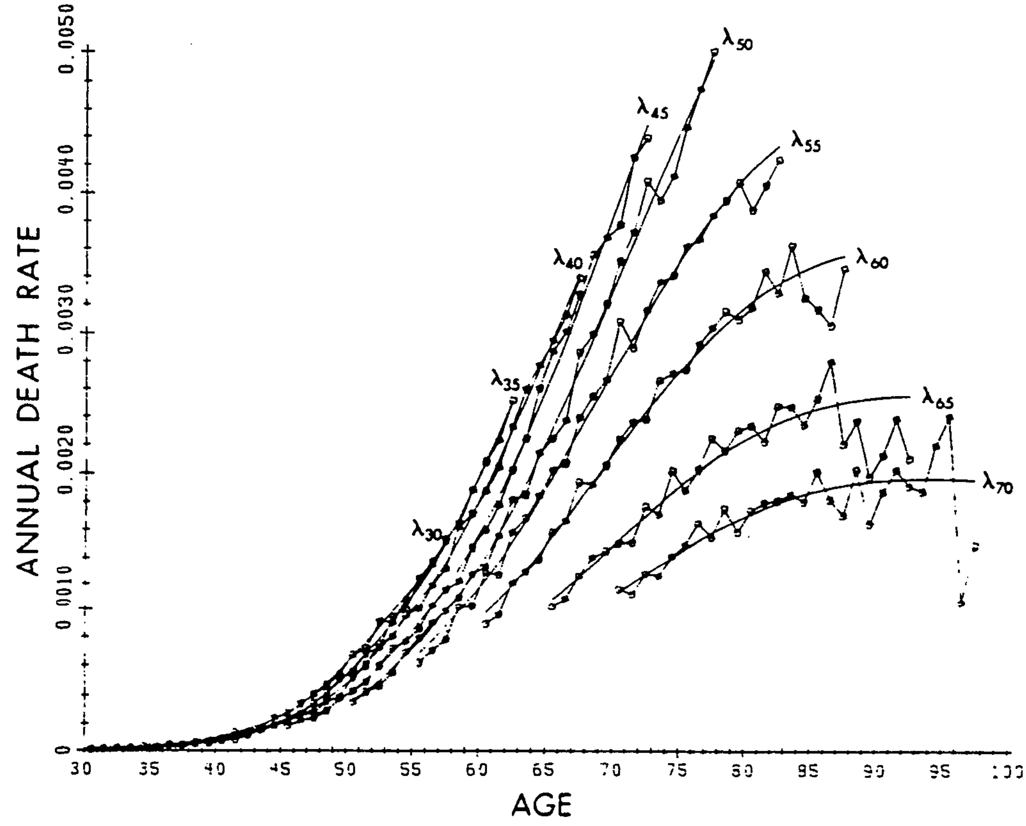
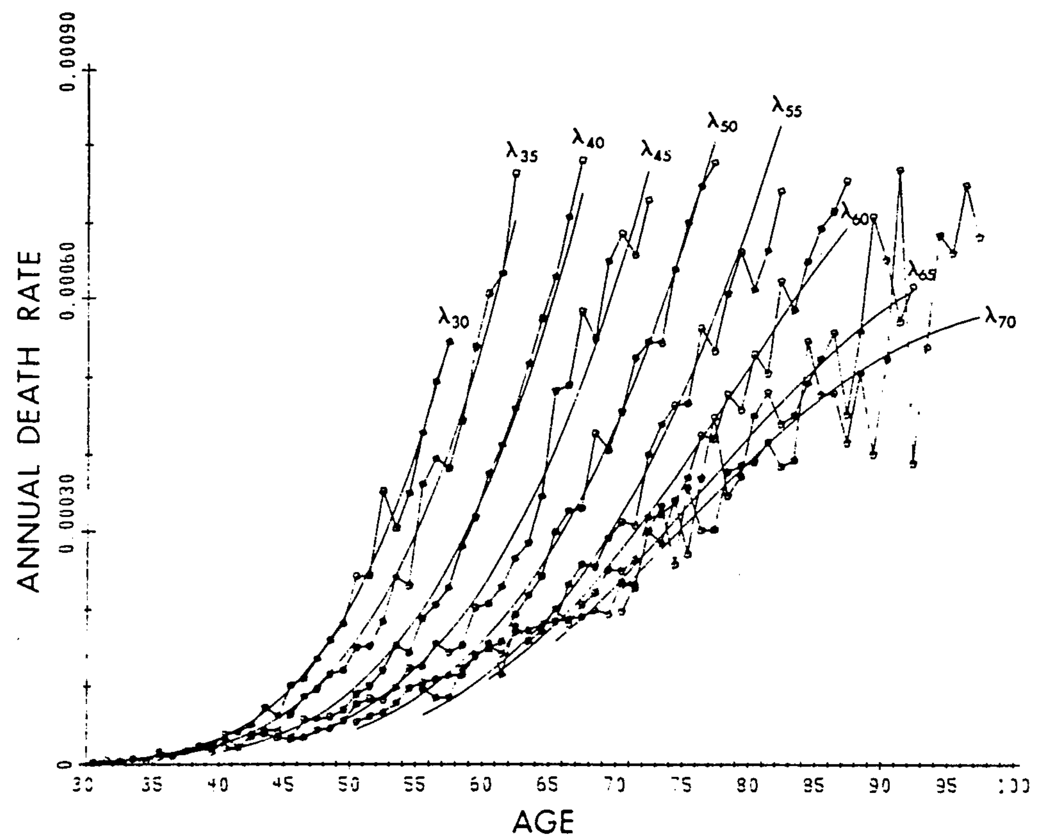


FIGURE 4
WHITE FEMALES
Lung Cancer Mortality



more, it has been observed that lung cancer mortality tends to decline at advanced ages. Both of these phenomena may be observed in the cohort plots for white males and females presented in figures 3 and 4.

In the figures we follow the experience of nine male and nine female birth cohorts (born 1880–1920) for 28 years (1950–77). The jagged lines indicate the observed cohort age-specific mortality rates, while the smooth lines indicate the values fit to those points by our analysis—i.e., by fitting a gamma-mixed Weibull hazard function (Manton and Stallard, 1982). The most recent male cohorts (i.e., those marked by γ_{30}, γ_{35}, γ_{40}, and γ_{45}) show only small increases. In contrast, females show rapid increases for the more recent birth cohorts. This is consistent with the fact that reductions in female smoking lag 20 years behind reductions for males (Harris, 1983).

In addition to the large cohort differences in figures 3 and 4, we also observed the tendency for mortality to increase less rapidly at advanced ages. The slowing again may be a consequence of the effect of selection on the age trajectory of risks described in equation (1), i.e., that the higher risk persons are more rapidly removed by mortality from the populations.

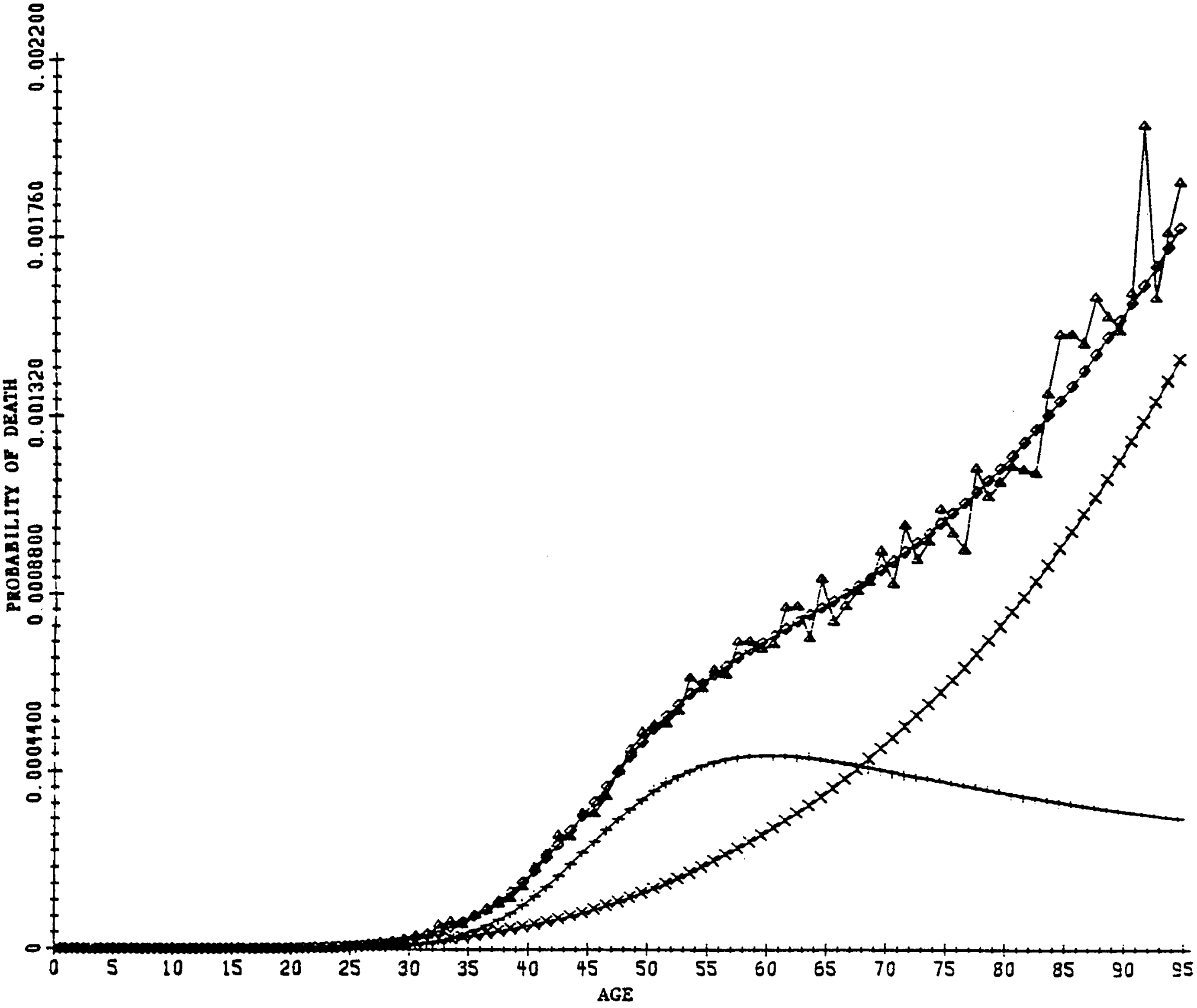
The decline in risk at more advanced ages for lung cancer is also observed for other chronic diseases with an early mean age at death, e.g., diabetes, cirrhosis, and chronic respiratory disease (Manton, 1982b). Interestingly, as the force of mortality for disease decreases, its prevalence is likely to increase. For example, as stroke and other conditions associated with diabetes decrease in mortality risk, the population prevalence of diabetes may increase. The decrease in stroke mortality has, in part, been attributed by some to be a consequence of the reduction in risk of other associated conditions, e.g., heart disease (Hachinski, 1984).

The tendency for some chronic diseases to decline in risk at advanced ages is probably a function of their typical age at death. Thus, for diabetes (and cirrhosis) the mean age at death is low relative to other chronic diseases. Thus persons with the risk attributes for these diseases (e.g., obesity for diabetes, drinking for cirrhosis) will die out of the population at earlier ages, causing the cause-specific rates to decline (due to selection) at later ages. If, as modeled for lung cancer, the *individual* risks tend to increase with age, future shifts in the mean age at death for different diseases will have important implications for manifest disease prevalence patterns at later ages.

One version of this problem can be illustrated for breast cancer. It has been argued that there may be two distinct forms of the disease process generating the complex hazard function form known as Clemmensen's hook (Manton and Stallard, 1980). (See figure 5.) We see that the "hook" is manifest as a flattening of the observed hazard function (top line) after age 50. It has been hypothesized that early increases in breast cancer mortality hazards are due to a "premenopausal" disease component and that this component has a genetic

FIGURE 5

Observed and predicted single year of age probabilities of death due to breast cancer for white females in the United States in 1969.



NOTE: Δ = Observed probability of death caused by breast cancer, ◇ = predicted probability of death caused by breast cancer, + = hypothesized probability of death caused by premenopausal disease, × = hypothesized probability of death caused by postmenopausal disease.

base. The late portion of the hazard function, it is argued, is due to a "postmenopausal" disease component that is not linked so strongly to family pedigree.

In Manton and Stallard (1980) it was found possible to explain this complex hazard function using a two-disease model. The persons succumbing to the early disease component were found to have a high degree of risk heterogeneity—a degree of heterogeneity high enough that "susceptible" persons are exhausted at a very high rate from the population after age 50. The degree of heterogeneity estimated by the model for this component of the disease process is consistent with the high relative risks determined for women with certain high-risk pedigrees (Anderson, 1975). The late disease component, in contrast, behaved much more like other solid tumors, where the age increase in the risk of the disease increased as the sixth or seventh power of age. The individual contribution of the two diseases to the total breast cancer mortality risk is illustrated in figure 5 by the two bottom lines.

We illustrate in table 5 the effects of debilitation by examining the very early stages of lung cancer mortality for birth cohorts 1880–1940, followed from 1950–77. The coefficients in this table represent the risk multipliers for the function describing the age increase in the lung cancer cohort mortality rates. If we read down the diagonals, we see that, for cohorts at least age 35 in 1950, the relative risk is constant, i.e., we have assumed that the major risk factor exposures have occurred by age 35. If we read across the first row in the table, we see that the risk at ages 35–39 of the 1915–40 cohorts peaked for the 1930 cohort (in 1965–69, shortly after the 1964 Surgeon General's report on smoking hazards). This suggests that male birth cohorts born after 1930 will have declining risks so that, after the birth cohort of 1930 reaches the peak lung cancer risk age (around age 70), there could be a decline in male rates. Actually, this cohort experienced the highest risk in the interval 1965–69. After that period the cohort risk declined, suggesting that the risk of lung cancer changed within cohorts, probably due to changing exposure to cigarettes. Such changes in disease risk can reflect the impact of debilitation, i.e., the period-specific accumulation of risk factor exposure.

The issues of population heterogeneity, mortality selection, the multidimensionality of the aging process, and the different age pattern of mortality for specific diseases raise the issue of "competing risks" (Chiang, 1968). Competing risks represent the censoring of the manifestation of a particular disease by mortality from another cause. Competing risks can be dealt with in one of two ways. The first, the usual demographic approach, assumes that diseases operate independently. Thus, if a person were not to die of a given condition at the observed time, then his theoretical second age at death would be determined by the age-specific mortality risks observed for all other causes of death in the population. The second approach views causes of death, or, more precisely, the morbid processes generating death, as interacting. To illustrate, consider the simple illness-death process in figure 6 (Manton, 1985).

For simplicity, we have divided the set of all diseases into a disease of interest and a group of all other diseases. In the figure we describe the effects of the two sets of diseases on the population by five health states. The first is the well state. Since we are dealing with chronic disease, all persons are assumed to be born into the well state, free of disease. The person can make one of two types of transitions from this state. The first, $\nu_1(a)$, is the age-specific mortality risks for all other causes of death. The second, $\lambda_1(a)$, is the age-specific incidence function for the disease of interest. If we are describing a model of individual health changes in figure 6, this incidence would increase without the effects of selection. At the population level, however, we could observe a decline in risks if the most highly susceptible persons were removed from the population (Brody, 1985).

The second health state describes the preclinical phase of the disease. The individual can also make two types of transitions from this state. The first is to the death from other causes state, with a transition rate $(1 + \beta_2) \cdot \nu_1(a)$. The parameter β_2 reflects the degree of interaction between the condition of interest and the risk of death from all other causes. The interaction may function in one of two ways.

One way the interaction may function is for the mortality risk of one disease process to be enhanced by another disease process. This is illustrated by the interaction of diabetes mellitus and stroke. Diabetes causes circulatory degeneration and

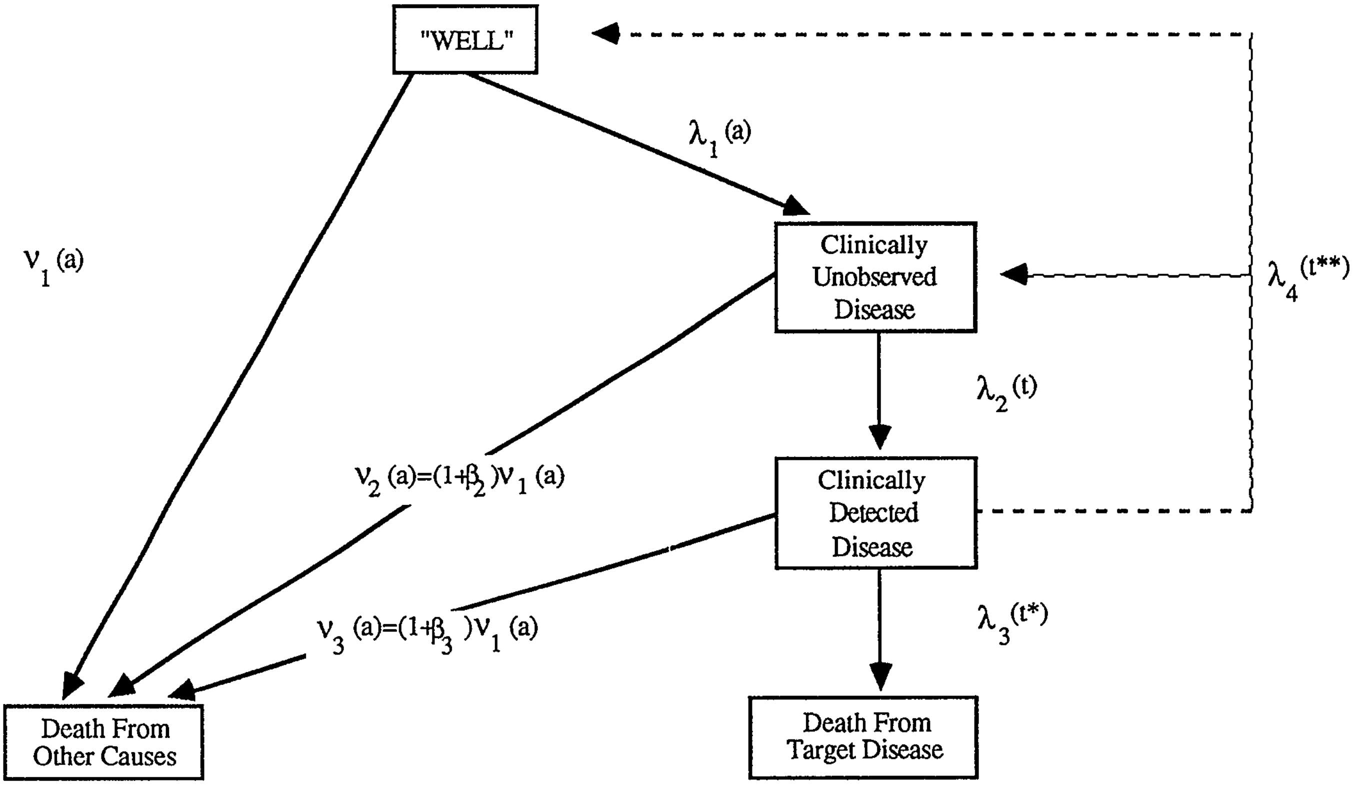


FIGURE 6: Illness-Death Process

enhances the risk of stroke (possibly from hypertension) and other chronic circulatory diseases. Generally, the person will die of a stroke before the primary effects of diabetes cause death. Indeed, the example given earlier of the increase in the prevalence of diabetes due to the decrease in the risk of stroke death illustrates a case where β_2 was reduced (by reducing the mortality risks of stroke through hypertension control), so that the prevalence in the preclinical (and clinical) state for diabetes increased (Whisnant, 1984).

Another way a dependency (represented by $\beta_2 \neq 0$) may be generated is through changes in the population distribution of a risk factor common to two diseases. In this case, persons who develop a particular disease will have a greater probability of having certain risk factor exposures than those who do not. The risk factor exposures increase the risk of both causes of death. Thus $\beta_2 > 0.0$ because people who enter the preclinical disease state are a subpopulation systematically selected into that morbid state because of particular risk factor exposures.

The third state is the clinically observed portion of the disease process. The transition to this state is a function of the rate of progression of the disease process. Clearly, at the population level, the rate of disease progression may vary over individuals, so that we will again find that persons who clinically manifest their disease will be selected to have the most rapidly progressing disease processes. For example, many elderly males manifest prostatic tumors at autopsy, but far fewer manifest them clinically. Those who manifest the disease clinically (for a given age at onset) probably have a greater susceptibility to onset and rapid growth. This may engender an entirely different disease dependency, say β_3, so that the risk of death from other cause is $(1 + \beta_3)\nu_1(a)$. Likewise, since there may be a selected group of persons who clinically manifest the disease, there may be implications for the probability of disease cure or remission.

To illustrate the implications of dependency, consider table 6, in which $\beta_2 = \beta_3 = \beta$, by assumption. In this table we present (1) the number of persons who died of lung cancer in 1977, (2) the number of persons projected to die of another disease with a tumor growing with ($\beta = 1$) and without ($\beta = 0$) dependency in 1977, and (3) the number of persons in the population projected to have the disease but who died of another cause with ($\beta = 1$) and without ($\beta = 0$) dependency in the year 2000. Since the number of deaths in 1977 is an observed quantity, it cannot be changed by assumptions about β. However, the number of persons with the disease in the population is strongly affected by assumptions about β. For example, we see that the number of persons who can be projected to die of another disease but with a tumor increases dramatically under the assumption of dependency. Thus, if the risk of death from other causes decreased (equivalent to an increase in the mean age at death from those causes), we could expect much larger increases in the amount of disease manifested (and the number of deaths generated by the target disease) if the true value of β is 1.0 (dependent competing risks) than if it is 0.0 (independent competing risks).

One empirical manifestation of such disease interactions is the high prevalence of multiple chronic diseases at advanced ages. This is a particular reason why the "multiple" cause of death mortality data are so informative about mortality at advanced ages (e.g., Manton, 1985). For example, in table 7 we present the age-specific ratio of total to underlying cause mentions of lung and prostatic cancer. We see that the relative prevalence of prostatic cancer as other than the underlying cause of death is much greater than the relative prevalence for lung cancer and that the relative prevalence increases with age. This is due to the slower rate of progression of prostatic cancer, with the greater likelihood of death from other causes. There is a consistent positive relation, for different tumor sites, between the ratio of total to underlying occurrence and the clinical survival time determined from the Survey of Epidemiology and End Results study (Manton, Myers and Cohen, 1987).

III. Health transitions at advanced ages: Categorical patterns

In the prior section we discussed the relation of individual-level and population-level morbidity and mortality hazards and how these relationships had to be analytically adjusted in order to use population data to make inferences about the aging trajectory for individuals. In this section we will describe individual physiological changes in a population where the physiological and health state of individuals was measured longitudinally. In describing those longitudinal aging changes, we will not make assumptions about either (a) the form of the age trajectory of physiological status or mortality risks or (b) the distribution of health or physiological parameters in the population. In order to avoid making assumptions about either factor, we will need as an analytic tool a general pattern recognition model that can identify patterns both in the grouping of cases and in the trajectory of change in a complex multivariate profile of physiological and health measures.

A pattern recognition model which fulfills these restrictions is called the Grade of Membership (GOM) model. This model was originally developed in order to identify characteristic symptom profiles for persons with particular disease clusters (Woodbury and Manton, 1982). The basic logic of the model is that there exist K profiles that simultaneously describe (a) the grouping of individuals according to their attributes and (b) the multivariate profile describing each subgroup. The K profiles are obtained by first recording the information on each person ($i = 1, 2, 3, \ldots I$) into ℓ binary responses ($\ell = 1, 2, \ldots, L_j$) for J different variables where an individual can have only one (i.e., have the value 1.0) of the possible responses for a given variable. We will designate these binary variables as $x_{ij\ell}$.

To explain each binary variable, two types of coefficients are estimated. The first type, $\lambda_{kj\ell}$, describes the multivariate pattern for the K profiles in terms of the J variables and

L_j responses. These coefficients represent the probability distribution of the L_j responses for the jth variable (hence $\sum_{\ell} \lambda_{kj\ell} = 1.0$). The kth profile may be interpreted, in much the same fashion as factor analysis, by examining the set of $\lambda_{kj\ell}$ for the kth profile. The second type of coefficient, g_{ik}, represents how strongly the ith person's observed responses (i.e., his $x_{ij\ell}$) relate to the pattern of responses for the kth profile. It is a measure of the closeness of $x_{ij\ell}$ to the $\lambda_{kj\ell}$. When a $g_{ik} = 1.0$, then $x_{ij\ell}$ and $\lambda_{kj\ell}$ will be identical. The g_{ik} are constrained to have the properties $\sum_k g_{ik} = 1.0$ and $g_{ik} \geqslant 0.0$. Thus the $x_{ij\ell}$ for a person will be explained as a weighted combination of some set of $\lambda_{kj\ell}$. The basic equation can be written $\hat{x}_{ij\ell} = \sum_k g_{ik} \lambda_{kj\ell}$.

The $\hat{x}_{ij\ell}$ are equal to $Pr(x_{ij\ell} = 1.0)$, or the probability predicted by the model that the ith person has the property $x_{ij\ell} = 1$. The values of the coefficients g_{ik} and $\lambda_{kj\ell}$ are determined by maximum likelihood procedures with Kuhn-Tucker constraints to impose boundary restrictions on the numerical range of the two sets of coefficients.

The mathematical structure of the model gives it special properties for studying longitudinal change. First, the g_{ik} and $\lambda_{kj\ell}$ are simultaneously estimated in the model. Since the g_{ik} represent the distribution of cases on each of the K profiles, this means that no assumptions are required in the model about the distribution of cases. Second, since all information is coded in binary form and we attempt to explain the probability of each binary response in a pattern, no assumptions are made about the functional form of specific types of response. Third, the model deals appropriately with missing data. As a consequence, we do not lose cases from an analysis of a longitudinal data set because of gaps in measurement. Finally, the amount of information in the model increases as a function of both the number of variables and the increase in the number of cases. As a result, small data sets with lengthy followup periods can yield considerable statistical power.

This general model can be specifically structured to identify patterns of temporal and age change in a longitudinally followed population. This can be done in one of two ways. The first way involves representing the temporal path of individual changes. In this situation, the number I refers to the number of individuals or individual episodes in the study. In the simplest case (i.e., where the episode refers to the full event history of the person observed in the study), the number J will refer to the number of variables that are measured at each wave of measurement in the study times the number of waves of measurements made. If five physiological measurements were taken at each of five biennial exams, there would be 5 × 5, or 25, variables. Aging would be reflected in the change of the response probabilities for each type of variable over the five times of measurement. Thus, if the distribution of blood pressure for a given profile shifted toward higher levels across waves, we would infer a tendency toward blood pressure increasing with age. Since, however, there are no constraints on how the distribution of response levels for a variable changes from one wave of measurement to the next, the blood-pressure measurements could first increase and then decrease with age. Indeed, this nonlinear pattern is what is typically observed for diastolic blood pressure among survivors, with the highest levels observed in the late sixties. In contrast, pulse pressure tends to remain unchanged through late midlife, then to gradually increase.

In this way of describing change, the GOM model isolates K patterns of change which represent the shift with age of the distribution of responses for a specific type of measurement. In any longitudinally followed population, one is likely to have considerable individual heterogeneity in the trajectory of physiological (and cognitive) aging changes. These individual differences would be captured in the g_{ik}; that is, while the model identifies K typical patterns of change, the g_{ik} relate each of those basic patterns of change to the observed pattern of change for each individual. This type of analysis may be viewed as a generalization of event history analysis, where unobserved factors are allowed to affect the operation of the discrete state jumps, or shifts.

This heterogeneous nonparametric event history analysis can be roughly illustrated by an evaluation of the use of type D living arrangements (i.e., nursing homes) by Supplemental Security Income (SSI) recipients. In table 8 we present the probability that each of 5,482 episodes of cases funded under the SSI program ended by one of four types of changes (i.e., left the active payment state, changed living arrangements, died, or came to the end of the study) occurring after 1, 3, 12, 18, or 24 months. Also contained in the table is the distribution of the episodes over age and program type.

At the left side of the table, the variables and their response levels are described. Next, the column labeled "Frequency" contains the observed distribution of responses in the sets of individual episodes. The last four columns describe the four profiles ($K = 4$) by presenting the probability that an episode with a given profile will exit the SSI population in one of several ways. We can see that the first profile describes episodes with a high probability of changing living arrangements, which is consistent with its strong likelihood (44.2 percent) of representing episodes for children who return to their parents. The fourth profile describes episodes with a strong likelihood of ending in death, which is consistent with persons in those episodes being very elderly (85 percent 65 years and over; 63 percent 75 years and over). The second group represents episodes for young adults (19–50 years) who have low probabilities of death. The third group represents episodes for elderly persons (somewhat younger than group 4) but with roughly one-half the risk of ending in death.

To relate these patterns to individual episodes, we need the distribution of the g_{ik}. This is presented in table 9. The high values of g_{ik} indicate episodes which are very closely represented by the kth pattern. We see that the fourth group of episodes is the most prevalent (i.e., 473 episodes with a $g_{ik} = 1.0$ and a total $\sum_i g_{i4} = 1{,}827$). Group 3 is least prevalent.

As suggested above, this analysis can be viewed as extending event history analysis (Tuma, 1982) in two ways: (a) the transition probabilities vary over individuals because of unobserved covariates affecting the level of the transition rate, and (b) the hazard function describing the time dependency of the transition to one of the outcome states is nonparametric. The reason that we can analyze the history of multiple-state changes in this way (i.e., instead of as in mortality analysis, where there is only one type of absorbing transition to the death state) is that the likelihood function can be shown to independently factor into event episodes (Manton, Stallard, Woodbury, and Yashin, 1986). Given this factorization, the unobserved heterogeneity is reflected in the distribution of the g_{ik} where they are similar to the posterior probability of a person's observed transition history being a given type. The fact that we have four types is a generalization of the models of mortality for heterogeneous populations discussed earlier because, instead of the one-dimensional heterogeneity in those models, we have four different unobserved dimensions. It should also be noted that, in addition to the information on transitions, a set of fixed covariates is included. Thus the four-event history profiles represent information on fixed individual characteristics as well as their transition histories.

A second way of describing transitions is by describing the states that a person passes through. In this case, the number I no longer represents individuals or episodes. Instead, it is expanded to represent the number of measurements made; that is, if a person were observed at three of five measurement times, we would treat the three observations as independent cases. Thus I, the number of observations in the analysis, would represent the number of persons times the average number of waves of measurements at which each person was assessed. For example, in a recent analysis of the 267 persons in the Duke Longitudinal Study of Aging (1955–76), persons were assessed at an average of 4.3 waves. Hence $I = 1{,}167$, or 267×4.3. Clearly, this reorganization of the data is possible because, in the model, given the selection of the correct number of profiles, the observed quantities, $x_{ij\ell}$, are independent. Thus the measurements of the same variable made at different times are independent. This means that J, the number of variables used to represent the set of measurements made on each individual, will have to be redefined. Instead of, as in the prior analysis, having five variables measured at five waves, in the current analysis we have only five variables (but five times as many "cases").

In this type of analysis, the $\lambda_{kj\ell}$ represent the states that persons possess at a specific point in time and do not represent the transitions between those states. Change is described in terms of the change in the prevalence of each of the K states over time. Hence the information on transitions is now contained in the g_{ik} instead of the $\lambda_{kj\ell}$. Heterogeneity is still reflected in this analysis, since the g_{ik} represent how close a person is at a given time to one of the K states. Since each person will have as many sets of g_{ik} as waves of measurements in which he participated, we can examine the pattern of change in an individual g_{ik} to see how he transitions between multivariate states (defined by the $\lambda_{kj\ell}$).

To illustrate this type of analysis, we present table 10. In this table we present the $\lambda_{kj\ell}$ derived from an analysis of the 21 years of followup on the first Duke Longitudinal Study of Aging (1955–76). These coefficients describe five basic states manifested in the study population over the study. As we can see, the five profiles describe a consistent pattern of physiological decline.

What is interesting is to examine the probability distribution for the additional measurements in table 11. We see that the first variable describes the distribution of ages at which each profile was observed. It is interesting that the mean ages across the profiles are 75.0, 75.6, 79.3, 83.2, and 74.8. Thus there is a correlation of physiological decline with the mean age of persons in each state. What this suggests is that there is a morbid, relatively young subgroup that entered the study and died out quickly. The exhaustion of this population from the study is evidenced by the next two variables, which show that no one in profile 5 survived past the seventh wave of the study. Also of interest is the distribution of these profiles by sex, race, and education. We find that the probability of being black is high in both profiles 4 (long survivors) and 5 (short survivors). This is consistent with the model of the black–white crossover. It is interesting that the fourth group is less educated than the fifth group—so it is not possible to explain these profiles by socioeconomic differences. Also, though there are differences in the proportion female in the two profiles, they are not as great as differences between other profiles where the differences in survival are less. Thus the GOM analysis has picked up a pattern of state changes that seems to identify a terminal drop subpopulation with poor, early physiological characteristics.

IV. Mechanisms of health transitions at later ages

In the previous section we described analyses which could identify basic health transition patterns and subgroups in longitudinal data. In this section we describe models that go beyond simply identifying patterns to attempting to describe the basic mechanisms of physiological aging changes. The model we will employ to do this is the Random Walk model of human aging and mortality (Woodbury and Manton, 1977). This model describes aging changes in terms of two correlated stochastic processes.

The first type of process describes changes in individual risk factor values over an interval among persons who survive the interval. For a set of J risk factors, these equations may be simply written,

$$\underset{\sim}{x}_{t+1} = \underset{\sim}{u}_t + (\underset{\sim}{I} - \underset{\sim}{A}_t)\underset{\sim}{x}_t + \underset{\sim}{e}_t, \qquad (2)$$

where $\underset{\sim}{x}$ represents the vector of measurements made on person i (index i suppressed) at times t and $t+1$, $\underset{\sim}{u}_t$ is the vector of regression constants, $(\underset{\sim}{I} - \underset{\sim}{A}_t)$ is the matrix of regression coefficients ($J \times J$), and $\underset{\sim}{e}_t$ is the vector of J error terms.

These J equations describe the change in the risk factors as a function of three types of change—"drift," "regression," and "diffusion." These three types of dynamics are illustrated in the univariate case in figures 7 to 10.

"Drift" (change between figures 7 and 8) represents systematic changes in the mean of the risk factor values over time. It is reflected in the constant, u_t, and in the coefficients for the other risk factors in the multivariate case (i.e., in the matrix $\underset{\sim}{I} - \underset{\sim}{A}$). "Regression" (figure 9) represents the

Figure 7

$Q_0 \; N(\mu_0, \sigma_0^2)$

AREA UNDER CURVE IS Q_0
POPULATION SIZE IS Q_0

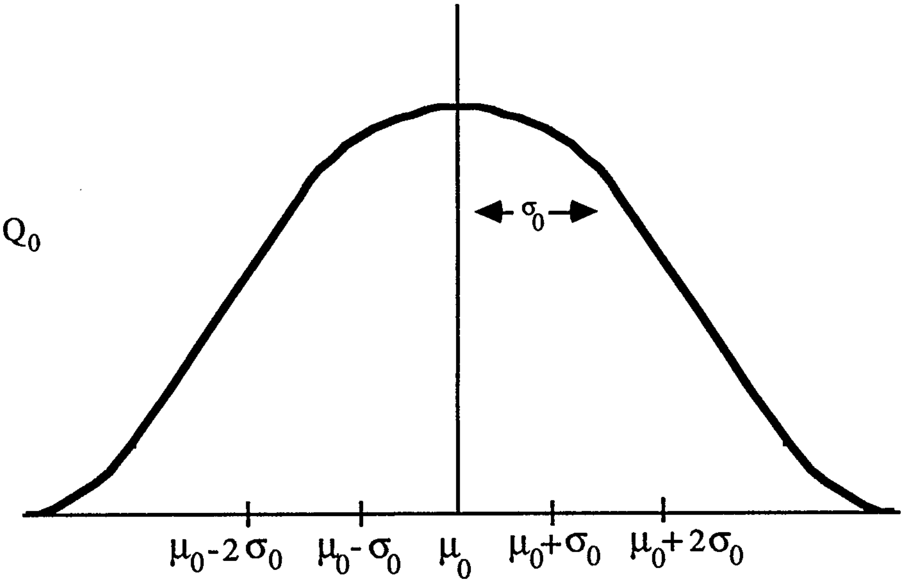


Figure 8

FREQUENCY FUNCTION OF RISK VARIABLE AT TIME 0 ABOVE
1 BELOW

$Q_0 \; N(\mu_1, \sigma_0^2)$

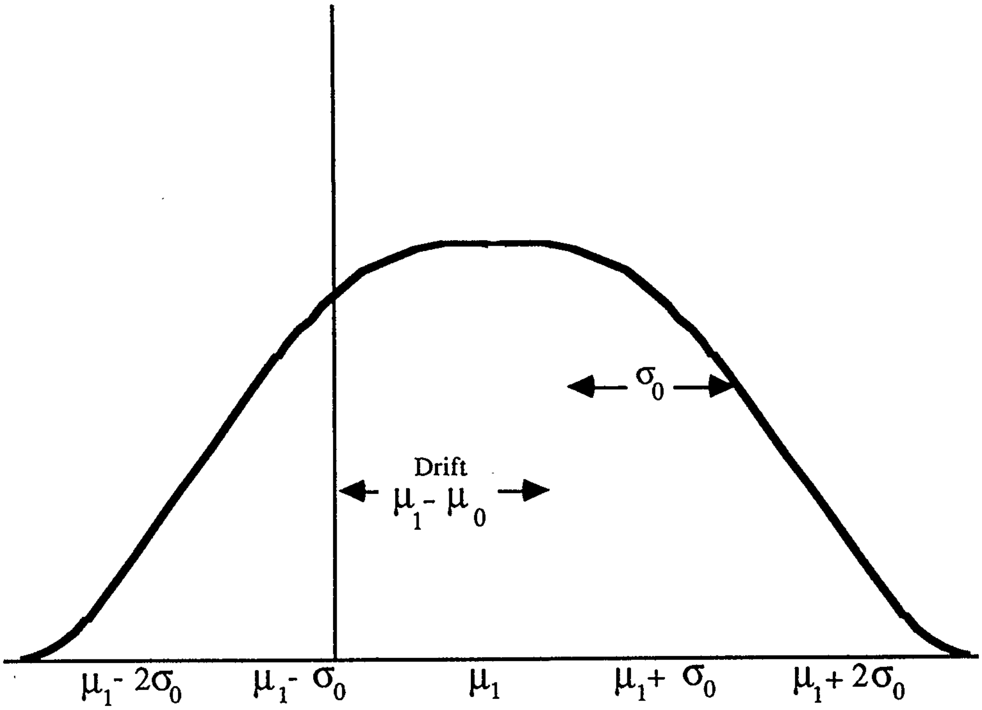


Figure 9

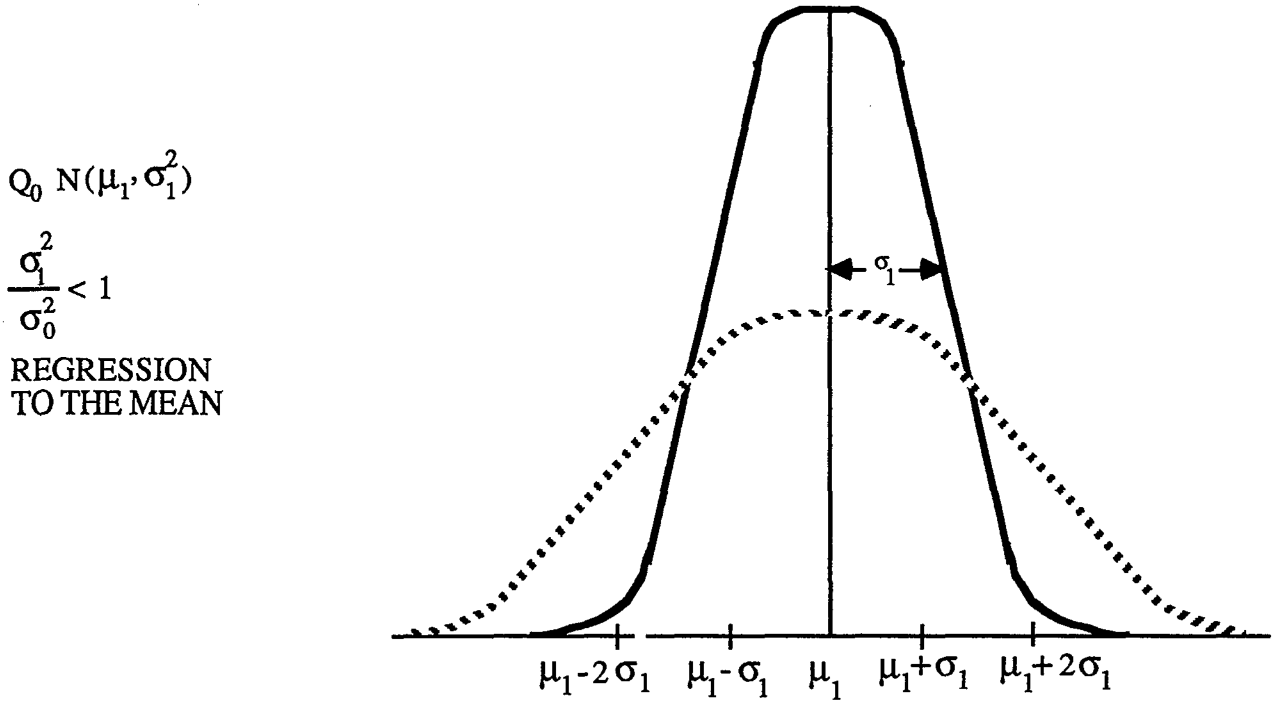
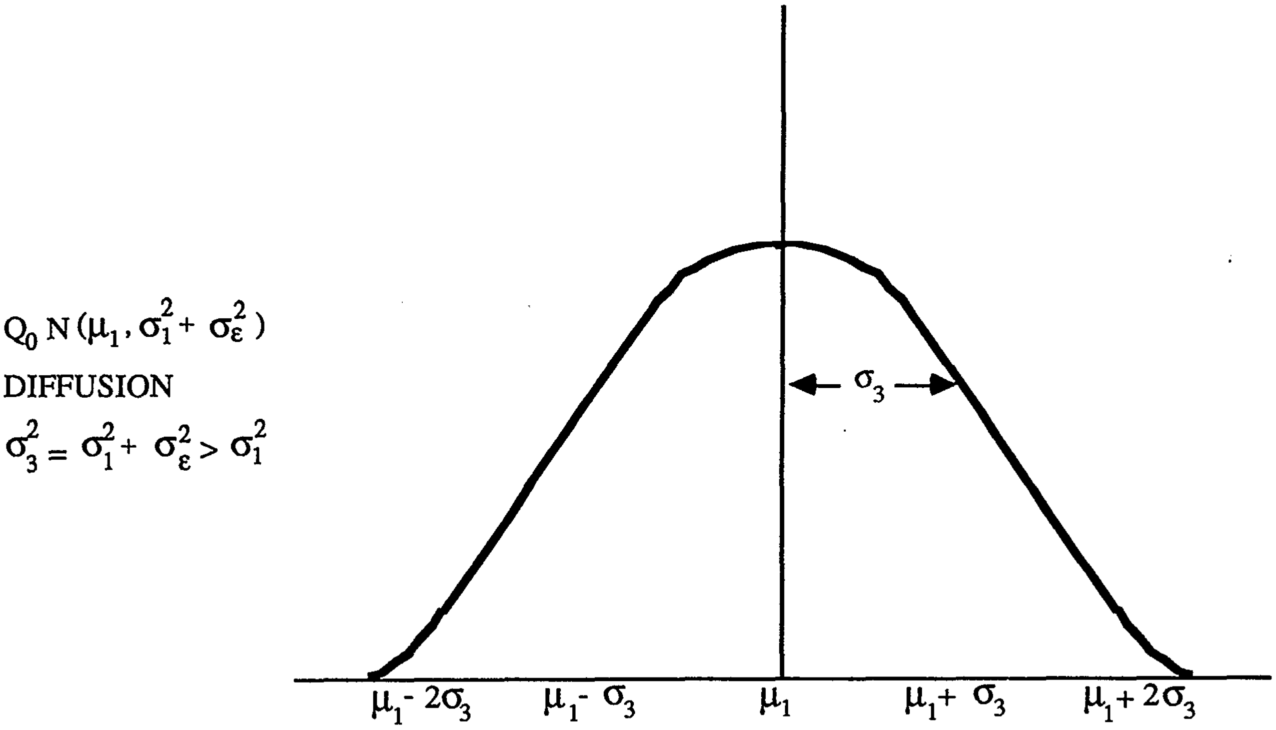


Figure 10



stochastic tendency for an individual to return to the "average" value of the risk factor—with the temporal change in the average risk factor value being determined by "drift." "Diffusion" (figure 10) represents the lack of predictability in risk factor values over time—represented by the error terms in the equations. These three types of dynamics describe both systematic and stochastic aging among individuals in a population to the degree that the physiological age status of the person is described by the risk factors in the system. Age, as a risk factor, is a proxy measure for the physiological factors not explicitly measured.

One potentially important modification of the model in order to explain aging mechanisms is the effect of "tracking"—i.e., the tendency for persons to persist at certain physiological risk factor levels (e.g., high diastolic blood pressure levels). Tracking could be represented, for example, by allowing individual constants (i.e., $\underset{\sim}{u}_{ti}$) in the regression equations, in which case all stochasticity would involve diffusion about individual level means (with the individual means changing over time due to "drift"). Tracking is one method to adjust aging dynamics for the effects of influential but unobserved physiological processes (e.g., Yashin, Manton, and Stallard, 1987).

Each of the types of dynamic forces represents possible ways that one could intervene in the mortality process by controlling risk factor change. For example, one could reduce the upward drift of a risk factor with age. Alternatively, one could reduce diffusion, which would reduce mortality because higher variances imply persons at more extreme risk factor levels.

To illustrate this type of process, we present table 12. The coefficients in this table represent the change in nine risk factors over 2-year intervals for roughly 2,330 males followed for 20 years in Framingham, Massachusetts. We see that there is potentially a large amount of diffusion for certain variables, like diastolic blood pressure (i.e., because the diagonal term is small). Others exhibit very strong persistence, e.g., weight-height index.

Associated with the dynamics of physiological changes among survivors is a discrete state process that describes the risk of death (or some other discrete health status change) as a function of the current risk factor levels. This risk is modeled as a quadratic function of the risk factors. The hazard function could be written

$$\underset{\sim}{u}_t(\underset{\sim}{x}_t) = \mu_{0t} + \underset{\sim}{b}_t^T \underset{\sim}{x}_t + \tfrac{1}{2}\underset{\sim}{x}_t^T \underset{\sim}{B}_t \underset{\sim}{x}_t. \qquad (3)$$

The extended matrix, including the constant (μ_{0t}) and linear ($\tfrac{1}{2}\ \underset{\sim}{b}_t^T$) coefficients, say Q_t, as well as the quadratic and interaction terms ($\tfrac{1}{2}\underset{\sim}{B}_t$), is presented in table 13.

Note that the matrix does not contain terms for age. This is because we represent the effects of age by multiplying the whole matrix by a Gompertz function, or

$$\underset{\sim}{Q}_a = e^{\theta a} \cdot \underset{\sim}{Q}, \qquad (4)$$

where the exponent in the Gompertz term was estimated to be 0.0887 (compared with the value for θ in table 4), and a = AGE – 50.

This means that each type of term in $\underset{\sim}{Q}$ is multiplied by a function of age. Specifically,

$$\mu_a = e^{(0.0887)a} \cdot \mu_0, \qquad (4a)$$

$$\underset{\sim}{b}_a = e^{(0.0887)a} \cdot \underset{\sim}{b}_0, \qquad (4b)$$

$$\underset{\sim}{B}_a = e^{(0.0887)a} \cdot \underset{\sim}{B}_0. \qquad (4c)$$

This representation of age is critical to the model being biologically realistic. For example, an alternative strategy for analyzing the effects of age is to include it simply as a risk factor. This, however, does not truly represent age changes in the model. Rather, it simply means that age is statistically controlled. Consequently, not all risk factors have their effects modified by age. The result is that the age effect may be isolated from the other risk factor coefficients.

The problem with the model where age is simply introduced as a risk factor is not statistical. It can produce nearly as good a statistical fit to the data as the Gompertz-type model (equation 3), and it can produce forecasts that are very similar. The problem is that, if the quadratic function is to be taken seriously as a model of physiological processes, its minimum point must represent the physiological homeostatic point. When age is included as a covariate in the hazard function, it forces the minimum point for the other risk factors to physiologically unrealistic ranges. The Gompertz (and Weibull) quadratic hazard models produce physiologically plausible values. This is illustrated in table 14, where we present the minimum mortality points for pulse pressure and diastolic blood pressure over age for the two models.

We see that the changes when age is included as a risk factor are not realistic (e.g., a pulse pressure of –15 at age 45), whereas they are reasonable for the Gompertz model. Therefore, though a risk model may perform well statistically, and forecast well, it may not be an acceptable model of the actual underlying biological risk mechanisms.

The dynamic and hazard equations—i.e., (3) and (4)—may be used to describe the mortality and physiological change of a population by integrating their effects in a forecasting model. The change in the probability of surviving to the next measurement time may be generated by

$$S_t^* = S_t \left| \underset{\sim}{I} + \underset{\sim}{V}_t \underset{\sim}{B}_t \right|^{-1/2}$$

$$\exp\left\{\frac{\mu(\underset{\sim}{v}_t) + \mu(\underset{\sim}{v}_t^*)}{2} - 2\mu\left[\frac{\underset{\sim}{v}_t + \underset{\sim}{v}_t^*}{2}\right]\right\} = S_{t+1}\,. \qquad (5)$$

We can see that the probability of survival (S_t^*) is a function of the variability of persons on risk factors ($\underset{\sim}{V}_t$) as well as the average risk factor values ($\underset{\sim}{v}_t$). This variability increases mortality risks regardless of whether it is due to fixed factors or diffusion. Clearly mortality is also driven by drift, i.e., systematic changes in the risk factor means.

The next two equations show how the mean and variance of the risk factor distribution among survivors is changed by systematic mortality:

$$\underset{\sim}{v}_t^* = \underset{\sim}{v}_t - \underset{\sim}{V}_t^* (\underset{\sim}{b}_t + \underset{\sim}{B}_t \underset{\sim}{v}_t), \qquad (6)$$

$$\underset{\sim}{V}_t^* = (\underset{\sim}{I} + \underset{\sim}{V}_t \underset{\sim}{B}_t)\ \ {}^{1}\underset{\sim}{V}_t\,. \qquad (7)$$

Finally, to alter the risk factor values to their future values, we must apply the dynamics as,

$$\underset{\sim}{v}_{t+1} = \underset{\sim}{u}_t + (\underset{\sim}{I} - \underset{\sim}{A}_t)\,\underset{\sim}{v}_t^* \tag{8}$$

$$\underset{\sim}{V}_{t+1} = \underset{\sim}{\Sigma}_t + (\underset{\sim}{I} - \underset{\sim}{A}_t)\,\underset{\sim}{V}_t^*\,(\underset{\sim}{I} - \underset{\sim}{A}_t)^T. \tag{9}$$

We can utilize the coefficients in tables 12 and 13 in these five equations to produce a synthetic cohort life table starting at age 30 with risk factor covariates that describe both survival *and* physiological changes. This is illustrated in table 15. Clearly, this table differs from a standard life table in that, in addition to S_t and life expectancy, we present the means and standard deviations of the nine risk factors among survivors to age a_t (i.e., v_t and (diag $\underset{\sim}{V}_t)^{1/2}$). The S_t values in this table are very close to the S_t values in the cohort life table for U.S. males provided by the Social Security Administration (1983). The risk factor means, since they are derived from equation (8) applied to projections for 30-year-old males, can be compared to the observed age-specific means in the Framingham population. The correspondence of the risk factor means (projected and observed) is quite close over time (up to age 80—the last age observed in the 20-year followup). Thus, the life table provides an accurate picture of the survival and physiological status of the cohort followed over time.

These tables, and the equations that generate them, can be used in several ways to understand the mechanisms underlying physical changes. First, since the tables are adjusted for mortality as it is systematically related to the individual values on the physiological variables, they unconfound individual changes from the temporal trajectory of the population mortality rates. Second, if we decompose total mortality into its disease-specific elements (e.g., cancer and heart disease), we can study the dependency of different disease processes. Specifically, if we estimate separate quadratic hazard functions for diseases, we can examine the coefficients for the same risk factors in the different equations. If the coefficients are positive, there is, conditional upon risk factor values, "positive" dependency between the diseases (implying that the elimination of one condition would be compensated for by the other conditions so that the effect on survival would be *less* than expected under the assumption of independence). If the signs are different, then there is "negative" dependency. Thus one could determine what the effect would be on the force of mortality of all other conditions if a condition were eliminated and persons at certain risk factor levels survived to later ages. These simulations would also take into account the change in the impact of a risk factor on cause-specific mortality over age. In a series of such simulations, we found the actual level of dependency to be relatively small. This is illustrated in table 16.

We see that the effects of dependency are largest for cardiovascular disease. However, even in that case it is only 0.65 year—or 6.1 percent of the change under the assumption of independence. Clearly, if there are major unobserved risk factors, this could increase the estimate of the dependency effect. We are investigating the effect of such unobserved factors by including tracking effects in the dynamic equation. The small effect for disease dependency occurred because diffusion tended to cloud systematic shifts in the risk factor distributions caused by systematic mortality.

The current model could be used to investigate the effects of proposed risk factor interventions in detail. It has been observed that, in some community-based trials, the effects of intervention were not as great as implied by the association of risk factors with risk in longitudinal studies would suggest. The model presented earlier may help us to understand why. The failure to observe an effect of the anticipated size might result because several types of dynamic factors were not represented in the original risk factor analyses. Consequently, the appropriate age and time dynamics of risk factor interventions in a population were not obtained from those analyses. Specifically, those analyses generally did not represent (a) age and risk factor interactions, (b) the trajectory of change in risk factor values, and (c) the duration of specific chronic disease states. The potential effects of these factors in terms of the economic cost of illness are illustrated in table 17.

We see that reducing diastolic blood pressure and pulse pressure to what are usually viewed as clinically desirable levels produces an actual decline in life expectancy at age 30 and increased costs (though by age 47 this has reversed). In contrast, smoking control produces a large positive effect at age 30. The reason for the early increased costs for blood pressure control is evident. The trajectory of the blood pressure mean under intervention is not like the actual population trajectory, which first increases and then declines. Furthermore, the standard cost function strongly weights premature mortality at early ages (i.e., the life expectancy decrease is quite small). After age 60 there is a very large positive impact of blood pressure control on both costs and life expectancy. The reason for the early discrepancy is that the age × risk factor interaction effects were quite strong for blood pressure, and the intervention in no way reflected those effects. Thus intervention should reflect the age-specific optimal risk factor levels. This can be validated in table 17 by examining the columns where all risk factors are fixed at "optimal" levels. This produces a large improvement in survival because the effects of the risk factor implications are controlled.

V. Implications of health status transitions

In the preceding sections we (a) described the relation of individual health transitions to the average rate of change of population health characteristics, (b) showed how patterns of physiological change and subgroups could be identified, and (c) illustrated how the physiological mechanisms of aging changes could be described. In this section we will briefly identify some of the implications of those health transition models.

One set of implications has to do with changes in the Social Security entitlement age. These changes were introduced because it was assumed that life expectancy increases at an advanced age (i.e., 65) reflected improvements in the health status of the elderly. In a minority report to the Commission on Social Security Reform (Feldman, 1983), it was suggested that this might not be so because improved survival might be concentrated among persons with chronic diseases and impairments, so the prevalence of such conditions in the population might increase. We examined such relations in the first section and suggested that, in the case of diabetes mellitus, reductions in stroke mortality may have increased the population prevalence of diabetes at later ages. The implications of multiple-cause mortality data and dependent competing risks were also discussed.

A second area where there are serious implications in inappropriately modeling health transitions is in estimating the need and demand for health services—especially long-term care services for the extreme elderly population. Certain projections (e.g., Brody, 1985) show the serious consequences of population aging on the prevalence of hip fracture and Alzheimer's disease. What the analysis of certain longitudinal data sets suggested is that survivors to extreme old age are generally a highly selected group. Therefore, under current mortality conditions, their average health status is kept relatively high because the survival time, once a person enters a morbid state, is short. If life expectancy increases, this may allow certain morbid subgroups to survive longer in a disease state. This would imply even higher levels of demand for health services.

The third set of implications has to do with the clinical case management of chronic diseases and risk status over age. We have begun to recognize that the management of elderly patients is very different from that of younger patients. What the results on the physiological aging mechanisms suggest is that case management should change over age. Indeed, the results suggest that optimal physiological values for risk factors change in complex ways with age and must be evaluated in the context of other physiological variables. The fact that such factors were not fully taken into account in past risk factor intervention attempts may be one reason why certain interventions failed to produce the anticipated population effects in some community population trials.

VI. Data needs

The statistical methodologies and analyses reviewed in this paper also serve the purpose of identifying critical data needs. We can identify some of these.

One need is for long-term followup of well characterized cohorts. In this followup, there is a need for repeated measurements of detailed physiological characteristics. Such data would better help us understand the age dynamics of physiological risk factors at advanced ages. For example, we might be able to determine why certain risk factors cease to be so strongly associated with disease risks at advanced ages. Such followup data are necessary to help us disentangle the effects of systematic mortality selection from physiological aging dynamics. A cost-effective way to produce these data is to have further followup on existing longitudinal populations.

A second need is to determine morbidity and mortality risks among nationally representative samples of already morbid and disabled persons. This would help us resolve some of the questions about the societal impact of life expectancy gains at later age. Illustrations of such surveys are the 1982 and 1984 National Long Term Care Surveys. A nationally representative sample of 6,300 persons with chronic limitations in activities of daily living and instrumental activities of daily living were followed for 2 years to examine (a) their risk of death, (b) their risk of institutionalization, and (c) the trajectory of change in dependency level. Such data are very important in forecasting future health service needs.

A third type of data that would be useful could be obtained by systematically extending data collection for clinical studies to measure comorbidities. Not only is the issue of comorbidity important for describing "normal" aging changes, but it is important for determining what are the appropriate clinical responses to disease at advanced age.

A fourth data requirement is for data that systematically relate chronic disease diagnosis to level and type of disability. Such data would allow us to generate the many-to-one mapping functions of diseases to disabilities. This would enable us to utilize the extensive epidemiological data on disease risk factor associations in forecasting future demand for long-term care services.

A fifth data requirement is for more spatially disaggregated data. Spatial disaggregation would allow us to take better advantage of naturally occurring population differences in risk. This would be a low-cost way of increasing the power of currently existing data.

Finally, it is clear that the interactions of chronic diseases and aging changes are such complex phenomena that no single data source will suffice to fully characterize them. This suggests the need for biologically motivated models of the basic physiological processes that can be used to integrate parameter estimates developed from different data sources. Such a strategy for integrating and evaluating multiple data sources must be pursued both as a way of systematizing our knowledge about health dynamics *and* as a strategy for identifying critical data needs.

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TABLE 1

Health expectancy at birth, by sex, Canada, 1978 (in years)

State of health	Males	Females	Total
Long-term institutionalization	0.8	1.5	1.1
Cannot do major activity	3.0	1.3	2.1
Restricted in major activity	5.4	8.7	7.1
Minor activity restriction	1.3	2.2	1.8
Only short-term disability	1.1	1.8	1.4
Not restricted in activities	59.2	62.8	61.0
Total life expectancy	70.8	78.3	74.6

SOURCE: Wilkins and Adams, 1983.

TABLE 2

Health expectancy by age and sex, Canada, 1978 (in years and percentage of remaining life expectancy)

Sex/Age	Life Expectancy[a] Remaining		Quality-Adjusted[b] Life Expectancy		Disability-Free[c] Life Expectancy	
	N	%	N	%	N	%
Males						
0	70.8	(100)	65.8	(93)	59.2	(85)
15	57.2	(100)	52.4	(92)	46.2	(81)
25	48.1	(100)	43.5	(90)	37.6	(78)
45	29.6	(100)	25.6	(86)	20.6	(70)
65	14.4	(100)	11.5	(80)	8.2	(57)
75	8.9	(100)	6.9	(78)	4.6	(52)
Females						
0	78.3	(100)	71.7	(92)	62.8	(80)
15	64.5	(100)	58.1	(90)	49.4	(77)
25	54.8	(100)	48.7	(89)	40.4	(74)
45	35.7	(100)	30.5	(85)	23.6	(66)
65	18.7	(100)	14.7	(79)	9.9	(53)
75	11.7	(100)	8.6	(74)	5.2	(44)
Total						
0	74.6	(100)	68.7	(92)	61.0	(82)
15	60.9	(100)	55.2	(91)	47.8	(78)
25	51.5	(100)	46.1	(90)	39.0	(76)
45	32.7	(100)	28.1	(86)	22.1	(68)
65	16.7	(100)	13.3	(80)	9.1	(54)
75	10.6	(100)	7.9	(75)	5.0	(47)

Notes:

a. All states of health together

b. Weighting factors used were as follows: INST = 0.4, CDMAJ = 0.5, RMAJ = 0.6, MINOR = 0.7, OSTD = 0.5, NODIS = 1.0.

c. Free of any health-related activity restriction (all categories of severity, institutionalized or not).

SOURCE: Wilkins and Adams, 1983.

TABLE 3

Health expectancy at birth, by sex, Canada, 1951 and 1978 (years)

Health Expectancy	Males	Females	Total
Life expectancy[a]			
1951	66.3	70.8	68.6
1978	70.8	78.3	74.6
Change: 1951-1978	+4.5	+7.5	+6.0
Disability expectancy[b]			
1951	6.6	6.1	6.3
1978	9.7	12.2	11.0
Change: 1951-1978	+3.2	+6.1	+4.7
Disability-free life expectancy[c]			
1951	59.8	64.7	62.2
1978	61.1	66.1	63.6
Change: 1951-1978	+1.3	+1.4	+1.3
Quality-adjusted life expectancy[d]			
1951	63.1	67.8	65.4
1978	66.0	72.2	69.1
Change: 1951-1978	+2.9	+4.4	+3.7

Notes:
a. All states of health combined.
b. Long-term disability or activity limitation, excluding institutionalization and purely short-term disability.
c. Life expectancy less disability expectancy.
d. Disability expectancy counted as 50 per cent of disability-free life expectancy.

SOURCE: Wilkins and Adams, 1983.

TABLE 4: Parameter Describing Age Rates of Increase in Risk for Weibull Hazard Function for Female Medicare Recipients Aged 65-84 in 1968 Followed to 1978

Cohort/	Weibull Function (m+1 = β parameter)		Gompertz Function (θ parameter)	
Age Range	Homogeneous	Heterogeneous	Homogeneous	Heterogeneous
1902	5.44	5.77	6.26	7.34
65-75	(0.04)	(0.06)	(0.06)	(0.10)
1901	5.46	5.82	6.20	7.36
66-76	(0.04)	(0.07)	(0.06)	(0.10)
1900	5.46	5.86	6.11	7.38
67-77	(0.04)	(0.07)	(0.06)	(0.11)
1899	5.59	6.02	6.21	7.57
68-78	(0.04)	(0.07)	(0.06)	(0.11)
1898	5.69	6.16	6.26	7.73
69-79	(0.04)	(0.08)	(0.06)	(0.12)
1897	5.69	6.20	6.18	7.75
(70-80)	(0.05)	(0.08)	(0.06)	(0.13)
1896	5.75	6.31	6.18	7.88
71-81	(0.05)	(0.09)	(0.06)	(0.14)
1895	5.90	6.51	6.30	8.13
72-82	(0.05)	(0.10)	(0.06)	(0.14)
1894	5.91	6.58	6.22	8.20
73-83	(0.05)	(0.10)	(0.06)	(0.15)
1893	6.15	6.89	6.46	8.60
74-84	(0.05)	(0.11)	(0.06)	(0.17)
1892	6.11	6.91	6.32	8.65
75-85	(0.05)	(0.12)	(0.06)	(0.18)
1891	6.29	7.17	6.48	8.97
76-86	(0.05)	(0.13)	(0.07)	(0.20)
1890	6.33	7.29	6.44	9.14
77-87	(0.06)	(0.14)	(0.07)	(0.21)
1889	6.38	7.43	6.44	9.35
78-88	(0.06)	(0.16)	(0.07)	(0.22)
1888	6.36	7.51	6.34	9.48
79-89	(0.06)	(0.17)	(0.07)	(0.24)
1887	6.53	7.78	6.46	9.85
80-90	(0.07)	(0.19)	(0.08)	(0.26)
1886	6.33	7.69	6.17	9.81
81-91	(0.07)	(0.20)	(0.08)	(0.28)
1885	6.42	7.90	6.20	10.12
82-92	(0.07)	(0.22)	(0.08)	(0.30)
1884	6.38	7.98	6.09	10.29
83-93	(0.08)	(0.24)	(0.09)	(0.32)
1883	6.23	7.97	5.86	10.37
84-94	(0.08)	(0.25)	(0.09)	(0.34)

(Standard errors in parentheses)

TABLE: 5 MLE's of $\bar{\alpha}$ with m = 6, and t estimated to be 20.4 Years, Where $\bar{\alpha}$ is modeled as a Step Function for Cohorts Born in 1920 or Later. White Males, Lung Cancer, United States

		$\bar{\alpha} \times 10^{11}$ PERIOD					
Year Of Birth	Age At Start Of Interval	1950–1954	1955–1959	1960–1964	1965–1969	1970–1974	1975–1977
		YEAR OF BIRTH					
		1915[1]	1920[2]	1925[1]	1930[1]	1935[1]	1940[1]
1915[1]	35	2.38	3.01	3.77	4.56	4.40	4.20
1910[1]	40	2.17	2.38	2.88	3.20	3.61	3.26
1905[1]	45	1.75	2.17	2.38	2.79	3.24	3.13
1900[1]	50	1.50	1.75	2.17	2.38	2.58	2.83
1895[2]	55	1.35	1.50	1.75	2.17	2.38	2.47
1890[2]	60	1.05	1.35	1.50	1.75	2.17	2.38
1885[3]	65	0.73	1.05	1.35	1.50	1.75	2.17
1880[3]	70	0.56	0.73	1.05	1.35	1.50	1.75
	75		0.56	0.73	1.05	1.35	1.50
	80			0.56	0.73	1.05	1.35
	85				0.56	0.73	1.05
	90					0.56	0.73
	95						0.56

[1] Ratio of $s/\bar{\alpha}$ constrained equal for 1900–1940 birth cohorts

[2] Ratio of $s/\bar{\alpha}$ constrained equal for 1890 and 1895 birth cohorts

[3] Ratio of $s/\bar{\alpha}$ constrained equal for 1880 and 1885 birth cohorts

NOTE: In all models parameter estimates for cohorts age 35 and over in 1950 were constrained to be constant over entire interval 1950–1977. The sequence of parameter estimates for each cohort is obtained following diagonally down the table from the entry in the first column or row.

TABLE 6: Lung Cancer Mortality Observed in 1977, and Lung Cancer Morbidity Observed and Predicted Under Two Dependency Assumptions

	Number Observed Dead From Lung Cancer	Number Who Died of Another Cause With Tumor Growing		Number Projected to Have Died of Another Cause but with a Tumor Growing	
	1977	1977		2000	
AGE		$\beta=1$	$\beta=0$	$\beta=1$	$\beta=0$
0-9	2	0	0	0	0
10-19	7	5	2	3	2
20-29	42	76	37	64	31
30-39	448	442	208	644	302
40-49	3,223	3,027	1,371	4,708	2,135
50-59	12,056	12,462	5,259	13,580	5,749
60-69	21,592	45,667	17,601	31,125	10,935
70-79	17,649	84,464	25,993	79,324	18,096
80-89	5,381	76,784	14,091	112,339	21,495
90+	373	9,040	1,796	26,253	7,652
TOTAL	60,773	231,968	66,359	268,040	66,397

TABLE 7: Age and Sex Specific Ratios of Total to Underlying Cause of Death Occurrence of Cancer of Bronchus and Lung (ICD 162.1) and Prostate (ICD 185) in 1970 for White Males for Five-Year Age Groups

	Lung and Bronchus			Prostate		
Age Range	# Underlying Cause Occurrences	# Total Occurrences	Ratio	# Underlying Cause Occurrences	# Total Occurrences	Ratio
35-39	351	358	1.02	2	2	1.00
40-44	1,114	1,161	1.04	14	16	1.14
45-49	2,314	2,391	1.03	45	49	1.09
50-54	4,063	4,247	1.05	150	167	1.11
55-59	6,540	6,934	1.06	445	508	1.14
60-64	8,295	8,882	1.07	1,065	1,287	1.21
65-69	8,605	9,382	1.09	1,801	2,345	1.30
70-74	7,352	8,232	1.12	2,677	3,730	1.39
75-79	5,130	5,794	1.13	3,414	5,128	1.50
80-84	2,415	2,780	1.15	2,957	4,867	1.65
85-89	775	910	1.18	1,609	2,834	1.76
90+	197	250	1.27	496	973	1.96
TOTALS	47,149	51,321	1.09	14,675	21,906	1.49

TABLE 8: Probability of Being Ended by One of Four Types of Change for 5,482 Episodes of Cases Funded by Supplemental Security Income Program, and Distribution Over Age and Program Type

Variable	Frequency	PROFILE			
		1	2	3	4
REASON FOR TERMINATION					
Up to One Month Length of Stay					
Non-Payment	0.0487	0.0650	0.0379	0.0574	0.0419
Change in Living Arrangement	0.0657	0.0861	0.0827	0.0319	0.0632
Died	0.0327	0.0	0.0	0.0474	0.0654
End of Study	0.0117	0.0	0.0342	0.0146	0.0
One to Three Months Length of Stay					
Non-Payment	0.0456	0.0	0.0	0.2109	0.0
Change in Living Arrangement	0.0618	0.0352	0.1128	0.0390	0.0542
Died	0.0224	0.0	0.0	0.0	0.0654
End of Study	0.0161	0.0270	0.0143	0.0338	0.0
Three to Twelve Months Length of Stay					
Non-Payment	0.0540	0.0795	0.0878	0.0234	0.0345
Change in Living Arrangement	0.0925	0.0	0.2011	0.0	0.1240
Died	0.0547	0.0	0.0	0.0612	0.1210
End of Study	0.0560	0.0880	0.1012	0.0284	0.0227
Twelve to Eighteen Months Length of Stay					
Non-Payment	0.0139	0.0267	0.0296	0.0064	0.0
Change in Living Arrangement	0.0239	0.0	0.0513	0.0230	0.0180
Died	0.0208	0.0	0.0	0.0464	0.0314
End of Study	0.0412	0.0747	0.0536	0.0190	0.0275
Eighteen to Twenty-Four Months Length of Stay					
Non-Payment	0.0093	0.0185	0.0098	0.0086	0.0043
Change in Living Arrangement	0.0109	0.0191	0.0	0.0165	0.0108
Died	0.0144	0.0	0.0	0.0224	0.0279
End of Study	0.1474	0.2462	0.0760	0.1428	0.1466
At Twenty-Five Months Length of Stay					
End of Study	0.1563	0.2341	0.1078	0.1669	0.1412
AGE IN YEARS					
<19	0.0930	0.5346	0.0	0.0	0.0
19-24	0.0923	0.0	0.2901	0.0	0.0
25-50	0.2258	0.0	0.7099	0.0	0.0
51-64	0.1468	0.2757	0.0	0.2685	0.1533
65-74	0.1419	0.1896	0.0	0.2115	0.2162
75-89	0.2379	0.0	0.0	0.3882	0.5133
90+	0.0622	0.0	0.0	0.1318	0.1172
PROGRAM TYPE					
Adult	0.3594	0.1033	0.0	0.6192	0.6763
Blind Adult	0.0104	0.0139	0.0049	0.0074	0.0146
Disabled Adult	0.5328	0.4408	0.9584	0.3734	0.3092
Disabled Child	0.0974	0.4420	0.0367	0.0	0.0

TABLE 9: Distribution of g_{ik}, Supplemental Security Income Program

	PROFILE			
Range	1	2	3	4
<0.1%	2,818	2,493	3,098	2,179
0.1-25%	752	753	441	373
25.1-50%	884	1,238	945	1,190
50.1-75%	704	625	582	921
75.1-99.9%	132	89	186	346
100%	192	234	230	473
Sum of g_{ik}'s	1,199	1,293	1,160	1,827
Prevalence of episode type	1199/5482	1293/5482	1160/5482	1827/5482

TABLE 10: The Probability of Five Analytically Defined States (K=5) Having Specific Physiological Characteristics

		PROFILE				
Variable	Frequency	1	2	3	4	5
Pulse Pressure						
<50	0.135	0.324	0.0	0.0	0.0	0.303
50-60	0.173	0.427	0.0	0.0	0.142	0.184
61-70	0.181	0.222	0.206	0.100	0.398	0.0
71-80	0.187	0.0	0.794	0.0	0.0	0.514
81-90	0.123	0.027	0.0	0.220	0.459	0.0
90+	0.201	0.0	0.0	0.680	0.0	0.0
Diastolic Blood Pressure						
<86	0.134	0.414	0.0	0.0	0.0	0.0
86-95	0.610	0.586	1.000	0.0	1.000	0.0
96-115	0.208	0.0	0.0	1.000	0.0	0.550
116+	0.049	0.0	0.0	0.0	0.0	0.450
Infarction (EKG)	0.142	0.0	0.0	0.0	0.0	1.000
Injury (EKG)	0.022	0.0	0.0	0.0	0.0	1.000
Ischemia (EKG)	0.243	0.0	0.0	0.0	0.0	1.000
Arteriosclerotic Etiology	0.486	0.0	0.0	1.000	0.0	1.000
Hypertensive Etiology	0.294	0.0	0.0	1.000	0.0	1.000
Rhemuatic Etiology	0.068	0.0	0.0	1.000	0.0	0.0
Cholesterol						
>206	0.246	0.0	0.692	0.0	0.804	0.0
206-255	0.410	0.602	0.308	0.396	0.196	0.311
256-305	0.270	0.319	0.0	0.440	0.0	0.610
306+	0.074	0.080	0.0	0.165	0.0	0.079
Hematocrit						
>40	0.253	0.0	0.0	0.557	0.659	0.0
40-41	0.199	0.372	0.0	0.250	0.0	0.402
42-45	0.386	0.439	0.546	0.194	0.341	0.425
46+	0.161	0.189	0.454	0.0	0.0	0.173
Arteriosclerotic Retinopathy						
None	0.162	0.0	0.999	0.0	0.0	0.0
Grade 1	0.527	0.997	0.0	0.999	0.0	0.0
Grade 2	0.286	0.0	0.0	0.0	0.942	0.893
Grade 3	0.025	0.0	0.0	0.0	0.057	0.107
Grade 4	0.001	0.003	0.001	0.001	0.001	0.0
Hypertensive Retinopathy						
None	0.625	0.682	1.000	0.556	0.537	0.0
Grade 1	0.263	0.318	0.0	0.444	0.463	0.0
Grade 2	0.097	0.0	0.0	0.0	0.0	0.870
Grade 3	0.015	0.0	0.0	0.0	0.0	0.130

TABLE 10 (continued)

Overall Cardiovascular Functional Status						
No Disease	0.546	1.000	1.000	0.0	0.0	0.0
Definite Disease, Not Limiting	0.280	0.0	0.0	0.693	0.0	0.512
Moderate to Severe Disease	0.174	0.0	0.0	0.307	1.0	0.488
Tobacco Use	0.253	0.0	1.000	0.0	1.000	0.0
Sugar						
Absent	0.965	1.000	0.963	0.918	0.965	0.961
Trace	0.006	0.0	0.012	0.0	0.0	0.039
1+	0.010	0.0	0.025	0.0	0.035	0.0
2+ More	0.019	0.0	0.0	0.082	0.0	0.0
Albumin						
Absent	0.877	1.000	0.924	1.000	1.000	0.230
Trace	0.105	0.0	0.0	0.0	0.0	0.770
1+	0.012	0.0	0.076	0.0	0.0	0.0
2+ More	0.006	0.0	0.0	0.0	0.0	0.0
Subjective Health						
Very Poor	0.029	0.0	0.0	0.0	0.0	0.311
Poor	0.073	0.0	0.0	0.0	0.371	0.0
Fair for My Age	0.037	0.0	0.0	0.070	0.124	0.0
Fair	0.202	0.011	0.215	0.0	0.506	0.569
Good	0.280	0.314	0.366	0.560	0.0	0.0
Good for My Age	0.181	0.363	0.0	0.370	0.0	0.0
Excellent	0.108	0.312	0.0	0.0	0.0	0.120
Excellent for My Age	0.090	0.0	0.420	0.0	0.0	0.0
Verbal Scaled Scores						
>31	0.114	0.0	0.0	0.0	0.251	1.000
31-50	0.296	0.0	0.0	0.0	0.749	0.0
51-70	0.295	0.0	1.000	0.0	0.0	0.0
71-90	0.253	0.798	0.0	1.000	0.0	0.0
91+	0.042	0.202	0.0	0.0	0.0	0.0
Performance Scaled Scores						
>26	0.412	0.0	0.0	0.0	1.000	1.000
26-40	0.410	0.421	1.000	0.643	0.0	0.0
41-55	0.165	0.521	0.0	0.358	0.0	0.0
56-70	0.014	0.058	0.0	0.0	0.0	0.0
Height (Inches)						
<60	0.094	0.0	0.0	0.452	0.077	0.0
60-62	0.253	0.0	0.0	0.0	0.923	0.0
63-65	0.273	0.610	0.0	0.548	0.0	0.340
66-68	0.221	0.390	0.243	0.0	0.0	0.660
69+	0.160	0.0	0.757	0.0	0.0	0.0
Obesity						
2	0.053	0.0	0.0	0.0	0.0	0.375
3	0.672	0.770	0.557	0.804	1.000	0.0
4	0.237	0.230	0.443	0.083	0.0	0.519
5	0.038	0.0	0.0	0.113	0.0	0.105

TABLE 11: Conditional Probability of the Five States Defined on Physiological Variable Having Certain Survival and Demographic Characteristics

Variable	Frequency	PROFILE 1	2	3	4	5
Age						
59-64	0.053	0.073	0.116	0.0	0.0	0.083
65-69	0.119	0.169	0.099	0.104	0.0	0.199
70-74	0.208	0.280	0.233	0.155	0.091	0.237
75-79	0.250	0.229	0.300	0.256	0.225	0.269
80-84	0.209	0.188	0.118	0.284	0.314	0.104
85-89	0.115	0.052	0.120	0.160	0.206	0.072
90+	0.047	0.010	0.014	0.041	0.164	0.036
Years to Death						
<1	0.028	0.012	0.047	0.0	0.056	0.055
1	0.079	0.0	0.044	0.118	0.200	0.068
2-4	0.234	0.114	0.178	0.277	0.390	0.291
5	0.078	0.089	0.039	0.141	0.010	0.073
6-10	0.305	0.254	0.394	0.299	0.323	0.310
11-15	0.162	0.285	0.194	0.103	0.021	0.133
16-20	0.088	0.183	0.104	0.043	0.0	0.051
21+	0.027	0.064	0.0	0.020	0.0	0.019
Sex						
Male	0.412	0.417	0.788	0.127	0.315	0.536
Female	0.588	0.583	0.212	0.872	0.685	0.464
Race						
White	0.650	0.765	0.860	0.662	0.437	0.411
Black	0.350	0.235	0.140	0.318	0.563	0.589
Occupation						
Professional	0.218	0.298	0.400	0.237	0.043	0.022
Management	0.124	0.153	0.241	0.096	0.002	0.187
Clerical	0.231	0.220	0.216	0.097	0.341	0.288
Laborer	0.128	0.010	0.035	0.063	0.326	0.288
Never Employed	0.300	0.318	0.108	0.506	0.288	0.216
Education (Years)						
0-4	0.265	0.059	0.184	0.106	0.580	0.471
5-9	0.190	0.136	0.197	0.117	0.263	0.291
10-15	0.281	0.292	0.333	0.531	0.090	0.199
16+	0.264	0.513	0.286	0.247	0.067	0.039
Wave						
1	0.200	0.292	0.194	0.079	0.0	0.447
2	0.145	0.224	0.180	0.128	0.0	0.093
3	0.159	0.156	0.144	0.110	0.213	0.207
4	0.103	0.077	0.174	0.035	0.128	0.171
5	0.081	0.050	0.072	0.146	0.100	0.036
6	0.080	0.044	0.021	0.162	0.123	0.045
7	0.059	0.046	0.086	0.059	0.111	0.001
8	0.050	0.059	0.046	0.043	0.091	0.0
9	0.047	0.012	0.030	0.073	0.132	0.0
10	0.041	0.035	0.010	0.082	0.062	0.0
11	0.034	0.006	0.042	0.083	0.039	0.0

TABLE 12: Dynamic Equation Coefficients for Risk Factor Changes, Framingham Males Over Two-Year Intervals

		(I - A)								
	u	AGE_t	PP_t	DBP_t	QI_t	$CHOL_t$	$BLDSUG_t$	$HEMO_t$	$VITC_t$	CIG_t
AGE_{t+2}	2.00	1.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
PP_{t+2}	-5.89	$2.84x10^{-1}$	$6.04x10^{-1}$	$1.49x10^{-1}$	$-8.01x10^{-3}$	$-2.17x10^{-3}$	$2.68x10^{-2}$	$2.23x10^{-3}$	$-3.66x10^{-3}$	2.42x
DBP_{t+2}	19.65	$-5.90x10^{-2}$	$7.39x10^{-2}$	$6.10x10^{-1}$	$2.40x10^{-2}$	$7.05x10^{-4}$	$5.00x10^{-3}$	$3.03x10^{-2}$	$4.6x10^{-3}$	-7.76x
QI_{t+2}	23.64	$-8.63x10^{-2}$	$-3.99x10^{-2}$	$-3.58x10^{-2}$	$9.51x10^{-1}$	$-7.00x10^{-3}$	$-1.26x10^{-2}$	$4.71x10^{-3}$	$8.63x10^{-3}$	-8.43x
$CHOL_{t+2}$	78.21	$-2.07x10^{-1}$	$-6.24x10^{-3}$	$-3.82x10^{-2}$	$-7.28x10^{-3}$	$7.88x10^{-1}$	$-4.76x10^{-3}$	$-8.91x10^{-2}$	$8.33x10^{-3}$	4.50x
$BLDSUG_{t+2}$	2.29	$1.42x10^{-1}$	$4.22x10^{-2}$	$3.44x10^{-3}$	$1.23x10^{-2}$	$-4.60x10^{-3}$	$7.36x10^{-1}$	$7.34x10^{-2}$	$-7.89x10^{-3}$	-3.10x
$HEMO_{t+2}$	56.03	$6.32x10^{-2}$	$2.03x10^{-3}$	$-1.83x10^{-2}$	$2.03x10^{-2}$	$6.24x10^{-3}$	$-1.38x10^{-2}$	$5.69x10^{-1}$	$2.80x10^{-3}$	5.05x
$VITC_{t+2}$	21.06	$-1.90x10^{-1}$	$4.63x10^{-3}$	$-4.61x10^{-3}$	$1.35x10^{-2}$	$1.35x10^{-3}$	$-7.80x10^{-3}$	$-4.46x10^{-2}$	$9.22x10^{-1}$	-3.37x
CIG_{t+2}	4.63	$-5.83x10^{-2}$	$-1.50x10^{-3}$	$-6.27x10^{-3}$	$-5.60x10^{-3}$	$-2.55x10^{-4}$	$1.71x10^{-3}$	$7.20x10^{-3}$	$4.45x10^{-4}$	8.93x

TABLE 13: Extended Matrix, Quadratic and Interaction Terms, Framingham Study

	Constant	Pulse Pressure	Diastolic Blood Pressure	Quetlet Index	Cholesterol	Blood Sugar	Hemo-globin	Vital Capacity	Cigarette Consumption
Constant	$2.98x10^{-3}$ (2.40)								
Pulse Pressure	$4.31x10^{-5}$ (3.16)	$9.34x10^{-7}$ (1.29)							
Diastolic Blood Pressure	$-8.15x10^{-6}$ (-0.20)	$-1.09x10^{-6}$ (-1.48)	$6.80x10^{-6}$ (3.75)						
Quetlet Index	$-1.62x10^{-5}$ (-1.40)	$-1.56x10^{-7}$ (-0.55)	$-1.51x10^{-6}$ (-2.99)	$5.71x10^{-7}$ (2.89)					
Cholesterol	$-1.44x10^{-5}$ (-1.45)	$-2.68x10^{-7}$ (-1.39)	$-4.84x10^{-7}$ (-1.47)	$3.13x10^{-7}$ (3.32)	$2.15x10^{-7}$ (2.25)				
Blood Sugar	$-3.19x10^{-6}$ (-0.22)	$-2.34x10^{-7}$ (-0.79)	$1.01x10^{-6}$ (1.65)	$-1.76x10^{-7}$ (-0.99)	$-2.76x10^{-8}$ (-0.24)	$1.63x10^{-7}$ (0.91)			
Hemo-globin	$-9.95x10^{-6}$ (-0.33)	$1.37x10^{-7}$ (0.18)	$-2.71x10^{-6}$ (-2.14)	$7.80x10^{-7}$ (2.35)	$3.47x10^{-7}$ (1.24)	$-3.66x10^{-7}$ (-0.99)	$1.21x10^{-6}$ (1.30)		
Vital Capacity	$-8.42x10^{-6}$ (-2.23)	$-5.95x10^{-8}$ (-0.72)	$-3.31x10^{-7}$ (-1.66)	$1.18x10^{-7}$ (1.99)	$5.94x10^{-8}$ (1.61)	$-4.64x10^{-8}$ (-1.34)	$1.64x10^{-7}$ (1.66)	$4.30x10^{-8}$ (1.78)	
Cigarette Consump-tion	$4.88x10^{-5}$ (2.45)	$5.19x10^{-7}$ (1.00)	$-3.38x10^{-7}$ (-0.29)	$-3.77x10^{-8}$ (-0.13)	$-5.43x10^{-8}$ (-0.26)	$-2.66x10^{-8}$ (-0.10)	$5.54x10^{-8}$ (0.12)	$-1.41x10^{-7}$ (-1.71)	$1.07x10^{-6}$ (2.20)

t values in parentheses

TABLE 14: Minimum Mortality Points

	GOMPERTZ MODEL		AGE x AGE^2 AS RISK FACTORS	
AGE	Pulse Pressure	Diastolic Blood Pressure	Pulse Pressure	Diastolic Blood Pressure
31	30.38	72.25	26.95	81.32
33	35.05	73.91	23.70	84.36
35	37.94	75.36	19.56	86.41
37	39.88	76.58	14.50	87.70
39	41.25	77.56	8.50	88.36
41	42.26	78.32	1.55	88.49
43	43.02	78.89	-6.37	88.15
45	43.60	79.28	-15.26	87.40
47	44.04	79.52	-25.14	86.28
49	44.36	79.62	-36.02	84.82
51	44.58	79.60	-47.89	83.05
53	44.71	79.47	-60.77	80.99
55	44.76	79.24	-74.66	78.64
57	44.74	78.92	-89.57	76.04
59	44.65	78.53	-105.48	73.18
61	44.51	78.07	-122.42	70.08
63	44.32	77.55	-140.37	66.74
65	44.09	76.97	-159.35	63.18
67	43.82	76.35	-179.35	59.39
69	43.52	75.70	-200.36	55.39
71	43.21	75.01	-222.40	51.17
73	42.89	74.31	-245.46	46.75
75	42.58	73.60	-269.53	42.12
77	42.28	72.88	-294.63	37.28
79	42.01	72.18	-320.74	32.25
81	41.37	71.54	-347.93	27.02
83	40.46	70.96	-377.99	21.55
85	39.58	70.44	-409.10	15.91
87	38.74	69.99	-441.23	10.08
89	37.96	69.60	-474.41	4.06
91	37.27	69.28	-508.62	-2.14
93	36.66	69.05	-543.86	-8.54
95	36.16	68.89	-580.13	-15.13
97	35.76	68.82	-617.42	-21.90
99	35.48	68.82	-655.74	-28.86

TABLE 15: Life Table Parameters for the Total Mortality and Risk Factor Change Experience of Framingham Males

							MEANS/STANDARD DEVIATIONS							
$S_t x10^5$	$_2d_t$	$_2q_t$	$_1h_t$	$\overset{o}{e}_t$	COST	AGE	PP	DBP	QI	CHOL	BLDSUG	HEMO	VITC	CIG
100000.	0.002	0.00	0.00	44.26	18359.75	30	45.83	79.57	261.88	215.22	79.35	142.11	139.29	13.24
							13.70	12.53	34.44	41.41	29.63	10.25	31.11	11.53
99785.	0.003	0.00	0.00	42.35	17674.08	32	41.85	81.53	264.75	224.65	78.28	144.02	140.04	13.83
							13.70	12.53	34.44	41.40	29.63	10.25	31.11	11.52
99533.	0.003	0.00	0.00	40.46	16916.32	34	40.25	82.44	267.36	231.43	77.73	145.36	140.29	14.23
							13.70	12.53	34.43	41.40	29.63	10.24	31.11	11.52
99234.	0.004	0.00	0.00	38.58	16066.75	36	39.95	82.86	269.66	236.20	77.63	146.34	140.09	14.45
							13.70	12.53	34.42	41.40	29.62	10.24	31.11	11.52
98877.	0.004	0.00	0.00	36.71	15197.04	38	40.37	83.07	271.64	239.43	77.89	147.11	139.52	14.53
							13.70	12.53	34.42	41.40	29.62	10.24	31.11	11.52
98450.	0.005	0.01	0.00	34.87	14217.09	40	41.21	83.17	273.29	241.46	78.46	147.73	138.61	14.47
							13.70	12.53	34.41	41.39	29.62	10.24	31.11	11.52
97941.	0.006	0.01	0.00	33.04	13265.68	42	42.31	83.24	274.63	242.55	79.26	148.24	137.40	14.29
							13.70	12.53	34.40	41.39	29.62	10.24	31.11	11.52
97335.	0.007	0.01	0.00	31.24	12196.79	44	43.55	83.29	275.65	242.91	80.24	148.67	135.90	14.00
							13.70	12.53	34.39	41.39	29.62	10.24	31.11	11.52
96614.	0.009	0.01	0.00	29.47	10998.90	46	44.90	83.34	276.38	242.71	81.37	149.03	134.15	13.63
							13.70	12.52	34.37	41.38	29.62	10.24	31.11	11.52
95761.	0.010	0.01	0.01	27.72	9904.98	48	46.31	83.37	276.82	242.06	82.59	149.34	132.16	13.17
							13.70	12.52	34.36	41.38	29.62	10.24	31.10	11.52
94753.	0.012	0.01	0.01	26.01	8685.49	50	47.76	83.40	276.99	241.06	83.89	149.60	129.96	12.64
							13.70	12.52	34.34	41.37	29.62	10.24	31.10	11.52
93564.	0.014	0.01	0.01	24.32	7664.26	52	49.24	83.42	276.90	239.80	85.25	149.83	127.57	12.04
							13.70	12.52	34.32	41.36	29.62	10.24	31.10	11.51
92166.	0.016	0.02	0.01	22.68	6531.12	54	50.73	83.42	276.56	238.33	86.65	150.02	124.99	11.39
							13.70	12.52	34.29	41.36	29.62	10.24	31.10	11.51
90526.	0.019	0.02	0.01	21.07	5276.49	56	52.24	83.41	275.99	236.71	88.08	150.18	122.25	10.69
							13.70	12.52	34.26	41.34	29.61	10.24	31.09	11.51
88606.	0.022	0.03	0.01	19.50	4373.15	58	53.75	83.38	275.21	234.96	89.53	150.32	119.37	9.94
							13.69	12.52	34.22	41.33	29.61	10.24	31.09	11.51
86360.	0.026	0.03	0.02	17.99	3377.35	60	55.26	83.34	274.23	233.13	90.99	150.44	116.35	9.15
							13.69	12.51	34.18	41.32	29.61	10.24	31.08	11.50

TABLE 15 (cont'd)

83744.	0.030	0.04	0.02	16.52	2822.50	62	56.77	83.28	273.08	231.24	92.46	150.54	113.21	8.32
							13.69	12.51	34.13	41.30	29.60	10.24	31.08	11.50
80705.	0.035	0.04	0.02	15.10	2214.56	64	58.28	83.21	271.75	229.31	93.92	150.62	109.96	7.45
							13.69	12.51	34.08	41.28	29.60	10.23	31.07	11.49
77193.	0.040	0.05	0.03	13.74	1551.40	66	59.78	83.11	270.29	227.36	95.39	150.69	106.62	6.55
							13.69	12.50	34.01	41.26	29.59	10.23	31.07	11.49
73155.	0.046	0.06	0.03	12.45	1247.62	68	61.27	83.01	268.71	225.41	96.84	150.75	103.21	5.62
							13.69	12.50	33.93	41.23	29.59	10.23	31.06	11.48
68552.	0.052	0.08	0.04	11.22	920.78	70	62.75	82.88	267.04	223.48	98.29	150.80	99.73	4.66
							13.68	12.49	33.84	41.20	29.58	10.23	31.05	11.47
63357.	0.058	0.09	0.05	10.05	742.96	72	64.21	82.74	265.30	221.57	99.72	150.85	96.20	3.66
							13.68	12.48	33.73	41.16	29.57	10.22	31.03	11.46
57575.	0.063	0.11	0.06	8.97	556.23	74	65.66	82.58	263.52	219.71	101.14	150.89	92.63	2.62
							13.68	12.47	33.60	41.12	29.56	10.22	31.02	11.45
51253.	0.068	0.13	0.07	7.95	363.58	76	67.09	82.41	261.74	217.91	102.54	150.94	89.06	1.55
							13.67	12.46	33.46	41.07	29.55	10.21	31.00	11.44
44497.	0.070	0.16	0.09	7.01	263.81	78	68.50	82.22	260.00	216.20	103.92	150.99	85.48	0.43
							13.67	12.45	33.30	41.01	29.54	10.21	30.98	11.42
37476.	0.070	0.19	0.10	6.14	165.98	80	69.87	82.02	258.33	214.58	105.29	151.04	81.92	0.00
							13.66	12.43	33.11	40.94	29.52	10.20	30.96	0.00
30468.	0.069	0.23	0.13	5.33	116.36	82	71.25	81.78	256.57	213.17	106.57	151.19	78.28	0.00
							13.65	12.41	32.90	40.86	29.49	10.14	30.91	0.00
23583.	0.064	0.27	0.16	4.61	70.35	84	72.61	81.52	254.94	211.91	107.81	151.38	74.67	0.00
							13.64	12.40	32.66	40.77	29.47	10.12	30.87	0.00
17194.	0.055	0.32	0.19	3.97	30.05	86	73.94	81.26	253.46	210.79	109.01	151.61	71.09	0.00
							13.63	12.37	32.40	40.67	29.44	10.10	30.82	0.00
11661.	0.044	0.38	0.24	3.41	19.79	88	75.23	80.98	252.17	209.86	110.18	151.87	67.58	0.00
							13.62	12.35	32.11	40.56	29.41	10.09	30.77	0.00
7250.	0.032	0.44	0.29	2.92	12.07	90	76.48	80.70	251.08	209.12	111.32	152.15	64.15	0.00
							13.61	12.32	31.81	40.43	29.38	10.08	30.72	0.00
4064.	0.020	0.50	0.35	2.50	6.80	92	77.68	80.42	250.22	208.59	112.43	152.47	60.83	0.00
							13.60	12.29	31.48	40.29	29.35	10.07	30.67	0.00
2015.	0.012	0.57	0.42	2.15	3.61	94	78.83	80.13	249.60	208.28	113.52	152.82	57.66	0.00
							13.59	12.25	31.14	40.13	29.31	10.06	30.61	0.00
865.	0.006	0.64	0.51	1.86	1.91	96	79.93	79.85	249.21	208.20	114.59	153.19	54.65	0.00
							13.57	12.21	30.79	39.96	29.26	10.05	30.55	0.00
314.	0.002	0.70	0.61	1.65	1.14	98	80.96	79.57	249.04	208.34	115.64	153.58	51.88	0.00
							13.56	12.16	30.43	39.77	29.21	10.04	30.49	0.00
93.	0.001	1.00	0.61	1.65	0.85	100	81.94	79.31	249.07	208.70	116.67	154.00	49.34	0.00
							13.54	12.12	30.07	39.57	29.16	10.03	30.43	0.00

TABLE 16: Cause Elimination Life Expectancy at Age 30 Under Independent and Dependent Competing Risk Models

	Independent Competing Risks	Dependent Competing Risks
Cause	Hazard Multiplied by Gompertz	Hazard Multiplied by Gompertz
Cancer	46.94	46.85
CVD/CHD	55.27	54.62
Residual	46.33	46.26
	Change in Life Expectancy at Age 30	
Cancer	2.41	2.32
CVD/CHD	10.74	10.09
Residual	1.80	1.73
	Effect of Dependency	
Cancer	---	-0.09
CVD/CHD	---	-0.65
Residual	---	-0.07

TABLE 17: Effects of Control on Risk Variables on Costs of Mortality

Lost Future Lifetime Income (1977 Dollars) Due to Mortality at and Beyond Given Age

		RISK VARIABLES CHANGED ONE AT A TIME							
Age	Baseline Control Value "Ideal" Costs	PP+DBP	Q.I.	CHOL	BLDSUG	HEMO	VITC	CIG	All Risk Variables Changed Simultaneously
		45.87 81.38	258.82	215.24	78.26	143.76	140.74	15.02	
		45.00 65.00	250.00	150.00	75.00	145.00	145.00	0.0	
30	22270.10	34091.38	23526.07	29548.39	21500.23	22111.04	20738.20	17363.38	15847.04
32	20554.99	31403.23	21718.12	26768.68	19814.33	20409.36	19063.44	15989.34	14515.45
34	18998.95	28543.90	20093.50	24263.14	18263.06	18852.27	17534.40	14738.07	13270.91
36	17506.96	25325.41	18562.76	21994.50	16783.31	17365.28	16064.26	13564.75	12102.98
38	16160.82	22277.46	17201.10	20086.94	15446.39	16034.67	14738.14	12540.97	11099.32
40	14801.57	19208.56	15832.68	18269.93	14103.06	14700.79	13404.39	11544.28	10139.59
42	13605.98	16609.87	14621.77	16728.22	12924.22	13532.36	12236.99	10697.58	9334.22
44	12374.70	14102.79	13350.08	15163.05	11717.11	12330.08	11048.11	9850.13	8532.19
46	11090.54	11709.70	12009.12	13528.93	10467.39	11073.49	9825.49	8981.42	7711.09
48	9978.58	9850.88	10817.67	12102.18	9294.52	9980.95	8784.97	8230.68	7003.73
50	8779.14	8079.53	9508.22	19550.38	8247.75	8746.44	7683.97	7408.82	6236.77
52	7788.30	6797.55	8411.78	9264.10	7308.71	7812.88	6792.01	6709.57	5595.68
54	6686.17	5548.22	7183.44	7638.72	6212.23	6713.83	5817.64	5900.30	4871.64
56	5448.78	4308.72	5803.07	6236.10	5115.62	5475.36	4740.31	4950.12	4045.15
58	4539.55	3491.31	4793.26	5113.32	4269.36	4562.94	3957.95	4219.41	3427.59
60	3514.94	2647.94	3665.06	3853.90	3317.93	3532.97	3083.25	3359.33	2719.91
62	2932.60	2199.49	3031.19	3156.24	2777.47	2947.04	2588.11	2850.52	2310.83
64	2285.15	1723.12	2335.85	2401.85	2175.88	2295.38	2037.79	2264.07	1847.87
66	1573.69	1213.36	1582.79	1596.60	1513.02	1579.38	1431.12	1598.66	1320.27
68	1248.14	982.50	1243.35	1238.90	1208.43	1251.90	1151.69	1285.45	1086.85
70	901.37	735.66	887.18	869.10	882.17	903.31	851.09	943.40	822.26
72	716.18	601.64	899.72	677.40	706.69	717.30	688.42	756.67	676.94
74	526.69	461.43	510.61	486.98	525.62	527.14	519.17	561.91	523.32
76	337.30	316.30	328.04	302.18	342.83	337.28	346.56	363.95	363.87

TABLE 17: (Continued)

78	232.59	240.66	231.86	212.41	250.35	242.42	258.12	263.50	280.54
80	152.91	165.50	145.50	129.82	161.81	152.79	171.98	167.20	197.52
82	108.65	126.25	103.21	90.15	117.07	108.38	127.98	119.10	153.99
84	69.17	69.19	65.93	55.78	76.66	68.91	87.31	76.07	112.66
86	35.30	55.04	34.07	27.12	41.32	35.09	50.86	39.03	74.46
88	26.63	45.59	25.93	19.99	32.08	26.44	41.06	29.52	63.79
90	19.83	37.50	19.53	14.54	24.64	19.67	32.92	22.04	54.52
92	14.75	30.87	14.74	16.57	18.94	14.61	26.44	16.43	46.73
94	11.15	25.67	11.32	7.84	14.78	11.04	21.52	12.45	40.42
96	8.76	21.80	9.01	8.08	11.92	8.66	17.97	9.79	35.52
98	7.26	19.07	7.85	4.98	10.06	7.17	15.55	8.12	31.88
100	6.38	17.25	6.68	4.38	8.43	6.31	13.98	7.15	29.30

Residual Life Expectancy in Years

30	43.70	43.52	43.11	41.24	44.49	43.70	45.50	45.25	48.31
60	18.03	20.67	17.70	16.79	18.76	17.99	19.74	18.26	21.67

Maintenance of health, prevention of disease, a psychosocial perspective[a,b]

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Social variations in the distribution of health and disease have been observed for centuries; however, the reasons for these differences in physical health status are not well understood. For many years, it was assumed that these differences could be explained by variations in ethnicity or genetic stock, exposures to noxious stimuli in the physical environment, or access to medical care resources. While these factors undoubtedly account for some of the differences in disease rates among members of different social groups, evidence is now beginning to accumulate which indicates that certain conditions and circumstances within the social environment or sociocultural milieu per se have disease consequences.

What is striking about the associations between these social conditions and physical health is the nonspecific nature of the associations—that is, social conditions are associated with a very broad and diverse set of diseases and conditions. These findings force us to question traditional psychosomatic models of disease causation in which only certain diseases, for instance, peptic ulcer, hypertension, or colitis, are influenced by psychological and social conditions. Several investigators, notably Cassel (1976), Hinkle (1973), and Syme (1974), have pointed out that it may be more fruitful and accurate to envision psychosocial process as enhancing susceptibility to disease. As Hinkle stated in 1973: "It is evident that any disease process and in fact any process within the living organism, might be influenced by the reaction of the individual to the social environment or to other people." This line of reasoning fits the findings to date more closely than a traditional psychosomatic perspective, since social conditions have been found to be associated with infectious diseases, e.g., tuberculosis, pneumonia, and mononucleosis, as well as noninfectious diseases ranging from cardiovascular diseases to cancer.

How do social conditions influence health status?

Social conditions may influence human health in many different ways and through many different pathways, and none can be a priori rejected as irrelevant. Psychosocial factors can be represented (see Kasl, 1979) as those that affect: (a) initial immunity or susceptibility status, (b) exposure among susceptibles, (c) development of inapparent versus clinical illness or disease onset (incidence of new events), (d) course of illness or disease (exacerbations, repeat events), and (e) outcome of disease process and/or degree of recovery, including case fatality.

Of particular relevance to the field of aging research is the possibility that these factors could influence aging processes in some way that, in turn, advances or retards the onset of disease. One of the most persistent notions in gerontology is the concept of biological aging as an intrinsic, sui generis process that can be separated from the accumulation of environmental influences and insults that the aging organism also experiences. For example, Busse (1969) distinguishes between "biological aging," those genetic processes that are time related and independent of stress, trauma, or disease, and "secondary aging," which consists of disability resulting from trauma and chronic illness. However, despite a great accumulation of normative data on age and biological functioning (e.g., Finch and Hayflick, 1977), there are few biological aging processes that appear *not* to be modified or modifiable by stress, trauma, and disease. Biological theories of aging (Shock, 1977) can, at the moment, point us toward those age-dependent changes in biological functioning that are particularly uniform or particularly variable across diverse population groups. But it may be more fruitful to conceptualize "biological aging" as being influenced by both intrinsic (genetic, constitutional) and extrinsic (environmental, psychosocial) processes. This possibility opens up numerous pathways for research that focus on the wide variability reported for almost all physiological processes associated with aging.

The mechanisms by which conditions in the social environment might influence health status in human populations constitute a relatively unexplored area. In a search for such mechanisms, it is important to keep in mind that social conditions seem to be associated with a wide range of outcomes rather than any single disease entity. This observation would suggest that there are several pathways leading from social circumstances to illness and/or that such circumstances lead to a compromised resistance to disease in general. As Cassel (1976), a proponent of the latter hypothesis, suggests, it may also be that there are several clusters of diseases associated with different psychosocial situations. An elucidation of these issues is critical, since by understanding the process by which social factors lead to poor health, we can learn where to

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[a] Contents are the opinions of the author and not those of the Department of Health and Human Services or of the organization she works for.

[b]

intervene most effectively and prevent unnecessary illness and death.

If we take the approach that there are likely to be multiple biological pathways, several potential processes can be outlined: (1) behavioral processes whereby people living in certain social and cultural circumstances maintain health practices which are either beneficial (e.g., physical activity) or harmful (e.g., cigarette smoking) to their health or obtain a variable quality of medical care; (2) psychological processes whereby people respond to circumstances by becoming depressed or changing their coping and appraisal processes; (3) direct physiological changes in both known biological risk factors (e.g., blood pressure, serum cholesterol) and unidentified processes which are directly altered by exposure to certain environmental circumstances. In the exploration of this chain leading from environmental conditions to health outcomes, we must also recognize that factors which in this chain are considered mediators may also directly influence socioenvironmental factors, reversing the causal chain. Thus it is possible, for instance, that psychological states such as depression could influence social conditions. Studies in which these variables are being investigated will be most useful when the temporal chain of events can be identified. It is also likely that characteristics of the person and the environment, combined, will ultimately be the best predictors of disease risk.

Behavioral factors, including health practices, preventive utilization of health services, and compliance with treatment regimens, are obvious and likely candidates for linking socioenvironmental conditions to disease consequences; however, the evidence available thus far indicates that health practices are capable of explaining only a part of the environment/disease association. Studies in which this hypothesis was directly addressed (Marmot et al., 1978; Berkman and Syme, 1979; Marmot and Syme, 1976; Prior, 1974) suggest that other pathways must also be involved, although in most cases a cross-sectional association between the social condition and health behavior was noted.

Psychological factors such as depression or coping processes also seem likely candidates as mediators between environmental conditions and illness responses; and there is some literature to support this view. Of particular interest are the work by Seligman (1974) and earlier work by Rotter (1966) and others interested in feelings of internal and external control and learned helplessness, as well as a review of such coping mechanisms and social circumstances by Satariano and Syme (1979). These investigators have hypothesized that when individuals are habitually confronted with situations in which their responses either are or appear to be ineffective, they ultimately come to conclude that events in general are uncontrollable and that they are powerless to effect a particular outcome. Seligman (1974) indicates that such feelings are related to depression and perhaps to other health problems. Psychological responses may also predispose an individual to suicide or risk-taking behavior which could result in accidents. Engel and Schmale (1972) and Antonovsky (1979) also refer to the importance of "giving up" versus maintaining a sense of control or "coherence" to health maintenance. There is, as yet, little strong evidence in support of these positions in terms of prospectively predicting physical health status or of linking socioenvironmental processes to health outcomes in human populations. However, it is interesting to note the similarity of these positions with Cassel's (1976) characterization of stressful social situations as ones in which "the actor is not receiving adequate evidence (feedback) that his actions are leading to anticipated consequences."

Furthermore, this pathway also closely parallels the findings by Rodin (1977) and Langer and Rodin (1976) on control-relevant interventions among the elderly in nursing homes and the findings on the effects of depression on neuroendocrine function (Sachar, 1976; Amsterdam et al., 1983) and lymphocyte function (Schleifer et al., 1984).

While the previous hypothetical pathway suggests that the critical role social factors play in disease causation is not due to objective circumstances themselves but to the way in which such circumstances are more subjectively perceived and mediated, it is also possible that there may be a pathway leading directly from social circumstances to physiologic changes in the body which increase either general or specific disease susceptibility. Findings from the Human Population Laboratory study indicating that no psychological factors developed from items on the 1965 survey mediated between social isolation and mortality risk support this view, although none of the factors were created to tap the psychological dimensions just described (Berkman, 1977).

In this discussion it is important to keep in perspective that socioenvironmental conditions may serve as predisposing factors (Cassel, 1976) which affect a person's general resistance to disease and that other factors (e.g., genetic susceptibility, exposure to noxious stimuli) may determine specific disease vulnerabilities. Alternatively, socioenvironmental conditions may modify the impact of other risk factors on disease, or the progression of disease, or the impact of the disease on mortality risk.

Stressful conditions may lead to alterations both in known biologic risk factors (e.g., blood pressure, serum cholesterol) and in as yet unidentified processes. If they function, in part, by altering known risk factors, it will be a mistake in analyses to treat such risk factors as simple confounders of the relationship instead of more properly considering them as potential mediators or pathways leading from a social experience to a health outcome. While this might seem to some a technical point, in fact, it has profound implications for the design of effective interventions in this entire area. To give a hypothetical example, if social isolation influences cardiovascular disease by raising blood pressure and cholesterol levels, "controlling" for these biologic risk factors in an analysis may wipe out an association between social isolation and cardiovascular disease. The implication for intervention is clear (but misleading), that we should focus efforts on lowering blood pressure and cholesterol without any attention to the social condition that caused the original elevations. Similar examples can be found linking physical activity to coronary heart disease (CHD) via weight change or linking high-density lipoprotein/low-density lipoprotein ratios or diet to CHD via blood cholesterol levels or obesity. In all three cases, environmental factors must influence health status via some biologic pathway. Controlling for that pathway obscures the relationship between the environmental factors and detracts attention from focusing interventions at that level of disease causation. We will return to this issue of appropriate interventions at the conclusion of the paper.

The impact of risk factors on the health status of the elderly

Biological and psychosocial risk factors for a particular disease, or for adverse health status changes in general, may change in their potency as one goes from younger and middle-aged study samples to older subjects. The general issue here is the extent to which older age changes vulnerability to disease for a given level of risk factors. Of course, we can invoke many plausible explanations for why risk factors may change potency with age. If risk factors increase in potency with age, it may be that they simply represent an accumulation of exposure over time and may not be related to age per se, that the risk factor is actually occurring in a more severe and threatening form, or that the older person is physiologically or psychologically more vulnerable to the same exposure or stress and is unable to mobilize resources as effectively as younger or middle-aged people. Decreases in risk may simply represent a selective survival of the fittest. It may also be that older people are wiser, that past learning facilitates adaptation to the next experience, and that we have a very incomplete understanding of the positive factors in the lives of older people. Events may change in significance because of lifestyle changes in aspirations, expectations, and perceptions.

Changes in risk factors with age

Some of the most intriguing changes in risk occur among sociodemographic variables. Kitagawa and Hauser (1973) analyzed mortality data on U.S. residents in relation to age and education. Among white men, standardized mortality ratios (SMR's) for all causes revealed a negative gradient in relation to years of education only among those aged 25–64; white men 65 and older showed no gradient whatever. Among white women, a somewhat stronger negative gradient was observed in the 25–64 age group than in the group 65 and older, but the latter still revealed a definite negative association between SMR and education. Analyses by cause revealed that the disappearance of the gradient among men 65 and older held for all major causes of death except two: for influenza and pneumonia and for accidents, the higher levels of education conferred an advantage even in those men 65 and over. These data, overall, suggest a simple interaction between SMR, education level, and age, and a more complex interaction involving sex.

Analyses by socioeconomic level of city tracts and age (Antonovsky, 1967) reveal the expected negative gradient in SMR's and its weakening in the older age groups. However, unlike the data on education, these data show that the gradient never quite disappears even in the oldest group (75 and older) and is about the same for both sexes. Computations of SMR's for men 20–64 by age and occupation (Antonovsky, 1967) reveal that nonfarm laborers, the one group with a notable excess mortality, have an SMR of more than 170 in the 25–44 age group, but it drops to a little more than 120 in the 55–64 age group.

Race remains an ambiguous social indicator in health studies and presumably reflects many sociocultural and genetic and constitutional variables in addition to average social class differences. Consequently, the race-dependent differences in various health status indicators that are also modified by age are difficult to interpret. For example, age-specific death rates are higher for persons of races other than white only until age 74; the situation then reverses (National Center for Health Statistics, 1979). A recent paper from Evans County further indicates that the crossover effects are genuine and are not the result of misclassification of age or small numbers (Wing et al., 1985). However, these do not appear to be additional years free of disability; days of restricted activity and days of bed disability continue to be higher among persons other than white even in the age bracket 75 and older (National Center for Health Statistics, 1972). Other studies also suggest changing race differentials for specific diseases with change in age. For example, the strong increase in rheumatoid arthritis with age holds only for white persons; black persons have higher rates until age 64, while white persons have higher rates in the age group 65 and older (Cobb, 1971). Prevalence rates of diabetes, determined in a mobile multiphasic screening program, are much higher among black than white persons, but at ages 65 and over, the rates are virtually identical (Adler, Bloss, and Mosley, 1966).

Analyses of 1959–61 mortality by marital status (National Center for Health Statistics, 1972) clearly document the well-known excess mortality associated with the three marital status categories of single, widowed, and divorced (compared with married). Moreover, in 11 of the 12 sex-by-race-by-status groups, the elevated SMR goes down in the older age groups. Only among divorced women of races other than white does the SMR show no change with age, remaining in the vicinity of 135. Additional analyses of similar mortality data from 1940 and 1949–51 reveal one interesting secular trend: among divorced women of both races, the SMR went up with older age groups for the 1940 and 1949–51 years. In other words, in 1940 divorced older women had much higher SMR's than divorced younger women; by 1959–61, this trend was reversed for white women and wiped out for black women. Additional analyses of the 1959–61 mortality data by cause—e.g., arteriosclerotic heart disease, International Classification of Diseases (ICD) 420; vascular lesions affecting the central nervous system, ICD 330–334; and malignant neoplasm of digestive organs and peritoneum, ICD 150–159—repeatedly confirm the decline in SMR for single, widowed, and divorced people in older age groups.

Data from the Human Population Laboratory (HPL) survey of almost 7,000 adults in Alameda County have been examined for the relationship between health habits and mortality. Preliminary analyses (Belloc, 1973) suggested that only the benefits of physical activity persist into old age. More recent analyses with a refined health practices index (smoking, alcohol consumption, physical activity, sleep, and relative weight), however, reveal that even among subjects 70 and older, a low score on positive health practices is associated with significantly greater mortality (Kasl and Berkman, 1981). It is also worth noting that there was not much of an association between age and health practices for either men or women. These associations were not found in data from Massachusetts, where few behaviors persisted as risk factors in the older age groups (Branch and Jette, 1984).

The changing risk factor picture with advancing age becomes most complex—and most fascinating—when some factors become less potent, while others emerge as more potent. Haynes et al. (1978), in their report on the relationship of selected psychosocial factors to coronary heart disease in the Framingham study, showed that the Type A personality dimension was significantly associated with CHD among both men and women, but only in the younger age group (45–64); among older (65 and older) men and women, this association did not hold. On the other hand, marital dissatisfaction and/or marital disagreement were associated with CHD among men and women, but only in the older age group. Interestingly, an index called "aging worries" showed an association with CHD among younger men and women only. Equally fascinating results are to be found in the study of acculturation and CHD among Japanese men living in California (Marmot and Syme, 1976). The basic finding was one of low CHD prevalence among the more traditional Japanese-Americans, a result that could not be accounted for by differences in the major coronary risk factors. How did this picture change for different age groups? On one index, "culture of upbringing," the benefits of being traditional weakened considerably in the oldest of three age groups (55 and older). On another index, "cultural assimilation" (degree of retention of Japanese cultural forms), it was the oldest group that showed the biggest differences in CHD prevalence due to degree of assimilation.

In summary, then, the selected findings discussed in this section were primarily intended to alert the readers to a particularly interesting issue: the changing risk factor picture with age, and what that may say about the vulnerability of older people. Certainly it is possible that, in part, we are simply observing the selective survival of the fittest. Similarly, calculations intended to reveal the strength of the impact of a particular variable on health status, such as standardized mortality ratio or relative risk, are ratio calculations that encounter a ceiling effect when the outcome variable is quite common in the total group under observation (e.g., mortality among the very old). Calculations based on linear differences (e.g., difference in percentage between two groups) might lead to somewhat different statements regarding the changing risk factor picture. However, neither of these explanations is particularly compelling when one finds subgroup differences, such as the difference between men and women in the impact of education on mortality among younger and older persons, or when new risk factors emerge as others weaken among the progressively older age groups in the study sample.

In the long run, we need a substantive rather than methodological interpretation of the findings on the changing risk factor picture. This will call for a broad life-cycle perspective and for an understanding of the adaptation processes of different age groups. For example, the impact of social status variables may differ because lifestyle adaptations and aspirations change with age and because, in retirement, the effects of some components of social status may be considerably blunted. Ultimately, in order to understand the changes in biosocial vulnerability of people as they age, we will need to know more about the intrinsic, sui generis process of biological aging (if it exists), the cumulative impact of environmental conditions and experiences, and the changes in the meaning and dynamics of the psychosocial risk factors under scrutiny.

Clearly differences in risk factors may vary not only among age groups but among different subgroups of the population or among different cultures. The most striking differences in risk are frequently observed between men and women. Evidence to date indicates that widowhood is associated with greater mortality risk for men than women, that is, men do not seem to fare as well following the loss of their wives as women do following the loss of their husbands. Gender also seems to interact with many other traditional risk factors such as smoking, serum cholesterol, and alcohol consumption (Wingard, 1982) so that men with the same level of risk factor have a greater morbidity and mortality than women with the same amount of exposure to risk. The reasons for this phenomenon are poorly understood. Similar interactions may well exist across socioeconomic groups and across different cultures, though most research has not focused on these differences. We will come back to this topic in relationship to the impact of networks and support on health status in the conclusion of this paper.

Social networks and social support: A selected social condition and its influence on health status

The importance of maintaining social connections for the physical and mental well-being of an individual has been recognized for some time (Durkheim, 1951; Freud, 1926; Bowlby, 1958). Recently, investigators have hypothesized that social and community ties may alter host resistance and consequently play a role in the etiology of a wide range of diseases (Cassel, 1976; Kaplan, Cassel, and Gore, 1977; Antonovsky, 1972). Social isolation has also been proposed as a critical aspect of the aging process itself (Lowenthal, 1964; Cumming and Henry, 1961). It is commonly expressed that the elderly are an isolated group, with widowhood, retirement, and grown children leaving home bringing about an irreversible loss of social attachments and community ties. Thus, if the relationship between social isolation and poor health is a causally strong one, we would expect this to have profound effects among the elderly, for whom such losses are common. In fact, while there is some evidence to suggest that social networks play a role in disease etiology, there is less convincing evidence regarding increasing social isolation as an age-linked phenomenon, and even less evidence supporting the notion that the relationship between social networks and health status may be unique to, or different for, the elderly.

In the following pages, the research relating social and community ties to health status among people of all ages will be reviewed. I will then return to the issues pertaining to the social networks and social support of the elderly. I will start with a review of the literature on marriage and widowhood and move to a review of other kinds of social connections.

Marriage: A special kind of tie

Marriage is one of the most fundamental and intimate ties among people. Those who are not married, whether single, separated, widowed, or divorced, experience higher mortality rates than married people (Ortmeyer, 1974; Durkheim, 1951; Carter and Glick, 1970). This mortality risk does not appear to be as great for women as for men and seems to decline with age.

Mortality differences are not explained by any one cause of death. Using national data (Ortmeyer, 1974), divorced white men have been found to have higher mortality rates than their married counterparts for virtually every major cause of death except leukemia. This is also true of single white men, with the added exception of malignant neoplasms of genital organs. Compared to married men, those who are single have a mortality rate from cancer of the digestive organs and peritoneum that is four times higher. Widowed men have seven times the homicide rate, four times the suicide rate, and over six times the mortality rate for tuberculosis and cirrhosis of the liver. Divorced white women, compared to those who are married, experience higher death rates from almost all causes, and single white women have higher rates than married white women for most causes. The cause-specific ratios are not as great for women, however, as they are for men (Ortmeyer, 1974).

In the Israeli Ischemic Heart Disease Study, a prospective cohort study of almost 10,000 Israeli adult male civil service and municipal employees, psychosocial problems (particularly family ones) and wife's love and support were found to be important predictors of the development of angina pectoris over a 5-year followup period (Medalie and Goldbourt, 1976). Incidence cases were subjects at risk for angina pectoris (excluding known angina and myocardial infarction cases in 1963) who in 1968 were diagnosed as having definite angina (Medalie et al., 1973).

In this study family problems were measured by responses to four questions: (1) Did you have any problems (conflicts) with your family (wife, children) in the past? (2) Do you have any problems with your family at present? (3) How does it affect you when your wife or children do not listen to you or even oppose you? (4) Does your wife show you her love? In an analysis of 5-year angina incidence rates, family problems emerged as strong predictors after controlling for other biomedical and demographic covariates. In another analysis, wife's love and support were shown to buffer the effects of anxiety. When anxiety was low, wife's love and support were not associated with angina. When anxiety was high, men who did not have the love and support of their wives were 1.8 times as likely to develop angina during the followup period as those with support ($p < .05$). In this study, these same variables did not predict myocardial infarction in multivariate analyses (Goldbourt, Medalie, and Neufeld, 1975).

The existence of a supportive marriage has been shown to mediate between stressful life events and other poor health outcomes. In one study of the mental and physical health consequences of job loss due to a factory shutdown, Gore (1981) reports that those men who had "the emotional support of their wives while unemployed for several weeks had few illness symptoms, low cholesterol levels, and did not blame themselves for loss of job." In general, men who were both unemployed for a longer time and unsupported tended to have the worst health outcomes (Cobb and Kasl, 1977). In another study of psychiatric disturbance among women, Brown, Bhrolchain, and Harris (1975) found that having a husband or boyfriend who was a confidant served as a powerful mediator between a severe event or major difficulty and onset of psychiatric disorder. In this sample of women aged 18–65, 38 percent of those who had a stressful event and no husband or boyfriend as confidant had onset of disturbance. (For those without such a confidant or without a severe event, the percentage of psychiatric disturbance was under 4 percent.) When the confidant named was a sister, mother, or friend seen weekly, the relationship was not observed to mediate between life events and psychiatric disturbance.

Widowhood seems to have a profound effect on physical and mental health. Also, as noted earlier, this effect appears to be stronger for men than women and stronger in younger rather than older ages. Maddison and Viola (1968), Marris (1958), and early studies by Parkes (1964) indicate that widows, especially in the first year following bereavement, report many more complaints about their health, both mental and physical, and believe they have sustained a lasting deterioration to their health. The relationship between widowhood and increased mortality risk from a wide variety of diseases has been reported both in studies using vital statistics (Kraus and Lilienfeld, 1959; Young, Benjamin, and Wallis, 1963; Cox and Ford, 1964; McNeil, 1973) and in cohort studies (Rees and Lutkins, 1967; Clayton, 1974; Gerber et al., 1975; Ward, 1976).

In one of the first major studies, Parkes, Benjamin, and Fitzgerald (1969) report that of 4,486 widowers 55 and older, 213 died during the first 6 months following bereavement. This is 40 percent above the expected rate for married men the same age. After 6 months, the rates gradually fell back to those of married men and remained at that level. Through an analysis of husband's and wife's concordance rates for cause of death, the authors concluded that neither the sharing of similar pathogenic environment nor the tendency toward the selection of the unfit to marry the unfit (homogamy) was likely to explain more than a part of the increased 6-month mortality rate. While the Parkes study is a landmark study of widowhood, as Minkler (1985) notes, it suffered from its own methodological weakness, such as lack of attention to loss by migration, slightly older subjects than controls, and retention of remarried (and therefore possibly healthier) widows in the cohort.

To date, the most comprehensive and well-controlled analysis of widowhood is by Helsing, Szklo, and Comstock (1981), who found that being a widow or widower carried an increased mortality risk among men but not among women. Their 10-year retrospective cohort study of men and women in Washington County, Maryland, showed that the excessive risk in men persisted when age, education, age at first marriage, cigarette smoking, church attendance, and a proxy economic status measure were controlled. In contrast to other investigators, Helsing and coworkers reported that the increased mortality risk among widowers was not confined to the first 6 months of the bereavement but persisted throughout a 10-year followup period. If further studies confirm this finding, viewing widowhood as a chronically stressful situation, rather than attributing the increased mortality to the acute effects of the spouse's death, would seem reasonable (Helsing and Szklo, 1981; Susser, 1981). In addition, the increased risks were not observed in only one or two causes of death but were spread across many causes. Notable increases were found for infectious disease, accidents, and suicide for males and cirrhosis of the liver for females (Helsing, Comstock, and Szklo, 1982).

These data suggest that there is something protective about a supportive spouse or partner that is capable of shielding an individual against the otherwise deleterious effects of some objective life circumstances. The morbidity and mortality findings also indicate that the loss of a spouse, a major enduring tie to another person, may be at least a precipitating factor in the increased death rates found among widowers. The relationship appears to be at least to some extent independent of the traditional CHD physiological risk factors, homogamy, and equal exposure to pathogenic environment.

The elderly, particularly elderly women, are increasingly likely to lose a spouse with advancing years. Jacobs and Ostfeld (1977), in a comprehensive review on the mortality of bereavement, estimate that 2–3 percent of married Americans over the age of 50 will become widowed each year. At ages 65–74, 10 percent of men and 43 percent of women are widowed. For those 75 years and older, the respective percentages are 29.5 and 70.2 (Siegel, 1975). Clearly, this is an extremely frequent event among the elderly. However, there is also some evidence to suggest that the nature of bereavement is in some ways modified for the elderly. Several investigators (Stern and Williams, 1951; Gramlich, 1968; Gerber et al., 1975; and Heyman and Gianturco, 1973) indicate that grief among the elderly is not the same as grief at younger ages. Jacobs and Douglas (1979) have summarized this work, reporting that among the elderly a loss is faced with more cognitive acceptance and is associated with less numbness, denial, and guilt. However, hallucinations and illusions and psychosomatic symptoms may occur with greater frequency. Jacobs and Douglas (1979) suggest that these differential characteristics of grief among the elderly may be the result of the process of anticipation of death, which is probably associated with older age. This ability to anticipate and accept widowhood may also play some role in the decreased relative risks associated with bereavement at older ages reported by researchers (Kraus and Lilienfeld, 1959; McNeil, 1973). This finding also supports Neugarten's (1970) viewpoint that what makes events traumatic is their being "off time" and unanticipated. "Major stresses," she emphasizes, "are caused by events that upset the sequence and rhythm of the life cycle...when the empty nest, grandparenthood, widowhood, or retirement occur off time" (pp. 86–87). It may also be that the experience of becoming a widow or widower at a time when one's peers are also becoming single provides a structural support that buffers against some of the stressful circumstances encountered by younger widows and widowers. Economic and cultural conditions are likely to modify the impact of widowhood in the bereaved spouse, although little research has been done to explore these potential relationships.

Other social ties

In addition to spouses, other social ties are relied on by most people to fulfill a variety of emotional and pragmatic needs. Some of these ties are characterized by enduring and emotionally important relationships, while other contacts are characterized primarily by their task orientation. Some people in these links may fulfill a variety of needs; others may have one specific need for which they are relied on. Taken as a whole, these relationships and informal associations form a web or a social network in which most people spend a significant part of their lives. Although network configurations have been described in detail by many social scientists, relatively little is known about the impact that various network configurations have on health status. We will briefly review some of the evidence relating social networks to health status and then focus on situations of special interest to the elderly. For more extensive reviews on the topic of health and social networks, the reader is referred to several recent reviews (Kaplan, Cassel, and Gore, 1977; Cobb, 1976; Broadhead et al., 1983; Minkler, 1985; Berkman, 1984; Cohen and Syme, 1985).

Mortality

There have been three studies indicating that particular network or support characteristics are associated with mortality risk. One of these is an analysis of 9-year mortality data from 6,928 adult residents of Alameda County, California (Berkman and Breslow, 1983; Berkman and Syme, 1979). In the survey, basic information on several essential aspects of an individual's personal network was collected. A Social Network Index was developed based on four types of social connection: (1) marriage, (2) contacts with extended family and close friends, (3) church group membership, and (4) other group affiliations. Contacts with friends and relatives were measured by the number of close friends and relatives a respondent reported and the frequency with which he or she saw them. The age- and sex-specific mortality rates from all causes in relation to the Social Network Index reveal a consistent pattern of increased mortality rates associated with decrease in social connection. The age-adjusted relative risks were 2.3 for men and 2.8 for women ($p<.001$). When the Social Network Index was examined in relation to the separate causes of death, people with few connections were found to be at increased risk of dying from many separate causes of death: ischemic heart disease, cancer, cerebrovascular and circulatory disease, and a final category of all other causes of death.

In subsequent multivariate analyses using a multiple logistic risk model, the Social Network Index was found to be associated with mortality risk independent of initial physical health status, socioeconomic status, cigarette smoking, alcohol consumption, level of physical activity, obesity, race, life satisfaction, and use of preventive health services. In the multivariate analyses, when all variables were considered simultaneously, the approximate relative mortality risk was reduced but still remained over 2.

A prospective community study of adults in Tecumseh, Michigan, by House, Robbins, and Metzner (1982) has both extended and, in part, replicated the findings of the Alameda County study. In this analysis, 2,754 men and women who were interviewed and medically examined during the third round of the Tecumseh Community Health Study in 1967–69 and who were 35–69 years old at that time were included in a 10-year mortality followup.

Measures of social relationships and activities fell into four major categories: (1) intimate social relationships (marital status, visits with friends and relatives, going on pleasure drives and picnics), (2) formal organizational involvements outside of work (going to church or meetings or voluntary associations), (3) active and relatively social leisure (going to classes, movies, affairs, museums, etc.), and (4) passive and relatively solitary leisure (watching television, listening to radio, reading). Confounding variables considered in the analyses were age, cigarette smoking, alcohol consumption, education, employment status, occupation, weight and height, and a variety of morbidity measures assessed from physical examination. One of the major strengths of the study was the ability of the investigators to control for such factors as coronary heart disease—defined as probable history of myocardial infarction (MI), or angina, or electrocardiographic evidence of MI; chronic bronchitis or persistent cough of phlegm; probable hypertension; levels of serum cholesterol and blood glucose; and forced expiratory volume.

Among seven individual components of social integration and activities, four were statistically significant for men in multiple logistic analyses after adjusting for age and other risk factors: marital status, attendance at voluntary associations, spectator events, and classes and lectures. For women, only church attendance was significant. Frequencies of visits with friends and relatives and of going out on pleasure drives and picnics were not significant for either men or women. In two cumulative indexes of social integration using the same seven factors, multiple logistic analyses revealed that among men the indexes were related to mortality when confounding variables were considered. Among women, the relationships of both indexes to mortality were significant independent of age, but became nonsignificant when all risk factors were covariates.

A third study of mortality risk was conducted in Durham County, North Carolina, by Blazer (1982) on 331 men and women 65 years of age and older. Eleven items tapping social support were included in the original survey. These items from the Older Americans Resources and Sources Community Survey (OARS) Questionnaire were divided into three dimensions: (1) roles and attachments available (marital status, number of living children and siblings), (2) frequency of interaction (telephone calls and visits with friends and relatives during the past week), and (3) perception of social support (lonely even with people, someone cares what happens to you, difficulty speaking to new people, enough contact with confidant, seems like no one understands, someone would help if you were ill or disabled). Control variables considered in analyses were age, sex, race, economic resources, physical health, activities of daily living, stressful life events, symptoms of major depressive episode, cognitive dysfunction, and cigarette smoking.

In several types of analyses, the three parameters of impaired social support were significant risk factors for 30-month mortality independent of the 10 covariates. Using three binary regression analyses, the estimates of relative mortality risk were found to be 3.40 for impaired perceived social support, 2.04 for impaired roles and attachments, and 1.88 for impaired frequency of social interaction. Impaired perceived support and roles and attachments predicted mortality when the other two support parameters were controlled for. This was not the case for the third measure, tapping frequency of interaction. Thus, in this survey of older men and women, the parameter with the highest value was perceived social support, a measure (as Blazer correctly pointed out) that is a subjective appraisal of the adequacy of support rather than a more objective characteristic of a social network.

Following this study, Reed et al. (1983) examined the impact of social networks on CHD in the Hawaii cohort of Japanese-Americans. In 1971, 7,639 men who had completed the initial examination from 1965 to 1968 and who were thought to be alive and residing in Hawaii were given a psychosocial questionnaire: 61 percent of these people returned the questionnaire ($n=4{,}653$). Nonresponse, although high, does not seem to reflect any systematic nonresponse bias (Reed et al., 1982). Prevalent cases were defined as those CHD cases existing at the time of the survey; incident cases were new ones occurring during the followup period. At the time of the survey, 264 prevalent CHD cases were identified. In the subsequent time through 1978, 218 men developed new coronary heart disease.

In this study, nine questions were used in two network scales. The first included all nine items: (1) geographic proximity of parents, (2) geographic proximity of parents-in-law (3) marital status, (4) number of living children, (5) number of people in household, (6) frequency of social activities with coworkers, (7) frequency of discussing serious personal problems with coworkers, (8) frequency of attendance at religious services, and (9) number of social organizations attended regularly. The second scale included the first five of these items, which involve more intimate contacts. Among individual items, men who were never married and/or were living alone had a particularly high risk of both prevalent and incident heart disease, although these risks were not statistically significant.

In logistic analyses of the prevalence data, both scores predicted total CHD (an outcome measure including cases of myocardial infarction and angina pectoris) independent of such standard biologic risk factors as high blood pressure, serum cholesterol and serum glucose levels, as well as cigarette smoking, alcohol consumption, physical inactivity, and body mass. The set of five items tapping family contacts and household composition predicted angina pectoris; however, neither score predicted MI alone.

Different findings emerged from the analyses of incidence or prospective data. In logistic analyses with all potentially confounding variables, there was no significant association of either score with total CHD, fatal myocardial infarction, or angina. The second network score of more intimate contacts was of borderline significance ($p = .08$) in predicting nonfatal myocardial infarction. These findings must lead to the question of what might be responsible for the differences in prevalence and incidence data.

The most obvious possibility is that the experience of disease is antecedent to and influences a person's ability or desire to maintain social ties, thereby causing an association to appear in the prevalence data but not in the prospective incidence data. Some variables in this analysis are more likely to be influenced by health status than others (e.g., attendance at social activities and religious services as well as membership in and regular attendance at organizations). In fact, the scales including these items were more predictive of CHD prevalence than of incidence. Other variables are much less likely to be influenced by concurrent health status (e.g., never being married, geographic location of parents and in-laws, number of children, and household composition). If these variables predicted prevalence, then other explanations must be examined. In fact, these items were found exclusive of the others in the second scale. This second scale of marital status, contacts with relatives, and household composition predicted CHD prevalence and angina prevalence and was of borderline significance in predicting nonfatal MI incidence.

Is there another explanation for these associations? Because prevalence data obviously do not include fatal cases, there is a suggestion in this cohort that the network variables may have been more predictive of nonfatal CHD than of fatalities. The authors noted that the MI case fatality rate was higher in the group with most connections than in the group with fewer contacts (43 percent compared to 34 percent). In the univariate analyses of incident cases, the network scales showed no association or clear pattern with fatal MI. However, the scale of intimate contacts was significantly associated with nonfatal MI; the relative risk was 1.5 ($p = .04$). Thus, although the association of the network variables with prevalence data and nonfatal MI cannot fully be explained, they also cannot be dismissed lightly as being artifactual. In the long run, developing more substantive hypotheses to explain these findings will be useful.

In the Framingham cohort of women, clerical workers ($n = 142$) who had a nonsupportive supervisor were found to be at increased risk of developing CHD over an 8-year followup period (Haynes, Feinleib, and Kannel, 1980). Incidence of CHD was defined as diagnosis of MI, coronary insufficiency syndrome, angina pectoris, or CHD death. Nonsupport from supervisor predicted CHD incidence independent of other standard risk factors (high systolic blood pressure, high serum cholesterol levels, and number of cigarettes smoked) and other psychosocial scales (anger, job changes, and family responsibilities). This factor was not a significant CHD predictor for other working women or for men (Haynes, Feinleib, and Kannel, 1980). Framingham working women with the highest CHD risk were those in clerical jobs. Thus, women in this position may experience stress from several sources, including lack of autonomy and control over the work environment, underutilization of skills, and lack of recognition of accomplishment.

A recent study by Rubberman et al. (1984) of survivors of acute myocardial infarction who were participants in the B-Blocker Attack Trial (BHAT) reveal striking effects on 3-year mortality associated with social isolation and stress. The BHAT was a multicenter, randomized, double-blind, and placebo-controlled research project designed to test whether the regular administration of propranolol hydrochloride to men and women who had at least one myocardial infarction would result in a significant reduction in total mortality during a period of 2 to 4 years. Six weeks after MI, men were given an interview on a range of psychosocial topics covering life events, stress, difficulty coping, social isolation, depression, and Type A behavior. Twenty-five of the 31 BHAT clinical centers agreed to participate in this study. Among those 25 centers, the response rate to the interview was 90 percent, yielding 2,320 men. Social isolation in this study was defined by three responses to questions: (1) respondent did not talk with medical personnel (while in the hospital or soon after discharge) about any possible need for life changes; (2) respondent (at the time of MI) was not a member of any club, social or fraternal organization, church or synagogue; (3) respondent "hardly ever" visited friends or relatives in their homes.

Mortality analyses were based on standard life-table methods. High levels of social isolation were associated with roughly double the risk found among patients with low levels of isolation in uncontrolled analyses. The risk was comparable to that of persons who experienced other forms of stress and was slightly less than the risk associated with few years of education. When a combination of life stress and social isolation was entered into a multivariate regression model along with other biomedical risk factors, the stress/isolation measure was independently associated with both all causes of death and sudden death and among men in high-arrhythmia and low-arrhythmia groups. Social isolation alone was independently associated with mortality. Relative risks resulting from the Cox multivariate regression models, however, are provided only for the combined measure. They are 4.56 for all causes of death (comparing people who are high on both stress and isolation measures to those who are low on both factors) and 5.6 for sudden death from arteriosclerotic heart disease.

These results are similar to those reported by Chandra et al. (1983), who found marital status predictive of survival after myocardial infarction when adjusted for biomedical covariates, including clinical complications.

Conclusions and recommendations for future research

What is known about the relationship between social ties and physical health has been reviewed in the previous section. The focus of this section is on what we *need* to know—for it is clear that the studies produced so far raise many more issues than they resolve. For instance, they do little to inform us about which network characteristics are important or how such a social phenomenon "enters" the body to influence disease processes. In this section, I will discuss four issues raised by these studies.

1. Specificity of social network and support measures

Perhaps the greatest problem with the studies reviewed is the inadequacy of the social network and support measures. With few exceptions, the measures used in these studies have been developed post hoc from a few items included in questionnaires for other reasons. Thus, many studies purporting to measure social networks and support do not in fact do so, or do so in a very limited way. This is understandable in early studies when preliminary relationships are being uncovered; however, we now need to move on and take full advantage of the more sophisticated measures currently available which allow the measurement of *specific* network and support characteristics.

For instance, many of the studies completed to date have intermingled measures of support with measures of networks. As was stated earlier in this report, social networks might be seen as the web of social relationships that surround an individual and the characteristics of those social ties—that is, their size, composition, geographic dispersion, density, homogeneity, level of reciprocity, intimacy, frequency of contact, etc. (Fisher et al., 1977; Mitchell, 1969; Laumann, 1973). Social support might then be viewed as the aid (emotional, instrumental, financial) that is transmitted among network members (Mitchell and Trickett, 1980; House, 1981; Kaplan, Cassel, and Gore, 1977). As Wellman (1981) has so cogently argued, networks may or may not be supportive; that is an empirical question. We need to know specifically what network and support characteristics are related to morbidity and mortality, with the understanding that certain characteristics may even increase risk of one type of outcome and decrease risk of another. For example, some evidence indicates that individuals with large networks may increase their utilization of health services and independently decrease their risk of disease. This may come about because large networks may be stress reducing but at the same time be comprised of "cosmopolitan" members who have pro-medical-care orientations. We need to know if dispersed networks are as effective as networks of equal size where members are geographically proximate. Most of all, we need to move beyond measures of household composition, or presence of kin, or group affiliation as adequate measures of social networks and support.

It is also evident that social networks and social support are shaped by various cultural, social, environmental, and psychological forces and that they, in turn, influence others. Psychologists and psychiatrists point to the possibility that individuals with mental disorders are unable to maintain extensive social networks or mobilize support because of their mental state. It is this mental condition, they argue, which is etiologically related to the disease outcome. Other investigators point out that the social structure, to a great extent, determines the composition of networks and types of interaction among network members. Still others point to the psychological sequelae of social experiences—sense of coherence, internal/external control, fatalism, even Type A behavior—and suggest that these are the cause of disease since they are more proximate to it.

All of these positions are plausible, and all are at least in part correct. The choice of which of these important factors to study depends upon our orientation—professional, political, and personal—and upon where we foresee interventions to be most effective. No matter what our orientation is, however, our research efforts will be greatly strengthened by our ability to distinguish among these factors in terms of both measurement and temporal sequencing. Studies in which these variables are lumped together will do little to enhance our understanding of which psychosocial experiences are most noxious and how those factors interact with others to produce disease.

2. Social networks: Buffers or stressors?

Whether we consider social networks and support as buffers or stressors is dependent, in part, on statistical tests and model building, but also upon our conceptualization and measurement of social networks and support. Whether we consider death of a spouse or divorce as a break in networks or an acute life event is dependent upon our conceptualization, not a statistical manipulation. It has now been pointed out by several investigators (Mueller, 1980; Thoits, 1982; Gore, 1981; and Berkman, 1982) that stress and support are neither operationally nor conceptually independent variables. Many life changes are actually losses or breaks in social ties; others are not really life events at all but reflect ongoing poor or deteriorating social relationships. Many other events "may seriously disrupt, distort, reduce, or otherwise change existing network relationships" (Mueller, 1980). Moving, changing jobs, and retiring almost inevitably cause changes in networks.

Mueller has hypothesized that much of the impact of life events may result from the profound disturbances they introduce into one's social network. This possibility was discussed at the very beginning of this report. The extent to which life events and networks are overlapping and redundant severely hampers our ability to assess their relative impacts on health status.

How questions are framed can also influence the kinds of effects networks and support will have. For instance, if we have a study of occupational stress and the network measure involves discussing work-related problems with network members, such an item can have only buffer effects because one does not talk about job problems to anyone in the *absence* of such problems. On the other hand, having a "supportive" boss may be independent of other job stresses. Therefore, the Framingham data that show the significance of a supportive boss for clerical workers but *not* other workers probably reveal the buffering effect of this variable on the job stress of clerical employees.

The findings reviewed in this paper indicate the existence of both main effects and buffer effects. It may well turn out that certain network or support characteristics have buffer effects (perhaps emotional support buffers certain occupational stresses) and others have main effects (network size may influence mortality). In either case, we need to examine these relationships empirically, not assuming the validity of one model versus another a priori.

3. Cultural expectations and well-integrated communities

It is a cliche to say that responses to survey questions are influenced by cultural attitudes and expectations, yet this obvious fact has been ignored in most research to date. The reason that it is so important to pay attention to this possible influence is that there is a hint in the findings reviewed that in some populations known to be very socially cohesive and well integrated (i.e., women in Tecumseh, Japanese-Americans in Hawaii), differences in risks between isolated and nonisolated people are not great. One possible explanation for these findings is that those communities have such overall high levels of social contact and support that very few people are isolated in severe enough ways to reveal significant increases in risk. For instance, only about 2 percent of Japanese men in Hawaii live alone (Reed et al., 1983). Another possibility is that social contacts are so much a part of a routine in the lives of these people that they go unnoticed and unreported. As a result, the measures of social activities do not differentiate well in these groups (House, Robbins, and Metzner, 1982). For instance, there is some evidence that, in studies of older people, the daily visits to parents who live in in-law apartments or nearby commonly go unreported by their children as "visits." This seems to occur because they are so much a part of normal daily life that they are not seen as formal occasions worthy of reporting (Stueve and Lein, 1979). Similar experiences have been reported for women in Tecumseh (House, Robbins, and Metzner, 1982) and for the Japanese. In a cross-cultural study comparing the experiences of older Japanese and Americans, 42 percent of Japanese in Japan, compared to 78 percent of Americans, reported feeling rooted, that they belonged and were part of things (Hashimoto, 1983). This is in contrast to the fact that 68 percent of Japanese had lived in their town for 50 years or more, compared to only 24 percent of older Americans. Even comparing only those who lived in their town since before World War II, 46 percent of Japanese and 86 percent of Americans reported feeling that they belonged and were rooted (Hashimoto, 1983). Reporting those kinds of feelings may be very foreign to the Japanese in spite of our belief that this sense of fit is a common theme of Japanese culture.

Also, questions which tap discussion of personal or financial problems may be culturally unacceptable to different groups. For instance it appears to be very difficult for Japanese men to discuss personal problems with coworkers, since in the Japanese-American study in Hawaii only about 1½ percent reported that they do so (Reed et al., 1983). Studies designed to tap networks and support must take this into consideration in the future by probing more fully and developing more culturally sensitive questions.

4. Pathways leading to disease

Social networks seem to be related to disease states in a remarkably nonspecific way. It would be premature at this time to say that social ties are related to one category of disease and not to another. In fact, they may turn out to influence biologic mechanisms which increase an individual's vulnerability to a host of conditions. With regard to the spectrum of disease, the most consistent findings that have emerged to date are those relating network variables to mortality. In all mortality studies reviewed, including those on bereavement, various aspects of networks predicted mortality risks. Results are more mixed in morbidity studies. Two studies on case fatality (following MI) again show strong associations between social ties and survival.

The next question is: how might social networks and the functions they serve influence physical health status; that is, what are the biologic pathways linking these two phenomena? While there has not been much work in this area and space limitations preclude a lengthy discussion of this issue, several potential pathways leading from social networks to morbidity and mortality can be described.

The first is that, through the provision of advice, services, and access to new social contacts, individuals with particular network ties obtain better medical care than others. Through the transmission of certain pro-medical-care values, knowledge of how to obtain those services, subsequent access to and utilization of them, people simply get superior health care which, in turn, influences their physical health.

A second possible pathway is by the direct provision of aid, services, and tangible or economic assistance to individuals. According to this hypothesis, some networks take better care of their members than others—independently of professional medical services—and it is this factor that influences a member's health status.

A third mechanism related to social integration has to do with social control and peer pressure; that is, individuals in a network frequently feel constrained to behave like other network members. Thus, people who have ties with people who smoke cigarettes, drink alcohol, are physically active, or maintain certain dietary practices may follow the patterns set forth by their group simply to maintain their group identity (not because of the health value of the behavior). Therefore, groups or networks have the potential to be either health promoting or not; and this may influence the health status of individuals.

A final mechanism is a more direct physiologic pathway by which people who are lacking ties that provide for intimacy, a sense of belonging, opportunities for nurturance, and reassurance of worth are stressed. Some individuals may respond to this situation with a changing psychological state (becoming depressed or fatalistic, for example), and the psychological state may lead to alterations in physiologic functioning. In this instance, the psychological state would be viewed as a mediating factor. The stressful condition may also directly alter physiologic patterns without notable changes in psychological states. Social networks may well turn out to influence generalized susceptibility to illness, as has been hypothesized by some (Antonovsky, 1972; Berkman and Syme, 1979; Cassel, 1976), or they may affect the course of many diseases through multiple mechanisms. In any of these cases, the biologic responses to this stressful condition may lead to alterations in both known biologic risk factors (e.g., blood pressure, serum cholesterol) and in as yet unidentified processes. These findings were reviewed at the beginning of this paper.

Relevant issues in the study of the effects of social networks on the health status of the elderly

1. Social networks and social support may well play a role in the etiology of disease; however, there is little evidence to support the notion that the elderly are *particularly* fragile and vulnerable to the effects of social isolation. This relationship must be clearly documented and the reasons for it better understood. Also, as we learn more, there may be special subgroups of the elderly population identified (i.e., those who are ill or with limited functional abilities) for whom informal caretaking is the critical factor determining institutionalization or significant declines in physical and mental health.

2. There is a difference between social networks and social support. At this time, we have very little information on those networks that are supportive. Are daughters better than sons at providing help? Do neighbors help more than we suspect? While all self-reports are colored by social response patterns, feelings of supportedness are certainly molded, in part, by psychological factors. For accurate answers to questions about which networks are used for different support functions and which are most influenced by social desirability patterns, we must await information from new studies.

3. Social networks have most often been conceptualized and measured in static terms, as if they were a stable property of an individual. Clearly, this is not truly the case. Social networks are dynamic, perhaps especially so for the older person, who is confronted with significant exits and entrances. To date, there is very little information on social network patterns over time or longitudinally. Whether people maintain certain network patterns (although individuals may change) throughout the life course is unknown. The association between earlier patterns and patterns of social relationships in old age and their respective risks to health are also unclear. Some evidence indicates that the elderly who are lifelong isolates have better mental health than recent isolates (Lowenthal, 1964). However, these data are suggestive and need to be further corroborated. It is also possible that lifelong isolation represents a cumulative risk which becomes manifest in terms of disease consequences late in life, after a long latent period. Thus, the critical aspects of network and support would be the structure during early life and middle-age. Network structure measured in old age may or may not be a good "proxy" for the extent of earlier relationships.

4. It is most likely that networks both influence and are influenced by physical and mental health. It is important to realize that social networks and support are also correlated with a multitude of other psychosocial and behavioral factors that are also associated with disease risk. The degree to which they are colinear presents not only a statistical challenge to the investigator but a conceptual one as well. To the degree that studies are longitudinal and it is possible to sort out which factor precedes the others, we will be able to solve some of these problems of colinearity.

Although space does not permit a lengthy discussion of causal inference here, in order to assess the effect of social networks on subsequent physical health prospectively, one must adequately control for baseline health status. Generally in epidemiologic studies one identifies a cohort initially free of the specific disease in question and follows up the cohort, identifying incident cases. This method poses two problems with regard to studying the health impact of social networks in the elderly. First, social networks appear to be associated with a very wide range of health outcomes. Thus, it is questionable whom one should exclude from prospective analyses, except anyone with any disorder or condition. Secondly, in the elderly this poses an additional dilemma, since so few people are totally free of disease. Therefore, in order to study this issue most fruitfully, the researcher must pay very careful attention to the development of new conditions, the rate of progression or recovery from old conditions, declines in functional ability and general well-being, instances of hospitalization and institutionalization, and, of course, mortality. By rigorous monitoring of this broad range of outcomes and assessments at baseline, the investigator should be able to identify any impact social networks might have.

Another approach would be to focus on one particular outcome, say coronary heart disease, exclude all prevalent cases, and include the assessment of social networks along with other known risk factors in subsequent analyses of incidence. By doing this for a whole range of diseases, researchers might again profitably piece together from many studies the health effects of social disconnection.

5. Finally, while social and community ties are probably important to the maintenance of health, as yet we do not have three straightforward questions which clinicians can use to predict disease risk. It is not at all clear that living alone, being single, not having family necessarily imply social isolation. In fact, the data produced thus far argue for more complex measures. It may well turn out that some kinds of support have a negative impact on health and functioning, and others have a positive impact. Furthermore, most people, even older people, on the whole seem amazingly resilient and flexible. They seem to make new relationships and make suitable tradeoffs and substitutions. Older people seem to obtain support from many different sources of contact, kin and nonkin alike. If this is true, then our task must be to uncover the circumstances under which older men and women derive adequate support.

Data bases and future research approaches

There are currently a great many studies that have included measures of social networks and support on questionnaires and are of potential usefulness for our purposes. They can be divided into three categories (table 1). The first is comprised of studies using short instruments that were used to predict mortality (Alameda, Tecumseh, Durham). While these instruments are crude and were not originally intended to measure networks and support, all three have been shown to predict mortality. Another instrument developed by Donald and Ware (1982), which is similar to them in its focus on tapping the quantity of social ties, has been shown to be reasonably reliable in a test-retest assessment. Correlations of items over a 1-year period were 0.80 for church attendance, 0.64 to 0.66 for group membership activity, and 0.4 for contacts with friends and relatives. Thus, these measures are reasonable for use in situations where networks and support are *not* the major focus of studies but are to be included with a host of other risk factors. The problem with these instruments is that they tell us very little about what characteristics of ties are important or how they are interrelated. If they do not predict, we do not know if it was due to the "crudeness" of the measurement or because of a more substantive issue.

Table 1. Types and examples of survey instruments used to measure social networks and social support

Brief instruments with predictive ability (predict physical health outcomes):

1. Human Population Laboratory Study of Alameda County (8)
2. Tecumseh Community Health Study (53)
3. Elderly in Durham County (13)
4. Rand Corporation, Social Contacts and Resouces (31)

Lengthier instruments of social networks and support used in physical and mental health studies:

1. Schedule for social interaction (50)
2. Norbeck social support questionnaire (80)
3. Social support scales (30)
4. Social support questionnaire (92)
5. Social support questionnaire (94)
6. Social networks in adult life (57)
7. Johns Hopkins study of widowhood and networks (Goldberg)
8. Establishment of populations for epidemiologic studies of the elderly (Boston, New Haven, Iowa, North Carolina)
9. Systolic Hypertension in the Elderly

Instruments to measure social networks:

1. Northern California communities study (35)
2. East York social networks project (106)
3. Attitudes and relationships in the Detroit area (64)

The next set of questionnaires represents attempts by investigators to measure, in a sophisticated way, characteristics of social networks and social support in studies concerning health outcomes. Nearly all these studies are in the field, and they have produced few results so far. They are promising, however, since they were based on earlier theoretical works on networks and support. In some of the studies, individual scales have been created; in others, such scales are currently being developed. These survey instruments take much longer to administer (minimally 15 to 20 minutes). Two approaches are typically taken to elicit social contacts. One is to ask respondents to name a number of contacts, ranging from very intimate ones to more extended and weaker ties, and then to focus questions on each of the people specifically named in the respondent's network. This approach provides rich and detailed information on a subset of a respondent's network. Although time consuming, it is the only way to develop measures of network structure, as indicated by sociologists who do social network analysis. The second approach is to ask questions about friends, relatives, and neighbors without asking the respondent to name specific individuals. This method allows the investigator to construct variables similar to those used in social network analysis but not identical to them. For example, measures of density traditionally are developed by counting the number of people mentioned by the respondent who know each other. Using the second method, density is measured by responses to one item, "How many of your friends know each other?" The advantage of this method is that it is less time consuming, but it does not provide the rich information obtained by the first approach.

Choosing instruments of these latter two types allows the investigator with a major interest in networks and support to assess these characteristics in a substantial way. These instruments have disadvantages; we do not know yet whether they will predict health outcomes of major interest, and they are lengthy. In the next several years, the items included on these surveys may well be reduced and refined as their psychometric properties and predictive ability become known. At this time, however, these instruments will allow us, most definitively, to assess which network and support characteristics are of most value.

The third set contains instruments that were developed by investigators in the field of social network analysis. They represent the state of the art in this field. They uniformly ask the respondent to name specific individuals and then ask questions concerning these contacts. These questionnaires are the most lengthy ones and were developed to describe social network configurations in different populations. Since they were not initially developed to assess health outcomes, we must question whether the characteristics of interest to these investigators are the ones that we suspect of having health consequences. If they are, we may well want to adapt these instruments for use in health surveys. If they are not, we may not need to use such time-consuming instruments.

Concerning the use of all these groups of instruments, investigators must ask themselves what networks and support characteristics they suspect are important in causing disease and disability, which instruments best capture these dimensions, and how much time they can devote to obtaining the information. At this time, there are no clear frontrunners; however, the most potentially valuable instruments are probably included in the second group. We will know more about these instruments as findings from studies emerge.

The need now is to piggyback social network and support measures into ongoing studies in which health outcomes are measured rigorously (the Systolic Hypertension in the Elderly Project is a fine example) or to supplement social surveys in which the network and support dimensions are measured extensively with careful assessment of physical health. Both longitudinal and cross-sectional studies will be valuable. From cross-sectional studies, we can learn the association between social network factors and support and physiologic markers of aging, risk factors for disease, biological responses to stress, etc. Of course, associations between these factors will be of most interest in situations where the physiologic factor is unlikely to influence the maintenance of network contact or support. Longitudinal studies will be more helpful in sorting out cause and effect relationships, but they cannot be considered a panacea either, since they can do no more to overcome poor measurement of variables than cross-sectional studies can. Both well focused cross-sectional and longitudinal studies are needed.

Social intervention in the prevention of disease

Public health efforts have traditionally focused on primary prevention. With the increased prevalence of chronic diseases such as cancer and coronary heart disease, for which there are currently many unidentifiable causes, primary preventive efforts obviously must be limited. Clearly, the identification of causal factors in these diseases is of the utmost importance. If, as growing evidence suggests, there is a relationship between diseases and the social environment, primary preventive efforts aimed at modifying the disease-promoting aspects of the social environment should be considered. Though such interventions are relatively new with regard to improving health status, there is a long history in the United States of using social intervention to improve mental health as well as social and economic well-being (Zurchen and Bonjean, 1970; Caplan, 1974). In the following discussion, intervention in the area of social networks will be taken as an example of potential interventions.

At least three routes may be taken in modifying an individual's social network, depending upon the factors influencing the network: (1) sociostructural interventions: promoting opportunities for social contact; (2) social interventions: improving opportunities and skills for social contacts; (3) psychosocial interventions: providing psychological treatment and opportunities for social contact.

A. Sociostructural intervention

Interventions directed at the sociostructural level assume that network configurations are at least in part determined by structural aspects of the social environment. Networks and the extent of social connections maintained by an individual are seen as being primarily determined not by personal variables, but by the very real lack of opportunities providing for such contact by social situations. According to this view, such social circumstances as poverty, urbanization, migration, housing situations, and deviancy may be the major barriers to making social connections. If these factors are found to be determinants of networks, several interventions might be useful in promoting adequate contacts:

1. Poverty: Poor people appear to have economic barriers which prevent them from maintaining many kinds of social connections. Lack of adequate transportation and communication channels across distances, lack of economic ability to provide for families, as well as to join organizations, may encourage isolation and social disconnectedness. Interventions in this area may be mostly economic, providing income supplements, job opportunities, and access to good transportation and communication resources.
2. Community disintegration: Frequently, because of changes in industrial sites, urban planning or renewal efforts, or population shifts, older communities begin to disintegrate, disrupting both family and community organizations. Ethnic working-class communities, communities of older people, and often even neighborhoods filled with transients have developed ways of functioning and surviving which are complex. When these communities are disbanded or relocated, new social connections are difficult to form. An example of such social disruption resulting from an urban renewal program in which predominantly Italian working-class residents of Boston's West End were relocated is poignantly documented by Gans and Fried (Gans, 1963; Fried, 1966). Appropriate community intervention may, in some cases, be a form of nonintervention. Leaving intact communities alone and helping other communities to remain intact may be, literally, the healthiest kind of action. Of course, urban planning has the potential both to alleviate unhealthy housing conditions and to promote adequate social support systems. Planning which takes into consideration the importance of both the physical and social environment might be a powerful form of intervention.

3. Deviancy: Though this word often carries a negative connotation, many people are deviants in the sense that they are placed in a position different from many of their peers, a situation which often makes it difficult or awkward for them to maintain many social ties. People who are widowed early in life, single parents, migrants who come to a country and live isolated from other people with similar backgrounds, and anyone who is surrounded by people in a different social position frequently find themselves segregated from people around them. Blau (1973), in her work on structural constraints on friendships in old age, has described this phenomenon in some depth. Two sorts of interventions are possible to increase these people's social connections: (1) Integration into the larger community through interventions aimed at increasing contact among these people and their work associates, neighbors, extended family. Examples of ways to bolster the older person's integration into an already existing community might take the form of income supplements to children of the elderly to keep them home, or adult day care and respite care. Both provide resources to caretakers to enable them to maintain their own lives and take care of the elderly. (2) Development of what has been called "an intentional community," based on some common interest. Co-ops, child-care centers, retirement communities, drug and alcohol abuse centers (e.g., Alcoholics Anonymous), Reach for Recovery, Parents Without Partners, organizations for people who are physically disabled (such as the Center for Independent Living), and communes are just some examples of groups organized for some common purpose by people who were otherwise having a difficult time maintaining enough social contacts to fulfill emotional and/or pragmatic needs.

B. Social intervention

While the only barrier against adequate social contact for some people is a simple matter of opportunity, others lack the social skills necessary to maintain and create opportunities for social contact. In fact, our culture, by encouraging independence and self-sufficiency, may in many ways be discouraging the development of such skills necessary to the development of strong and supportive social networks. For example, some men are socialized so that it is difficult for them to maintain intimate relationships. Other people are temporarily caught by a crisis, move, or job change with neither social contacts nor a vision of how to create opportunities for such contacts. Older lower class women and women from certain ethnic groups have been described as not ever being socialized to make friends outside their family. All these people are similar in that they probably have a variety of potential sources of social support of which they are either unaware or feel unable to utilize.

A form of intervention, appropriately called Social Network Intervention, has evolved which was created to deal with situations of just this nature. In this intervention, a team of intervenors assembles all members of a kinship system, all friends and neighbors, and anyone else who is of significance to the individual. The process which then ensues is complex and has been described in greater detail than is possible here by Speck and Attneave (1971).

This form of network intervention provides both opportunities and skills for utilizing the potential links in an individual's network structure. In this way, it is possible to structure networks in homes for the aging, residence clubs for younger people, and work groups in which many members are highly mobile, as well as in traditional family structures.

C. Psychosocial intervention

Although many people are isolated because of few opportunities for contact or because they lack certain social skills, some people are isolated either by choice or because serious psychological difficulties prevent them from maintaining relationships with other people. The issue of appropriate intervention for the individual who actively refuses social contact is a difficult one. Certainly, if a person does so by choice and is satisfied with his or her circumstances, no intervention ought to be attempted. After all, many people who are isolated enjoy good health, are very satisfied with their lives (Berkman and Breslow, 1983), and would be far more unhappy being forced into social situations.

For the group of isolates who would prefer having more social contacts but appear to be psychologically unable to do so, several different forms of intervention might be examined. Social Network Intervention might be appropriate under certain circumstances; other forms of family, crisis, and group therapy might also be attempted. Encouraging those individuals to engage in nonthreatening social encounters or providing protected living conditions such as halfway houses could be suggested.

These ideas are only examples of potential forms of intervention and are not presented as definitive answers to the problems of isolation and social disconnection. Rather, they are offered with the aim that people in the fields of public health, and medicine, will perceive that intervention in the social environment is not an impossible or utopian task. The issues raised here are complex and will not be resolved by a single formula or in a short time. However, if future research supports the importance of the social environment to the maintenance of health, hopefully this work will contribute to the development of sound and constructive social and health policies.

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Economic data and the analysis of health-related issues of the elderly[a,b]

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Introduction

Economic factors play a vital role for the elderly in maintaining their health and independence. The quality of life of the aged individual is in many ways a result of the allocation of available economic resources to sustain a desired standard of living. The choices the aging individual makes are in response to aggregate external economic factors such as economic growth and changes in prices, as well as individual decisions concerning consumption and savings preferences. The adequacy and availability of individual and aggregate economic data to describe such elderly economic behavior are the focus of this paper.

The paper is composed of three sections. The first section focuses on issues related to the distribution of income and wealth among the elderly. The second section discusses consumption and expenditure patterns of the elderly. The third section looks at economic factors related to access to health care. In each section the discussion will center around the availability and adequacy of existing economic data to address a series of topical issues. Introductory remarks in each section will address how various economic factors and data typically have been defined and used, and the subsequent results of such applications. An evaluation of general data requirements based on the scope of each issue will be included along with a discussion of needed data items and known data sources.

The three-part examination of data requirements will be prefaced by a discussion of the general types of economic information currently available, differences in its format, scope, and use. The discussion of data sources focuses primarily on the applicability of economic-oriented data sets. Data sets that generally can be described as primarily health oriented are, to a lesser extent, incorporated in this paper. The potential for integrating new private survey information also is highlighted.

Economic factors and health

Figure 1 presents a simple schematic drawing of the basic components and linkages related to individual health and well-being. In the discussion of various topics in this paper, the importance of economic data elements in terms of the various components and linkages in this system will be analyzed. It is important to remember that the type and pattern of health services utilization are the result of individual or collective actions. Discretionary *resources* are inputs in the health care system composed of income, assets, and wealth. These system inputs are made *available* as a result of individuals' productive efforts or by societal transfer. They are transformed into *health services*, a consumable product or service, and *utilized* to maintain or improve health status. The *effectiveness* of the allocation and subsequent consumption process is the individual's resulting *quality of life* and *state of health*. To effectively achieve a preferred state of health, the individual must have the resources available to utilize health services in an efficient and effective manner. Thus, the system is an economically motivated and directed process, and can be evaluated within such a context.

A series of economic relationships need to be examined to describe the elderly population's utilization of health care services and the impact on their quality of life. The pivotal relationships involve how availability, access, and effectiveness of health care goods and services interact as the elderly individual attempts to maintain a preferred state of health. The type of tradeoffs elderly individuals make—work versus retirement, present versus future consumption, accumulation or depletion of assets, and use of private or public facilities and programs—either directly or indirectly are related to economic factors. Although this paper focuses on the role of economic factors, the primary determinants of the elderly's health status and utilization of health services are noneconomic factors. The elderly's health status, prior and current, has been found to be the most important explicans of health expenditures and utilization. The importance of such noneconomic factors will be incorporated in the discussion in conjunction with economic factors. A complete discussion of the interaction and importance of noneconomic factors separately is, however, beyond the scope of this paper.

General data requirements

Economic information can be expressed in two principal formats. Aggregate economic data, macrodata, describe the allocation and distribution of society's total resources in response to collective actions. The value of aggregate economic data is in their use to describe the overall actions or status of a large group in conjunction with changes in the health care environment and the economy. Such measures help define

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[a] Contents are the opinions of the author and not those of the Department of Health and Human Services or the organization he works for.

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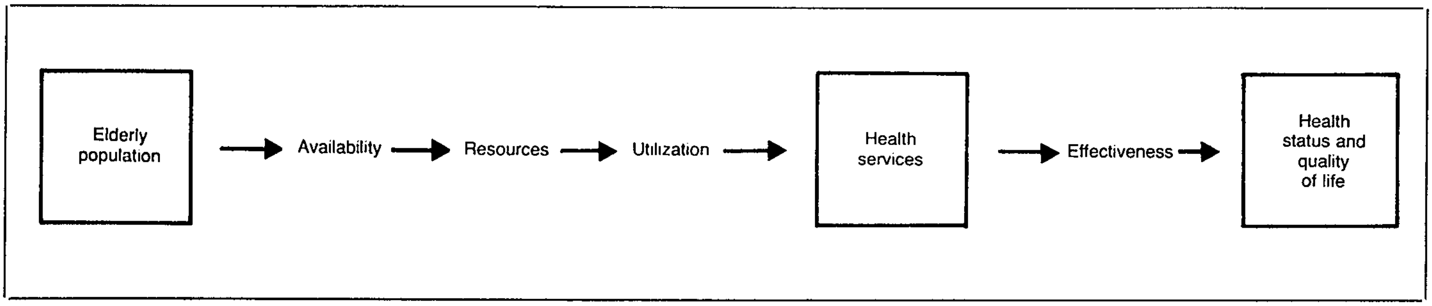

Figure 1. Components and linkages in health care system

the extent to which the resources of the economy are being allocated and consumed by the elderly proportion of society. Information about individual economic behavior, microdata, describes individuals' responses to external and personal factors, such as changes in prices or changes in individual health status. The value of disaggregated economic microdata is in their use to describe individual elderly economic behavior and preferences. It is important to be able to isolate and identify individual actions and decisions in order to ascertain how important health, health care, and quality of life issues are relative to the other uses of available individual and public resources.

Data sources

The adequacy of data sources to examine the importance of economic factors pertaining to elderly health issues has improved greatly in the past few years. Several large national surveys have been completed and are now becoming available for public use. (A nonexhaustive listing of major data sets pertaining to health and economic factors is included in appendix C.) The availability of current survey information will provide more accurate and timely information related to economic status and expenditure patterns. However, many of these new survey panels are based on a general population sample with only a limited number of elderly respondents. The heterogeneity of the elderly population in terms of economic resources, health status, and health care utilization necessitates a large broad-based sample of elderly individuals. The limited representativeness of many of the new large public data sets will restrict their use in analyzing the elderly population unless they are coordinated with other public and private data sources.

Private data sets

Large public data sets have been the primary source researchers have employed in doing analytical studies related to the analysis of the elderly. However, changing demographic, political, and legislative factors will cause the adequacy and applicability of many of these data sets to diminish. For example, recent legislation related to private retirement plans has had considerable impact on the type and availability of private income sources that are now being offered as retirement support for the elderly. In addition, these regulatory and legislative changes also will have an important impact on the way private income sources and mechanisms will be coordinated with public retirement sources such as Social Security, Medicare, and Medicaid in the future. In lieu of such changes, it seems that research and policy studies should attempt to make more use of available private data as a supplemental source to update existing data bases.

The majority of private data are gathered on a specific industry, regional, or worker-demographic basis. In most instances, health and economic data are related to changes in worker pension, health, and retirement benefits on an industry-wide, and in some cases on a nationwide, basis. Although privately gathered data are seldom nationally representative, they can be quite informative and beneficial in addressing specific questions. For example, recent changes in the rules governing retiree medical benefits have resulted in a significant shift in the type and provisions of medical retiree coverage provided by the private sector. (See Washington Business Group on Health, 1985.) Although public data gathered as recently as 2 years ago would indicate that the majority of retirees have medical coverage, they would fail to reveal that over two-thirds of the plans providing benefits have shifted from a noncontributory to a contributory basis within the last 2 years. This shift in terms of copayments will act only to further raise the elderly's out-of-pocket medical expenditures and reduce their discretionary income, important changes that need to be documented and analyzed.

Initially, the use of private data may be slowed because of issues of confidentiality. However, private sources do release and sell data as well as participate in cooperative survey projects with various public agencies. The limited use of private sources in many instances may have been a consequence of researchers not being aware of the existence of the data. Therefore, the coordination of a better informational network in this area appears to be an important step to ensure access to the most current and appropriate data. Throughout this paper, the adequacy and availability of heretofore lesser known private data to supplement or complement existing public data sources will be examined. The emphasis on private data sources, relative to better known public sources, should not be construed, however, as an argument for their exclusive use. The purpose is to reveal how such data sources can provide additional updated economic information to facilitate the analysis and understanding of elderly economic/health issues.

Appendix A provides a list of organizations, insurance companies, hospitals, and software firms now involved in the collection of health data. Appendix B gives a list of the types of data typically found in private data sets pertaining to health.

Section I

Income and wealth

The distribution of income and wealth among the elderly reflects the receipt of income from a wide range of sources (Schieber and George, 1982). These sources can be grouped into five general categories:

1. Earnings from full- and part-time employment.
2. Financial assets and other wealth, such as home equity.
3. Employer pensions, including private and public sector benefit plans, individual retirement accounts (IRA's) and Keogh's.
4. Social Security, including retirement benefits under the Railroad Retirement Program.
5. Cash and in-kind benefits from public assistance programs such as Supplemental Security Income, Workers' Compensation, Medicare, Medicaid, food stamps, housing, energy assistance programs, family and external private support networks.

Table 1 presents the major income sources for aged individuals based on the latest study of Social Security beneficiaries (Reno and Maxfield, 1985). Panel A of the table gives the percent of elderly receiving income from various sources, based on marital status. Panel B of the table provides the mean and median levels of these various income sources. The distribution of major income sources presented in table 1 provides the latest information as to the composition of the elderly population's financial resources.

The distribution of income sources varies among specific subgroups of the elderly because of prior work history, savings patterns, asset accumulation, and changes in the economic environment. The level of some types of income, such as earnings, can be altered by the individual modifying the number of hours worked or by simply choosing to retire. On the other hand, some income sources are fixed and vary only in response to the action of outside forces. For example, the level of an employer-provided pension is based on the individual's past work history. It is subject to change only at the discretion of the employer. Therefore, it is important in evaluating the distribution of income to carefully assess the elderly's ability and inability to control various income sources.

The assessment of the distribution of income and wealth of the elderly requires specific economic data elements that describe the major income categories (Grad, 1984). Employment earnings from full- or part-time work are important in determining the extent of labor force involvement, eligibility for Social Security, and private pensions. Financial assets in the form of accumulated savings, investments, and home equity are necessary to develop a measure of the net worth of the individual or family unit. Social Security benefits, employer pensions including private and public sector plans, individual retirement accounts, and Keogh plans help to define retirement income adequacy. Finally, cash benefits in the form of Workers' Compensation, veterans' benefits, public assistance cash payments, and in-kind benefits such as Medicare and food stamps help to determine the total financial resource base available to the elderly.

Data pertaining to elderly income also must be compared carefully in terms of equivalent economic units. Significant income differentials can result as a consequence of family size and composition, living arrangements, and age. The presence of one or more wage earners, pension recipients, or nonaged individuals can affect current and future income levels and assets. Individuals' living arrangements affect income in relation to the proportion of income needed to maintain a preferred standard of living in their own home, in an institution, or living with family or friends. The age of the individual affects income in terms of the rate of income and asset depletion, eligibility for public and private pensions, and the cost of health care. All of these factors alter the composition and receipt of income and need to be considered in the analysis of the elderly's economic status.

Data sources

Data sources on cash and noncash components of the elderly's income are numerous. Two recent nationally representative surveys containing such information are the New Beneficiary Study (NBS), conducted by the Social Security Administration in 1981, and the ongoing Survey of Income and Program Participation (SIPP), now being directed by the Bureau of the Census. NBS provides an indepth look at a new cohort of Social Security beneficiaries 62–72 years of age. Extensive information is provided in this cross-sectional sample on individual employment history, income, assets, and individual health. The SIPP survey is designed to provide information on income based on money and nonmoney income sources.

SIPP should become the primary source of economic information as its sampling frame expands, replacing information gathered in Current Population Surveys (CPS). The SIPP sampling procedure will interview selected households every 4 months, gathering an extensive array of economic information over a 2½-year period. This sampling procedure will give the file a longitudinal dimension that previous CPS surveys lacked. In addition, SIPP's sampling procedure will help to identify changes in both household composition and income over the survey period by continuing to interview individuals as they leave or enter the surveyed households.

Data elements

In the use of large data sets such as the NBS, SIPP, CPS, the Retirement History Survey (RHS), and the Program Study of Income Dynamics, income and wealth typically are analyzed in terms of some measure of economic well-being or retirement income adequacy. Economic well-being usually

Table 1. Receipt of income shares from major sources by marital status

Panel A

Income source	*Married men and their wives*			*Unmarried beneficiaries*		
	Couples	*Husbands*	*Wives*	*Total*	*Men*	*Women*
Total number (in thousands)	580.0	580.0	580.0	295.9	112.5	183.4
Percent receiving income from						
Social Security	98.3%	97.6%	51.0%	97.1%	97.6%	96.7%
Pensions	55.8	53.1	9.7	42.4	41.3	43.1
Private	38.3	36.1	5.9	26.8	26.0	27.3
Public	21.0	19.0	3.9	16.5	16.6	16.5
Assets[1]	83.8	(2)	(2)	69.1	63.0	72.8
Earnings	43.7	26.9	26.7	27.1	21.9	30.2
Other sources[3]	16.5	(4)	(4)	15.2	16.3	14.5
Welfare	2.0	(4)	(4)	7.1	6.8	7.2

[1] Includes receipt of income from at least one of the following: money market accounts, certificates of deposit, All Saver's certificates, checking or savings accounts, credit union accounts, stocks, bonds, annuities, IRA or Keogh plans, income from rental property or roomers, loan repayments, and estate, trust, or royalty income.
[2] Data were collected for the combined asset holdings and income of couples.
[3] Includes receipt of at least one of the following: veterans' pensions or compensation, Workers' Compensation, unemployment insurance, black lung benefits, contributions from others within or outside of the household, and welfare (Supplemental Security Income, Aid to Families With Dependent Children, and food stamps).
[4] Not tabulated separately.

Panel B[1]

Income source	*Percent receiving*	*Monthly income amount for recipients*	
		Mean	*Median*
		Married men and their wives	
Social Security, total	98.3%	$ 671	$ 646
Only husband receives	47.3	500	504
Both receive	50.3	836	838
Only wife receives	0.7	324	304
Earnings, total	43.7	972	617
Only husband receives	17.0	803	418
Both receive	9.9	1,613	1,054
Only wife receives	16.8	766	666
Pensions, total	55.8	656	490
Only husband receives	46.1	640	471
Both receive	7.0	899	757
Only wife receives	2.7	332	214
Asset income	83.8	539	180
		Unmarried men and women	
Social Security	97.1%	$ 432	$ 421
Earnings	27.1	588	392
Pensions	42.4	426	291
Asset income	69.1	299	99

[1] Percentages in panels may vary due to rounding.

SOURCE: Based on tabulations from: Distribution of income sources of recent retirees: Findings from the New Beneficiary Survey. *Soc. Secur. Bull.* 48(1):10–13, Jan. 1985.

is defined by two different, yet interrelated measures: objective and subjective assessments of income adequacy. Objective economic status is measured in terms of total family income, including gross income from employment, rent, interest, dividends, Social Security, other private and government pensions, welfare benefits, and intrafamily transfers. A complete measure of objective economic status also includes financial assets, defined as stocks and bonds, loans and mortgages, checking and savings accounts, life insurance, and annuities. While home equity is not considered an easily accessible liquid asset to most elderly people, it is usually included in a measure of economic status to obtain an overall gross measure of net worth.

Subjective measures of economic well-being attempt to reveal the stress-inducing effects of changes in financial status. Ideally, subjective measures capture elderly persons' perceived income adequacy, i.e., their ability to get along on their resources. They offer a different indicator of the elderly individual's perception of income adequacy in terms of his place in the income distribution and his ability to maintain his standard of living.

A complete measure of economic status would take into account both objective and subjective differences in income, wealth, and consumption. Incorporated in this measure would be adjustments for taxes, differential costs associated with working, the value derived from owner-occupied housing, and the value of in-kind benefits. The measure would then be standardized for the size and type of the household. However, there are not adequate data available to measure all the variables mentioned, or even agreement on the methods needed to measure them. The New Beneficiary Survey and the Survey of Income and Program Participation are two new data sources that provide extensive information on the necessary income compounds needed to evaluate the distribution of income and wealth. If the NBS can be matched with administrative records to provide information on earnings profiles and work histories, it can be a valuable cross-sectioned data source for development of a complete measure of economic status. As soon as SIPP panels are completed and released, it also will be an important data set for analytical research related to economic status. At present, use of the Retirement History Survey matched with Social Security records is a viable source of economic data for analysis of economic status in terms of both objective and subjective measures.

Income measurement

The most common approach currently used in evaluating the elderly income distribution is to define the individual's objective economic status in terms of a retirement income adequacy standard. The value of using some type of income adequacy standard is that it provides a frame of reference for evaluation among different subpopulation groups of the general elderly population. Three different types of standards are used: relative, absolute, and wealth measures of income. Relative standards usually base income needs on the adequate replacement of some proportion of preretirement income. Absolute income standards are based on judgments regarding the income level adequate to maintain a minimum subsistence standard of living. Wealth measures base adequacy on the amount of all available income sources necessary to sustain individuals during retirement or old age.

Whatever measure of income adequacy is used, complete and detailed information is needed on all forms of cash income, asset values, and in-kind benefits. In relation to income survey information, two general criticisms can be made about reliability and validity of elderly data. Similar to nonaged individuals, the elderly understate their economic status. Elderly individuals tend to have limited recall about the type and value of their income sources. They also have limited knowledge about the present value of their asset holdings, especially for stocks, bonds, and home equity. Therefore, the adequacy of such data must be closely scrutinized to determine whether it is representative of the elderly's asset base.

The poverty line

The poverty line, an absolute measure of income adequacy, has become the most widely used income distribution standard. Its extensive use reflects the fact that it is the U.S. Government poverty standard. It is adjusted for family size and characteristics, which other standards are not. Unlike the Bureau of Labor Statistics family budgets, an official poverty income level has been established for elderly families. Finally, unlike the relative income replacement rate concept, the poverty line measure can be used in evaluating the income levels of workers as well as nonworkers.

The poverty line has been criticized as a valid measure of income adequacy because of the definition of income used in its construction. Income is defined as all family members' cash income, including employment earnings, earnings from financial assets, and cash transfer payments. There are no adjustments for income tax payments or any in-kind benefits. The omission of taxes and the value of in-kind benefits has a substantial impact upon the viability of this measure as an indication of the elderly's financial status.

Taxes

The preferential tax treatment afforded the elderly provides for substantially higher tax-free income levels and discretionary income. Under current law, single elderly have a tax-free income of $10,640, including Social Security benefits, while elderly couples have a tax-free income of $18,990. In contrast, nonelderly single individuals have a tax-free income of $3,560, only 33 percent the size of the elderly exempt tax level income. Furthermore, nonelderly couples claiming four dependents have a tax-free income level of only $10,598, 56 percent of the elderly couple's exempt tax level income.

The impact of the special tax provisions also is substantial for the low-income elderly. The poverty line for nonelderly singles is $5,800, while the level of tax-free income is $3,560, making $2,240 subject to possible taxation. The poverty threshold for elderly singles is $5,400, but their income is not subject to tax through $10,640. A similar treatment is found for couples. The poverty line for nonelderly couples with four dependents is $15,000, with income through $10,598 exempt from taxes. The poverty line for elderly couples is $6,800, but with an allowance of $18,990 of tax-exempt income. Therefore, without consideration of elderly preferential tax provisions, estimates of the distribution of the elderly's real economic status and their relative poverty status will be biased upward.

A valuable data source to refine and analyze the real effects of taxes on the elderly's disposable income and relative income status is the March 1983 Current Population Survey data. The data file is the March 1983 CPS microdata, expanded to include estimated taxes paid (Federal and State individual income taxes, property taxes on owner-occupied housing units, Social Security taxes, retirement taxes) and after-tax money income. In addition, supplemental data are provided on work experience, types and amounts of "before tax" money income received during the previous calendar year, and information on nine noncash income sources.

In-kind benefits

The omission of the value of in-kind benefits in the evaluation of elderly income and poverty status is quite significant. If a person receives an in-kind benefit, his well-being is improved. However, the magnitude of the improvement is difficult to evaluate. Unless the individual can sell or trade his in-kind benefit, no substitute for such a benefit is available to estimate its worth. It may or may not have an equivalent cash value to that individual. Therefore, a dollar of cash may be worth more to the recipient than a dollar's worth of an in-kind benefit. The extent to which one measures the differential is based on the value one assigns to the benefit.

One valuation approach gives in-kind benefits "full market value," i.e., a $1 food stamp coupon is worth $1. A second evaluation approach, called the "poverty budget share," values in-kind benefits equivalent to the amount usually spent on such items by people at the poverty level. A third evaluation method, called the "cash equivalent approach," values benefits by the amount of cash the recipient would accept if he could trade his benefit for cash. Estimating the value of in-kind benefits with any one of the three methods significantly alters poverty rates among the elderly (Clark et al., 1984).

Table 2, Panel A, presents poverty rates for elderly singles and couples with income defined as combinations of different cash, in-kind benefits, and wealth values. The inclusion of selected income sources can reduce the poverty rate from 15 percent to 60 percent. Using only the cash income definition, 9.4 percent of elderly married couples and 26.3 percent of single persons are defined as living in poverty. The addition of asset income, benefits, and taxes into the income definition results in the poverty rate dropping to 5.4 percent for married couples and 14.4 percent for single elderly persons. Finally, the inclusion of Medicare and Medicaid values causes the poverty rate to fall to only 3.7 percent for married couples and 11.5 percent for single elderly individuals.

Alternative income standards

The use of alternative standards of income adequacy also can result in widely varying poverty rates. Panel B of table 2 presents the percentage estimates of elderly families with annual incomes below four different income standards in 1979 (Schieber and George, 1982). The four standards are:

1. The official poverty line.
2. The revised Orshansky Index.
3. The Bureau of Labor Statistics (BLS) lower, intermediate, and higher standard of living budgets for elderly couples.
4. Minimum wage index.

The poverty level is set at three times the cost of providing the economy food plan to a family unit, updated to reflect price changes of food budget items. The Orshansky Index is a revision of the poverty line family unit concept which uses a more recently developed food plan with a ratio of total expenditures to food expenditures of 3.4:1. The BLS Elderly Couples Budgets are based on the cost of maintaining alternative living standards by the purchase of a typical market basket of goods consumed by the elderly. The minimum wage standard is based on the annual earnings for full-time workers paid at the minimum wage.

Based on income, defined as cash income only and the after-tax value of cash income plus in-kind benefit values and the potential annuitized value of assets, the four adequacy income standards indicate widely different proportions of elderly individuals and families below the poverty income level. In reference to the more generous definition of income that includes in-kind benefits and asset values, the revised Orshansky Index indicates nearly twice as many elderly in poverty than the official poverty line standard indicates. Use of the minimum wage index indicates three times as many elderly families, 24.6 percent, had annual incomes below the poverty

Table 2. Poverty rates among elderly married couples and single persons under alternative income definitions and standards

Panel A

Income definition	*Married couples*	*Single persons*	*All elderly families*
Total cash income	9.4%	26.3%	18.5%
Medicare and Medicaid values not included in income definition			
Cash income, food stamps, and housing assistance	8.3%	22.9%	16.2%
Cash income, in-kind benefits, and annuitized wealth values	5.3	14.3	10.2
Cash income, in-kind benefits, and annuitized wealth values, less taxes	5.4	14.4	10.2
Medicare and Medicaid values included in income definition			
Cash income, food stamps, and housing assistance	5.6%	18.3%	12.4%
Cash income, in-kind benefits, and annuitized wealth values	3.7	11.5	7.9
Cash income, in-kind benefits, and annuitized wealth values, less taxes	3.7	11.5	7.9

Panel B

	Married couples		*Single Persons*		*All elderly families*	
Alternative standards	*Cash income only*	*Adjusted income*[1]	*Cash income only*	*Adjusted income*[1]	*Cash income only*	*Adjusted income*[1]
Official poverty level	9.4%	3.7%	26.3%	11.5%	18.5%	7.9%
Revised Orshansky Poverty Indexes	12.9	9.4	26.6	19.3	20.4	14.8
BLS Elderly Couples' Low Budget	12.6	9.4	N/A	N/A	N/A	N/A
Minimum wage index	13.0	9.7	50.3	37.5	33.0	24.6

[1] Income includes the after-tax value of cash income, the value of in-kind benefits, and the annuitized value of wealth.

SOURCE: ICF, Inc., analysis for Employed Benefits Research Institute of March 1980 Current Population Survey data.

income line. Using cash income only as the income measure results in a dramatic increase in the percentage of elderly in poverty. Over one-quarter of the single elderly are defined to be in poverty using the official poverty level and the Orshansky Index. The use of the minimum wage index results in one-half of the elderly being defined with incomes below the poverty line.

Home equity

Another important component of the elderly individual's wealth holdings is homeowner equity. It was estimated in 1981 that approximately 70 percent of the elderly own their homes. This provides a substantial, yet in many cases, an illiquid asset. The problem of illiquidity of home ownership stems from the fact that the elderly homeowner would have to either sell or take out some type of loan to gain use of his net home equity. As an alternative, reverse annuity mortgages have been proposed as a way to alleviate the problem. The idea behind the reverse annuity mortgage is that an elderly individual sells his home to a bank or lending institution. In return, the elderly homeowner will be paid a monthly stipend based on the value of his home and be able to remain in his home for a specified period of time or until his death. Upon death or the end of the specified period, the payment of the stipend would terminate and the home and the remaining equity in the home would go to the financial institution holding the house deed. The advantage of this type of arrangement is that it allows the elderly to tap home equity as a source of money income. A major drawback with such arrangements is the difficulty in estimating the payout time period. Secondly, a substantial number of elderly homes are not attractive to financial institutions because of their location and/or condition. A good illustration is among the low-income elderly homeowners. The vast majority of these elderly are in rural areas or the inner city. Although over one-half of this population own their home, the attractiveness of these older type dwellings in terms of an investment for a financial institution is quite limited.

In the future, reverse annuity mortgages may become more viable as an increasing proportion of elderly are homeowners in outlying suburban areas. As these individuals age, reverse mortgage arrangements may become attractive to financial institutions and act as a new vehicle for increased liquidity for this select group of the elderly population. However, these elderly typically are middle and higher income elderly, who, as a group, are not in the same financial need as low-income elderly, the group that would benefit proportionately much more by such arrangements.

The analysis of housing equity as a potential income source is restricted by the availability of reliable data. Various data sets do provide housing information for the elderly population. Matching county data based on the City/County Data Book with various Social Security and census files would be one way to look at the relationship between elderly homeowners and the income characteristics of the neighborhood. However, the difficulty with the use of such data is the reliability of the home's assessed value, its condition, and its potential market value. Finally, a series of estimation problems related to financial markets makes anything but broad aggregate findings difficult to verify in such an analysis.

Wealth profiles

Over the life cycle, individuals accumulate wealth (i.e., income-producing financial assets) through several mechanisms, such as savings, annuities, pensions, certificates of deposit, money market funds, securities, stocks and bonds, corporate equities, and life insurance. In examining the distribution of wealth, it is important to correlate changes in wealth holdings relative to various life events, such as retirement, death of spouse, and changes in health status. Interest in wealth accumulation relative to health has increased because of the need for additional information about the effect of changes in health on the depletion of wealth holdings, especially in terms of the exhaustion of assets to cover chronic and long-term care health expenditures.

Most studies of wealth accumulation have used cross-sectional survey data. Such survey information, however, introduces a selectivity bias into the analysis by looking only at surviving members of a particular cohort. As a cohort ages, the survivors represent an increasingly healthy proportion of the original sample. Healthier individuals tend to accumulate more wealth to provide for longer retirement periods. As a result, a spurious positive correlation between wealth and age has been observed.

The use of longitudinal data from retirement to death to determine age-wealth profiles and the correlation with health status is one approach to try to correctly analyze the problem. One data source to develop wealth-age profiles is the longitudinal Retirement History Survey (RHS). The RHS collected information on the net worth of respondents. It includes data on the value of owner-occupied housing, equity in business or from the net value of other property holdings, cash and financial assets (including stocks, bonds, bank accounts, checking accounts, and loans) minus total household debt. The RHS also provides extensive information on pensions and annuities. The ability to match the RHS with Social Security administrative records also enables calculation of earnings profiles. Although the use of RHS is hampered by incomplete data for some of the survey panels, it still may be the best available source at present to use in this type of analysis. With the release of the complete SIPP file and the new Survey of Consumer Finances, two additional data sources will become available to help develop wealth profiles and address concerns related to selectivity bias.

Projected income and wealth distributions of the elderly

In looking at the distribution of income and wealth for future elderly cohorts, it is evident that many of the forces that help determine the economic status of today's elderly will undergo substantial change. Improvements in health and life expectancy will make possible extended worklives, resulting in higher lifetime earnings profiles and greater accumulations of work-related benefits, income, and assets (Schieber and George, 1982). Extension of the working life also may be encouraged by employers as the number of younger workers declines and employers try to retain quality older workers.

The possibility of longer worklives may well be offset, however, by some countervailing forces. The most significant will be the continuing early retirement trend, especially among males. For the past 20 years, men have been leaving the work force at the earliest possible age based on receipt of retirement benefits. The trend toward early withdrawal from the labor force also may be exacerbated by the increased prevalence of dual career families. As the number of women in the labor force continues to grow, dual earner families should be able to take greater advantage of tax-deferred savings arrangements, such as Individual Retirement Accounts and 401(k) plans. These savings vehicles will provide new additional sources of retirement income, providing the means to retire early and maintain a desired standard of living.

Eligibility for private pensions also is expected to increase from slightly less than one-half to nearly three-quarters of the retiree population by the turn of the century. Increased private pension coverage as well as the expansion of provisions that expand joint survivor coverage and retiree medical benefits will act to ensure broader and more comprehensive retirement income security. Finally, the increasing prevalence of coordination of benefits among dual career families, i.e., having coverages between spouses coordinated to eliminate overlap, will help create more efficient and comprehensive benefit coverage. All of these factors should contribute to an improving economic status among future elderly.

The projected growth in various sources of income and accumulated wealth may be diminished somewhat by the interaction between public and private income and support programs. At present, Social Security provides the major source of income for nearly one-half of the retired population (Clark et al., 1984). The combination of Social Security benefits with the value of Medicare benefits accounts for more than one-half of the total retirement income for all but the wealthiest retirees. As various factors come into play and these programs are changed in terms of eligibility, coverage, and benefit levels, the direct impact upon the retirees' economic status could be significant. For example, legislative changes now being considered will eliminate and restrict many types of deferred compensation arrangements. With such changes, employers will provide more cash income but less generous types of benefit and savings retirement vehicles, resulting in lower future levels of the elderly population's savings and wealth. Moreover, the potential burden that health costs could place on all private employers may well result in the continuing reduction, if not total exclusion, of health coverage from the retiree benefit package. If this occurs, increasing pressure will be put on the public Medicare system and the elderly population itself to pay increased private insurance and out-of-pocket expenditures.

The analysis of future patterns of income and wealth requires detailed statistical information on labor force patterns of men and women. Longitudinal socioeconomic survey data that can be statistically or exactly matched with earnings and work history data would provide the most appropriate information. Complete data of a longitudinal nature concerning work histories also will help evaluate the role and impact that health has on work force patterns and future retirement income and wealth. Finally, work and earnings data that describe not only the type of private income support provided but also the characteristics of those income support vehicles would help clarify the extent to which future income needs will be met by private support mechanisms.

The adequacy and availability of data elements to analyze future elderly income issues continues to improve. Earnings and work history data have been made available by the Social Security Administration to match with the RHS. Employment, income, asset, and pension coverage information is available in the Department of Labor's Level of Benefits Survey and the Pension Beneficiary Master File. Another data source, the Survey of Consumer Finances, also provides extensive asset, wealth, work, and pension data. Finally, the recent supplement done in conjunction with the March 1983 CPS Survey is a new data source for information on pension eligibility and coverage.

Privately generated survey data related to income sources, pension eligibility, coverage, and plan characteristics are another source yet to be fully exploited. Information on individual earnings and work histories, pension benefits, and integration with public pensions is available. Although most private data sets are not designed to be nationally representative, characteristic profiles can be developed from these private data sources that can be used to describe key components of income and wealth for select populations of future retirees. Perhaps the usefulness of private data best can be illustrated in terms of postretirement medical benefits. Currently, over four-fifths of major employers provide some type of retiree medical coverage. However, in the past 2 years nearly three-fifths of these employers have altered their retiree medical plans, increasing retiree copayments and offering less generous coverage (Wyatt Company, 1984). It is such changes that need to be more closely examined in order to better predict the elderly's future health care utilization and quality of life. Private data constitute one potentially valuable source of such information. The types of private data available in relation to health and medical utilization are presented in table 3.

Table 3. Economic data in private surveys

Pension benefits	*Economic data*	*Medical data*
• Annual benefit accrued at retirement • Coordination and size of pension and Social Security benefits • Benefits as percentage of final pay • Postretirement benefit increases • Postretirement death benefits • Joint survivor benefits	• Average lifetime earnings • Work histories • Earnings profiles • Retirement patterns – Early – Normal – Late • Income replacement levels	• Pre/post-retirement medical coverage – Coverage limits – Continuations – Coordination with Medicare • Dental coverage • Flexible health plans – Choice of low or high options • Utilization patterns

Section II

Consumption and savings in later life

The basic decision the elderly individual makes in terms of income and expenditures is how much to allocate for the purchase of goods and services or to save. Consumption depends on the amount of income available, existing prices, and personal preferences relative to the goods or services needed. Savings depend on the availability of income in conjunction with the expected rate of return on the money invested and its perceived use.

Elderly expenditure patterns differ in comparison to the general nonaged population. Not only do elderly households spend less, they spend different proportions of their income for certain items relative to younger individuals. To examine how consumption and savings decisions change over time, it is necessary to look at the impact of various socioeconomic factors on expenditures. The availability of different income sources, such as public and private pensions, private insurance, and cash and in-kind benefit programs modifies the way the elderly consumer allocates his income. Reduced household size and labor market earnings also change the elderly household's consumption and savings patterns (Clark and Schrimper, 1984).

A major contributing factor to changes in the type and size of expenditures made by the elderly is their health status. Health status has been found to be a principal factor responsible for a reallocation of expenditures away from such items as apparel, transportation, and recreation and toward health care, insurance, and personal care. The examination of health and health-related expenditures is, however, complicated due to several specific data problems. Survey information on elderly expenditure patterns generally does not include specific price and quantity data. Without some disaggregation of expenditures, relative price movements are difficult to discern. For example, if the price of prescription drugs goes up while the price of physicians' fees declines, the response of the elderly consumer well may be masked if an aggregate medical services expenditure category is used to analyze elderly health expenditures. Furthermore, comparing changes in expenditures requires differentiating the effects of inflation from changes in consumer preferences due to age.

The most reliable and current data source for analyzing general elderly expenditures is the Consumer Expenditure Survey, conducted in 1980 and 1981. The survey provides comprehensive expenditure data which can be used to establish benchmarks for determining different expenditure patterns and the effect of differential changes in relative prices among subgroups of elderly households. The RHS is another data set that can be used to look at differential expenditure patterns. By using this longitudinal sample, one can evaluate changes in expenditure patterns in response to a host of both market-related and institutional factors, such as impact of eligibility for Medicare on consumption of both personal and subsidized health care. The drawback to the RHS information is that it is based on respondents' recall over the past year, raising concern about its completeness and reliability.

Two other large public data sets that provide extensive and detailed information about types of health care, services consumed, and the amount of dollars expended for such care are the National Medical Care Utilization and Expenditure Survey (NMCUES) and the National Medical Care Expenditure Survey (NMCES). The NMCES data set is a useful source of survey information on insurance coverage, use of health service expenditures, and sources of payment based on a national sample of over 40,000 individuals. Extensive economic and demographic data also are included in the data set. A sample group of approximately 4,560 persons ages 65 and over is included in the NMCES sample group, providing an adequate elderly survey population to address a number of health expenditure questions among specific subpopulations of the elderly. NMCUES is a second national health care survey that focuses directly on health-related characteristics of Medicare and Medicaid beneficiaries. It combines field and survey information collected directly from respondents and existing administrative data systems. This dual aspect of NMCUES is important because it gives detailed statistics on beneficiary characteristics and out-of-pocket expenditures that are not available from other data or administrative sources.

The NMCUES data are based on three separate survey components: a randomly selected national household sample, selected State Medicaid households, and Medicaid and Medicare administrative records linked to the national and State sample respondents. Through a series of five interviews, information was obtained from each household on the subject of sociodemographic characteristics, utilization, expenditure, and mobility for the calendar year 1980. NMCUES also gathered information related to health care access, health status, out-of-pocket expenditures, diagnosis and surgical procedures, income and employment, and health insurance coverage. The usefulness of the NMCUES sample is that it allows for analysis of different groups in terms of their health insurance coverage, poverty level, and other sociodemographic characteristics. The NMCUES survey is limited, however, in that it does not have a large elderly sample or include institutionalized individuals.

Health expenditure patterns

A number of factors can be correlated with the changes in health care expenditures among the elderly. One factor responsible for the increasing and disproportionate share of health care spending is a payment structure that tends to distort the typical income-consumption pattern associated with the purchase and consumption of most goods and services. Although employment status and money income influence the elderly's ability to finance consumption of health care, it is the availability of third-party reimbursement that alters the typical income-consumption link. The presence of a third-party payer has resulted in more health care being utilized with limited concern for price than would otherwise be the case. The almost universal eligibility for Medicare benefits, the availability of Medicaid, and increasing coverage through Medigap private insurance have effectively reduced concern for cost constraints and have resulted in increasing aggregate health expenditure and utilization patterns.

Numerous studies have been done using the Health Interview Survey, Medicare Administrative Data, the NMCUES and NMCES data that analyze various aspects of expenditures and utilization patterns related to third-party payment and individual out-of-pocket expenditures (Cafferata and Meiners, 1984; McMillan and Gornick, 1984; Dobson, Scharff, and Korder, 1983; Kovar, 1983). The findings from these studies could be verified and expanded by analyzing aggregate as well as individual elderly health care expenditures from another perspective, by making use of health care data from the health care provider community. In general, three types of data are available from the health care community: claims data related to benefits or entitlements; clinical data related to individual patient assessments or medical histories; and program management data related to monthly admissions and discharges. These data are used extensively now by employers to identify areas of overutilization and excessive costs for current and retired employees. It also could be used to verify and test hypotheses about elderly and nonelderly utilization patterns and expenditures related to third-party payments and out-of-pocket expenses.

Privately sponsored surveys and data projects also have evolved in response to employers' needs for improved data collection and data base systems to deal effectively with health care cost containment. For example, an independent health research organization, The Health Research Institute, began developing a national statistics data base project in 1982. The Institute solicits claims data from employers, edits the data, and then provides feedback to employers and carriers. At present this data base has medical information on over 10 million lives. Other types of organizations that also have become involved in data collection and analysis are employee benefit consulting firms, data consulting firms, insurance companies, third-party administrators, multihospital systems, health care software firms, and professional review organizations, including Foundations for Medical Care. A representative list of various types of privately oriented firms involved in the process of gathering health cost and utilization data is included in appendix A.

The fact that private organizations are gathering data on a large-scale basis has made many new additional data sources of potential use in health care analysis now available. Such data bases are of interest because of their focus on the problems of health care costs and utilization from an employer or health care provider perspective. They also are important as a source of information on the impact of the emerging alternatives to the traditional health care delivery systems such as health maintenance organization arrangements and the impact of various cost-containment procedures. With the utilization of such data, a wider range of questions can be addressed and analyzed related to the aged's health care use and expenditures.

Health care utilization, expenditures, and functional status

The elderly's expenditures for health care are correlated with the increasing incidence of chronic disease, acute conditions, and functional impairment. The demand for health care services and related expenditures are, however, subject to wide variation among the aged population. To clarify such variation, several important aspects of utilization related to health status and health care expenditures must be addressed.

One important aspect of utilization is the correlation between differences in functional capacity and personal health care expenditures. The tradeoffs the elderly make during a period in their life when they are in a declining financial position and are faced with buying increasingly expensive health care to maintain, let alone improve, their health status is a key component to understanding utilization. Health expenditures should be correlated with functional capacity to determine whether the health care being purchased and utilized by different economic subgroups of the elderly is beneficial. Not only should the level of expenditures be analyzed, but the type of health care also needs to be evaluated. Several researchers have addressed these issues, primarily focusing on health-specific factors using the NMCES and NMCUES data sets (Kovar, 1983; Berk and Wilensky, 1984; Berk, Cafferata, and Hagan, 1984; Kasper and Barrish, 1982; Farley, 1985).

From an economic perspective, the observed behavior of the elderly in terms of health care utilization, expenditures, and functional status also has been examined utilizing different explanations of individual behavior (Grossman, 1972; Menefee, 1980; Menefee, 1985). One approach looks at the relationship between age-related health changes and the perceived value of additional expenditures on health care. This approach defines health care as a priority consumption expenditure. Expenditures on health care services are viewed as an investment that is likely either to result in improved functional status or at least to ameliorate functional decline. Therefore, elderly individuals invest in health care because they perceive that they can slow the loss of their functional capacity. A second, somewhat seemingly unrealistic, approach suggests that the elderly consider personal health expenditures in an objective context. An expectation of a decline in functional capacity with age is assumed. Possibly faced with limited financial resources and/or access to care the elderly consider increased investments or expenditures in health care unlikely to reverse or change health or functional status significantly. Therefore, no attempt is made to offset the decline in functioning by continually increasing individual expenditures on health care services.

The use of these alternative views about the relationship between functional status and health expenditures results in very different findings. The first hypothesis suggests that older adults will increase investment and expenditures on health care based on the perception that additional expenditures will reduce or limit changes in their functional capacity. Adopting such an approach would restrict an individual only in terms of his available economic resources. In contrast, the second hypothesis suggests that age-related reductions in health care expenditures represent a logical response to the reduced value of increased health care expenditures to offset declining functional capacity with age. In this framework the increasing costs of medical care and/or limited individual resources are of secondary importance relative to the individual's belief that increasing health care expenditures are inefficient.

Analyzing functional capacity and health expenditures in either context requires a data source containing a wide range of multiple indicators of health status as well as detailed health expenditures data. Notwithstanding the problem of defining functional capacity, many data sets do contain multiple indicators of physical mobility, work-related impairments, mental outlook, sense of happiness, and capacity for self-care. Such information can be adapted to measure various dimensions of functional capacity. Past research has found that the most reliable use of such information involves the development of some type of functional capacity index to be used in a multidimensional assessment strategy of functional ability (Fillenbaum and Maddox, 1977; Fillenbaum, 1979). With such indexes, individuals can be classified in terms of physical, behavioral, and self-care functional capacity. Furthermore, the adaptability of these functional indexes for use with various data sets, specifically the RHS, has provided a viable data source to perform longitudinal analysis of functional capacity and health.

Finally, a somewhat different, yet potentially valuable way to look at aggregate patterns of elderly health costs is to forecast the incidence and prevalence of chronic diseases customarily associated with the elderly population. From an economic perspective, the value of estimating the distribution of chronic diseases is to refine the cost estimates for publicly funded and private third-party insurance contracts and, to a lesser extent, estimates of future capital outlays for health care facilities.

The development of such aggregate estimations of health costs has been proposed by Manton and Liu (1984) through the application of bioactuarial models. The attractiveness of using such a modeling framework is that it offers an estimation approach distinct from traditional economic projection methodologies. It provides additional information that can be drawn from existing census, epidemiological, and biomedical data about how private as well as public resources and funding should be allocated to improve the health care network. Further, linking the costs of health care with various states of chronic illness will facilitate forecasts of future costs associated with morbidity and disability among the elderly. With the projected deficit in the Medicare trust fund and continued reductions in private pension provisions for retiree medical costs, additional information on the trends in elderly health costs will be useful benchmarks in assessing future total health care costs.

Section III

Access to medical care

The enactment of Medicare helped reduce the financial barriers that increasingly had limited the elderly's access to adequate medical care. In addition, the commitment to provide adequate health care facilities, spurred by an expansive building program of hospitals during the 1950's and 1960's period, increased the size of the health care network. The increased provision of health care facilities and the expanded public health benefit structure made quality health care more accessible to the majority of older adults.

A thorough analysis of the distribution of health care facilities in a spatial context, however, reveals limited availability and access to medical care for specific aged. Using county-specific data from the Area Resource File on the location of health care facilities, a spatial access health network can be developed (Menefee and McCoy, 1982). Matching this data with elderly demographic patterns identifies the concentrations of the elderly population relative to health facilities. Such a spatial examination reveals that the elderly, especially the poor elderly, are more heavily concentrated in rural areas and the inner city. Similar, yet broader, findings related to access to medical care have been found in the analysis of the NMCES data set (Berk, Bernstein, and Taylor, 1983; Berk and Bernstein, 1982; Berk and Bernstein, 1985). Proximity to health care facilities was found to be a significant indicator of access and use, primarily for minority aged. Also, the importance of access was found to be correlated with the elderly's ability to pay for care and the type and extent of health insurance coverage (Berk and Wilensky, 1984; Cafferata and Meiners, 1984). In lieu of these findings, the analysis of access to care needs to be expanded, concentrating on specific elderly subgroups based on income, race, and place of residence. The use of the Area Resource File with the NMCES data would provide an appropriate data source.

Alternative delivery systems and access

The emergence of health maintenance organizations (HMO's) and comprehensive medical plans is providing a new type of option in terms of elderly medical care. An HMO receives a predetermined fixed payment which makes the HMO at risk for the total cost of health services. An HMO attempts to control the expense or cost side of the financial picture, in contrast to the "fee for service" system, which tends to concentrate on increasing the revenue size.

The attractiveness of the HMO arrangement to the elderly is that HMO's provide more services for the health care dollar. This is especially important for the older person on a fixed income. HMO's eliminate the incentive to hospitalize in order to ensure reimbursement. They provide comprehensive continuous health care services and take the responsibility to organize and arrange for the delivery of services. Therefore, elderly persons may receive the greatest benefit in a managed health care system, such as an HMO, that will provide experienced personal management of their total health care. There are also drawbacks for the elderly in terms of HMO-type arrangements. First, HMO's require a "lock-in" provision, which means that all services must be provided at the HMO's service area unless they have been authorized. Secondly, in order to maintain lower costs, HMO's may tend to undertreat and offer fewer services to their covered population. The interest of HMO's in elderly patients is only now becoming an area of research and evaluation by HMO's themselves. Information related to HMO's and other alternative health delivery systems can be found, to a limited extent, in privately sponsored surveys. However, the growing use of HMO's and similar health care arrangements necessitates the need for extensive and detailed utilization data related to the elderly's use of such services. A more concentrated effort should be made to ensure that the development of data sources containing such information is given high priority.

Summary

Economic factors play an important part in determining how the elderly maintain their health and independence. From a data perspective, this means that individual and market-related economic information is needed to integrate and express economic relationships pertaining to the elderly's quality of life. The adequacy and availability of economic data to describe elderly economic behavior pertaining to health can be summarized with the following general points.

- In examining the elderly's health and quality of life, the value of any type of economic information is subject to how various health and economic constructs are defined and formatted. Care must be given, when analyzing the adequacy of available data, to determining how restrictive the data are in terms of the way that various types of economic factors or economic relationships can be analyzed and evaluated.
- A number of new public data sets currently provide updated economic information that is helpful in analyzing questions related to economic issues. The usefulness of these data sets for analyzing the elderly population is, however, limited. Even though the new data sets provide new, better, and more detailed economic information, the elderly sample groups often are not large enough to allow for broad representative studies of specific elderly subpopulations.
- The current distribution of income and wealth reveals a growing percentage of the elderly with greater financial resources and a higher standard of living. Current trends indicate that the financial resources of future cohorts of the elderly should continue to improve. Expanded economic data concerning new income sources and saving mechanisms will become increasingly important to properly evaluate the elderly's economic status.
- Health utilization and quality of life among the elderly have increasingly become economic and political issues. The increasing impact of political decisions on the type, sources, and levels of various income sources has caused the economic status of the elderly to change rapidly. Thus, the usefulness and reliability of some data sources may be limited as a basis for policy.
- The changing nature of the health market will necessitate a closer look at the provision of health care not only from the user but also from the provider side. Such dual analyses will require more extensive information and data from the provider side of the market and may well be an opportunity to make more use of a growing number of private survey data sources as well as data bases.

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Wyatt Company: *Group Benefit Survey*. Washington, D.C., 1984.

Appendix A

Organizations involved in data collection and analysis include:

- Alexander & Alexander
- George B. Buck Consultants
- A. S. Hansen
- Data Resources, Inc. (a McGraw-Hill Company)
- Ernst & Whinney
- Frank B. Hall
- Hewitt
- Johnson & Higgins
- Meidinger/Mercer
- Tillinghast, Nelson & Warren, Inc.
- TPF&C
- Data Consulting Firms
- Commons Management Group
- Cost Care, Inc.
- Health Data Institute
- Health Risk Management
- Health Management Services
- Intracorp
- Ludy and Associates
- Medical Data Systems
- The Wyatt Company

Insurance companies

- The Metropolitan
- Corporate Health Strategies
- Connecticut General
- Health Systems International
- Travelers Corporation
- Center for Corporate Health Promotion, Inc.
- Massachusetts Mutual
- Puter Associates
- Health Care Alternatives, Inc.
- Blues
- The Travelers
- Equitable
- Health Data Institute
- Third Party Administrators (TPA's)
- Executive and Employee Benefit Plans Inc.
- James Benefits
- Alexander & Alexander
- U.S. Administrators

Multihospital systems

- Humana
- National Medical Enterprises
- Hospital Corporation of America

Health care software firms

- Bain and Company
- The Commission on Professional and Hospital Activities
- McDonnell Douglas Corp.

Appendix B
Private data base information

A. Individual company data

1. Sources of data
    - Claims information
    - Hospital medical abstracts
    - Utilization review program data
    - Medical department records
    - Medical benefit plans
2. Types of data
    - Hospital procedures
    - Medical services
    - Medical diagnoses
    - Source of medical service
    - Cost of service
    - Health status measures
    - Length of stay
    - Other health care services
    - Type or extent of insurance coverage
    - Medical coverage
    - Copayments

B. Comparative data for community

1. Sources of data
    - Hospital associations
    - Private utilization data systems
    - Medical foundations and professional standards review organizations
    - Health systems agencies
    - Other State and Federal agencies
2. Types of data
    - Aggregate data comparable to individual company data
    - Community health resources
    - Community measures of use of hospitals and other health resources
    - Cost and price data for the community's health care services
    - Epidemiological data

Appendix C
Public data sources

Annual Housing Survey
Housing Information, Decennial Census
Residential Finance
Employment & Unemployment Analysis
Earnings—Current Population Survey
Local Area Unemployment
Occupational Employment & Unemployment
State and Area Data—Demographics
Consumer Expenditure Survey
Consumer Price Indexes
Family Budgets
Producer Price Indexes
Retail Prices—Fuels & Utilities
Cost-of-Living
Area Wage Surveys
Level of Benefits Survey
Pension Beneficiary Master File
Survey of Low Income Aged and Disabled
New Beneficiary Survey
Summary Earnings Records
Survey of Disabled and Nondisabled Adults
Master Beneficiary Records
Retirement History Survey
The Medicare Statistical System
The Health Insurance Master File
The Provider of Service File
The Utilization File
Medicaid Minimum Data Set (MMDS)
The Medicaid Financial Data Set
The Current Medicare Survey
National Medical Care Utilization and Expenditure Survey (NMCUES)
The Health Interview Survey
Survey of Consumer Finances
National Longitudinal Survey
Program Survey of Income Dynamics
Hospital Discharge Survey
National Nursing Home Survey
Survey on Income Program Participation (SIPP)
Current Population Surveys (CPS)
CPS—Pension Supplement
CPS—Tax Supplement (1983)
Income Survey Development Program (ISDP)
Home Health Care Supplement to Health Interview Survey
Caregivers Supplement to Long Term Care Survey (1982)
Aging Supplement (1984)

Chapter II
Methodology issues

Methodologic issues in linkage of multiple data bases[a,b]

by Fritz Scheuren, Ph.D., Internal Revenue Service

Data linkage offers several obvious benefits in studying the dynamics of aging. Retrospective and prospective approaches are possible. Many ad hoc epidemiological studies could serve as examples here (e.g., Beebe, 1985). Perhaps of even more importance are broad-based statistical samples composed of linked administrative records, used either alone or in conjunction with survey data (e.g., Kilss and Scheuren, 1980; Scheuren, 1983).

In general, linked administrative records, when structured longitudinally (e.g., Buckler and Smith, 1980), can be very effective in tracing changes with age in income and family relationships—including the onset of some forms of morbidity (e.g., Klein and Kasprzyk, 1983) and, with the advent of the National Death Index, mortality as well (e.g., Patterson and Bilgrad, 1985).

Survey data can be used, among other things, to explore the underlying causal mechanisms for these administratively recorded outcomes. The design challenge, of course, is how to build a data collection process which exploits the comparative advantages of both administrative and survey information.

The present paper examines settings where linkages of U.S. Federal Government records for individuals are feasible and of interest in the study of the dynamics of aging. Both administrative and survey records will be considered. Our focus will be on the barriers to and benefits from data linkages, with examples drawn from studies conducted using records from the Social Security Administration (SSA), the Health Care Financing Administration (HCFA), the National Center for Health Statistics (NCHS), the Bureau of the Census, and, of course, the Internal Revenue Service (IRS).

Organizationally, the paper has been divided into three main sections. Structural questions (e.g., legal and procedural) in the development of a data linkage system are taken up first (Section 1). Technical issues in the matching process itself are discussed next (Section 2). The paper concludes (in Section 3) with some recommendations on areas for future study. An extensive set of references is also provided, along with some additional bibliographical citations. (See appendix A.)

1. Structural design considerations

During the last several decades numerous data systems have been built by linkage techniques in an attempt, among other objectives, to study various aspects of the aged population. Some of these, like the Continuous Work History Sample, remain enormously valuable (e.g., Kestenbaum, 1985) but are no longer fully exploited because of access problems and severe resource constraints (e.g., Cartwright, 1978). Others, notably the Retirement History Survey (Irelan and Finegar, 1978), have not been continued. Many studies had an ad hoc character to begin with. While successful, they have not been repeated (e.g., the 1973 Exact Match Study, Kilss and Scheuren, 1978; the Survey of Low Income Aged and Disabled, Barron, 1978). Still other studies originally envisioned as stand-alone survey systems have not exploited available data linkage opportunities to extend their useful life beyond the point at which interviewing has stopped (e.g., the National Longitudinal Survey, Parnes et al., 1979). What can we learn from these experiences and others that are similar?

- First, agency support for the activity has to be very strong and continuing. The Social Security Administration, which supported most of the projects listed previously, has moved away from such general research efforts and shifted toward examining improvements in program operations (Storey, 1985). A sustained longrun commitment to basic research simply may not be possible in what is inherently a policy-oriented environment (*President's Reorganization Project for the Federal Statistical System*, 1981).
- Second, strong user support is essential. The products must have high perceived public value, be delivered in a timely manner and with sufficient regularity to sustain continued interest. Startup problems with the Retirement History Survey caused it some major difficulties from which it may never have been able to fully recover (Maddox, Fillenbaum, and George, 1978). The Continuous Work History Sample has, especially in recent years, been unable to sustain user interest outside of Social Security because of access issues raised by the 1976 Tax Reform Act. Also, the emphasis on employee-employer relationships, long a main feature of the Continuous Work History Sample, may not have been seen to be as important as the resource commitment required to maintain it.

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[a] Contents are the opinions of the author and not those of the Department of Health and Human Services or the organization he works for.

- Third, startup costs may be high for data linkage systems, especially if based in part on survey data. Linkage systems tend to be easily maintained at low cost unless continued surveying is done; however, certain data problems, due to insufficient attention to obtaining good matching information, can cause continuing expense and difficulty at the analysis stage. Obviously also, as turned out to be the case with the Continuous Work History Sample, data quality limitations in the administrative records may necessitate considerable additional expense.
- Fourth, data linkage systems employ methods that may not be seen as entirely ethical (e.g., Gastwirth, 1986) or that have confidentiality constraints that make the systems hard to maintain, as with the Retirement History Survey, or hard to use, as with the Continuous Work History Sample (e.g., Alexander, 1983). These controversial elements in data linkage techniques, it may be speculated, could be one of the reasons linkages to the National Longitudinal Survey (NLS) have never been attempted (despite the collection of social security numbers in the NLS).

It is only with the last of these points that we touch on risks that data linkage systems encounter, which are not also encountered to some degree in more conventional data-capture approaches. The force of these concerns will be discussed.

Confidentiality and disclosure concerns

Data linkage operations bring us face-to-face with a "dense thicket" of laws, regulations, and various ad hoc practices justified on heuristic grounds. There are statutory considerations which apply either to the particular statistical agencies involved or to the Federal Government as a whole. These include the Privacy Act; the Freedom of Information Act; special legislative protections afforded to statistical data, for example, at the Census Bureau and the National Center for Health Statistics; and, of course, legislative protections afforded to administrative data, notably the 1976 Tax Reform Act. The paper by Wilson and Smith (1983) gives a good summary of the legal protections afforded tax data. For a more general treatment of legal issues and one which advocates change, see Clark and Coffey (1983). Also see Alexander and Jabine (1978).

The regulations and practices of each Federal statistical agency differ too, not only because of the different legislative statutes under which they operate, but also because of the varying approaches that they have taken in the accomplishment of their missions. Indeed, interagency data sharing arrangements almost defy description; they vary, among other reasons, depending on *which* agencies are sharing *whose* data and for *what* purpose. One excellent, albeit incomplete, taxonomy of current practice is found in the work of Crane and Kleweno (1985).

Despite the complexity of this topic, several general trends emerge that are worth noting:

- First, the American people are at best ambivalent about letting their government conduct linkages across data systems, specifically between different agencies and for purposes not obviously central to the missions of *both* agencies. For example, in a recent survey, questions were asked about the sharing of tax records with the Census Bureau, something which is a longstanding practice specifically permitted by law. Three-fourths of those surveyed did *not* support this use of administrative records even though an attempt was made to put the matter in a very favorable light, arguing for it on efficiency grounds (Gonzalez and Scheuren, 1985). See also appendix B for exact question wording.
- Second, bureaucratic practices which do not respect this general unease about linkage may need to be reexamined (e.g., Gastwirth, 1986). It is the duty, after all, of government statisticians to uphold both the letter and the spirit of the law. The whole tenor of the post-Watergate, Privacy Act and Tax Reform Act era has been to limit administrative initiatives (both big and little "a") and to permit the expansion of access only after the enactment of positive law. The failed initiative regarding Statistical Enclaves illustrates this point quite nicely. The Enclave proposal (Clark and Coffey, 1983) sought what many regarded as a degree of reasonable discretion on data linkage and data access; however, the authority requested was too broad for the current political climate. The arguments put forward in the proposed legislation's defense—for example, that it would increase efficiency and bring order to a patchwork of disparate practices—simply did not carry the day. In summary, we do not seem to be even close to a general solution on access to data for statistical purposes.
- Third, absent new legislation, many statistical agencies have begun to reexamine their traditional access arrangements and tighten still further their practices (e.g., Cox et al., 1985). For example, the use of special Census agents to facilitate linkages or to improve their subsequent analysis has been drastically curtailed, resulting in a clear shortrun loss in the utility to outsiders of linkage methods at the Census Bureau. On the other hand, new linkage practices have emerged from such reviews which may be superior to what otherwise might have been done. The linkage between the Current Population Survey (CPS) and the National Death Index is an excellent example (Rogot et al., 1983). Neither the Census Bureau nor the National Center for Health Statistics felt it could give up access of its data to the other agency; however, a compromise was worked out where joint access was maintained during the linkage operation, and this has proved satisfactory. In fact, similar arrangements have been made successfully between the Center and the Internal Revenue Service as part of a study of occupational mortality (Smith and Scheuren, 1985b).
- Fourth, the extent to which public use files can be made available from linked data sets has been greatly curtailed because of new concerns about what is called the "reidentification" problem (Jabine and Scheuren, 1985). Simply put, this means that if enough linked data are provided in an otherwise unidentifiable (public-use) form, then each contributing agency could reidentify at least some of the

linked units, almost no matter what efforts at disguise are attempted (Smith and Scheuren, 1985b). The only major exception occurs when the data made public from the contributing agencies are extremely limited (Oh and Scheuren, 1984; Paass, 1985); but usually the incentives for cooperation on the part of the contributing agencies are limited as well. In practice, of course, there is almost no incentive for the contributing agencies to reidentify; thus, legally binding contractual obligations might be entered into that could stipulate that there was no such interest. Contractual guarantees, however, may not satisfy all parties to the linkage because of the public perception issues mentioned earlier. It is conceivable, moreover, that no degree of legal or contractual reassurance would be adequate at the present time to permit the release of certain public use linked data sets—for example, those involving Census surveys linked to Internal Revenue Service information. Historically it was only the impossibility of reidentification which made the release of matched CPS-IRS-SSA public use files possible (Kilss and Scheuren, 1978).

It goes almost without saying that confidentiality and disclosure concerns pose the greatest barriers to the development of data linkage systems for studying aging. We will, however, defer to Section 3 a discussion of what might be done to deal with such issues and go on to explore the technical side of matching.

2. Matching design considerations

This section is intended to provide a brief discussion of matching design questions that must be looked at in developing data linkage systems. We begin with some historical background and then focus specifically on "person" matches, where the social security number is a possible linking variable. Linkage systems based in part on survey information are emphasized. Analysis problems also are covered, particularly ways of estimating and adjusting for errors arising from erroneous links or nonlinks.

Historical observations

The main theoretical underpinnings for computer-oriented matching methods were firmly established by the late 1960's with the papers of Tepping (1968) and especially Fellegi and Sunter (1969). Sound practice dates back even earlier, at least to the 1950's and the work of Newcombe and his collaborators (e.g., Newcombe et al., 1959).

The Fellegi-Sunter approach is basically a direct extension of the classical theory of hypothesis testing to the problem of record linkage. A mathematical model is developed for recognizing records in two files which represent identical units (said to be matched). As part of the process there is a comparison between all *possible* pairs of records (one from each file) and a decision is made as to whether or not the members of the comparison pair represent the same unit or whether there is insufficient evidence to justify either of these decisions. These three decisions can be referred to as a "link,""nonlink," or "potential link."

In point of fact, Fellegi and Sunter contributed the underlying theory to the methods already being used by Newcombe and showed how to develop and optimally employ probability weights to the results of the comparisons made. They also dealt with the implications of restricting the comparison pairs to be looked at, that is, of "blocking" the files, something that generally has to be done when linking files that are at all large.

Despite the early seminal work of Newcombe, Fellegi, and others, ad hoc heuristic methods abound. There are many reasons for this state of affairs:

- First, until recently (and maybe even now) there has been only a handful of people whose main professional interest is data linkage. This means, among other things, that most of the applied work done in this field has been carried out by individuals who may be solving matching problems for the first time. Because the basic principles of matching are deceptively simple, ad hoc solutions have been encouraged that could be far from optimal.
- Second, statisticians typically get involved very late in the matching step, often after the files to be matched have already been created. Even when this is not the case, little emphasis may be placed on the data structures needed for linkage because of other higher priorities. Design opportunities have, therefore, been generally limited to what steps to take *given files which were produced largely for other purposes*.
- Third, until the late 1970's, good, portable, general-purpose matching software had not been widely available (e.g., Howe and Lindsay, 1981), despite some important early attempts (e.g., Jaro, 1972). Even in the presence of general-purpose software, the uniqueness of each matching environment may lead practitioners to write complex customized programs, thereby absorbing resources that might have been better spent elsewhere.
- Fourth, especially for matches to administrative records, barriers to the introduction of improved methods have existed because cruder methods were thought to be more than adequate for administrative purposes.
- Fifth, the analysis of linked data sets, with due consideration to matching errors, is still in its infancy (Smith and Scheuren, 1985a). Qualitative statements about such limitations typically have been all that practitioners have attempted.

More will be said below concerning these issues in the context of computerized person matching.

Person matching

Typically in a computerized matching process there are a number of distinct decision points:

- First, design decisions have to be made about the linking variables that are to be used, including the extent to which resources are expended to make their reporting both accurate and complete. (This step may be the most important, but it is likely also to be the one over which statisticians have the least control, especially when matching to administrative records.)

- Second, decisions have to be made about what preprocessing will be conducted prior to linkage. Some of the things done might include correcting common spelling errors, calculating SOUNDEX or NYSIIS Codes, etc. (Winkler, 1985). Decisions about how to sort and block the files also fall here (Kelley, 1985).
- Third, decisions about the match rule itself come next. If a probabilistic approach is taken, as advocated by Fellegi and Sunter (1969), then we have to estimate a set of weights that represent the extent to which agreement on any particular variable provides evidence that the records correspond to the same person (and conversely, the extent to which disagreements are evidence to the contrary).
- Fourth, invariably there are cases where status is indeterminate regardless of the approach taken and a decision has to be made about excluding them from the analysis, going back for more information, etc.

To give some realism and specificity to our discussion, let us consider potential linkage settings in which we could bring together two files based on common identifying information: name, social security number, sex, date of birth, and address. As appropriate, we will contrast the linkage as taking place either entirely in an administrative context or between survey and administrative data.

Linking variables—The social security number (SSN) is the most important linking variable that we in the United States have for person matching purposes. SSN's were first issued so that the earnings of persons in employment covered by the social security program could be reported for eventual use in determining benefits. SSN's were also used as identifiers in State-operated unemployment insurance programs, but no other major uses developed until 1961, when the Internal Revenue Service decided to use the SSN as the taxpayer identification number for individuals. Other uses by Federal and State Governments followed rapidly, and now the social security number is a nearly universal identifier. The Privacy Act of 1974 placed restrictions on the use of SSN's but exempted those formally established prior to 1975. So far these restrictions have had only a minor impact on the widespread use of the social security number by governments and private organizations (Jabine, 1985).

The social security number is nearly a unique identifier all by itself and extremely well reported, even in survey settings and on records such as death certificates (e.g., Cobleigh and Alvey, 1975; Alvey and Aziz, 1979). In survey contexts, error rates may run to 2 or 3 percent; but this depends greatly on the extent to which respondents are required to make use of records in order to provide the requested information. Typically, driver's licenses, pay stubs, and the like are excellent sources (in addition to the use of the social security card itself).

Both administrative and survey reporting of social security numbers are subject to possible mistakes in processing, but these can be guarded against by using part of the individual's surname as a confirmatory variable. For example, IRS and SSA use this method as one way of spotting keying errors.

A difficulty with current administrative approaches is that name changes (especially for females) may lead to considerable extra effort in confirming (usually through correspondence) that the social security number was indeed correct to begin with. (It is a requirement of the social security system that notification is to be made when name changes occur, but many people fail to do this until the omission is called to their attention.)

One disadvantage of the social security number is the absence of an internal check digit allowing one to spot errors by a simple examination of the number itself. At the time the social security system started in the midthirties, the widespread use of the SSN as an identifier was not envisioned. Indeed, there is not a one-to-one correspondence between individuals and the social security numbers they use. In some instances, more than one person use the same social security number. Historically, the most important cases of this type arose because SSN's were used by advertisers in promotional schemes. Perhaps the best known such instance is the number 078-05-1120 (Scheuren and Herriot, 1975). It first appeared on a sample social security number card contained in wallets sold nationwide in 1938. Many people who purchased the wallets assumed the number to be their own. The number was subsequently reported thousands of times by different individuals; 1943 was the high year, with 6,000 or more wage earners reporting the number as their own.

While there have been over 20 different "pocketbook" numbers, like 078-05-1120, they are probably no longer the main cause of multiple use of the same number. Confusion can arise (and go largely undetected) when one member of a family uses the number of another. Also, there are incentives for certain individuals, like illegal aliens, to simply "adopt" the social security number of another person as their own. The extent to which these problems exist is unknown, but they are believed, at least by some authorities, to be less prevalent than the opposite problem—issuances of multiple numbers to the same person (Secretary of Health, Education, and Welfare's Advisory Committee, 1973).

Until 1972, applicants for SSN's were not asked if they had already been issued numbers, nor was proof of identity sought. This led to perhaps as many as 6 million or more individuals having two or more social security numbers (Scheuren and Herriot, 1975). A substantial fraction of the multiple issuances have been cross-referenced so that multiple reports for the same individual can be brought together if desired. Based on work done as part of the 1973 Exact Match Study, it appears that, despite the frequency of the problem, multiple issuances can largely be ignored unless one is looking at longitudinal information stretching back to the early days of the social security program. (In other words, people tend consistently to use only one of the numbers they have been issued.)

While the social security number is nearly ideal as a linking variable, it is not always available. For example, in the Current Population Survey for adults the number is missing 20–30 percent of the time (Scheuren, 1983). Evidence exists, however, from work done in connection with the Survey of Income and Program Participation, suggesting that with a modest effort the SSN missed rate can be lowered significantly, to less than 10 percent in Census surveys (Kasprzyk, 1983). Recent experience with death certificates shows a missed rate of about 6 percent for adults (Patterson and Bilgrad, 1985).

What, then, do we do when the SSN is missing or proves unusable? We are obviously forced either to seek more information or to try to make a match using the other linking variables. Now, as a rule, none of these other linking variables is unique alone, and all of them, of course, are subject in varying degrees to reporting problems of their own. Some examples of the problems typically encountered are—

- *Surname*—As already mentioned, name changes due to marriage or divorce are, perhaps, the main difficulty. For some ethnic groups, there can be many last names and the order of their use may vary.
- *Given name*—The chief problem here is the widespread use of nicknames. Some are readily identifiable ("Fritz" for "Frederick") but others are not (like "Stony" for "Paul").
- *Middle initial*—People may have many middle names (including their maiden name), and the middle name they employ may vary from occasion to occasion. Often, too, this variable may be missing (Patterson and Bilgrad, 1985).
- *Sex*—This is generally well reported and, except for processing errors, can be relied upon. The main difficulty with this variable is that it is not always available in administrative records. (IRS does not have this variable except through the recoding of first names, which simply cannot be done with complete accuracy.)
- *Date of birth*—Day and month are generally well reported even by proxy respondents. Year can be used *with a tolerance* to good effect as a matching variable. Again, as with "sex," this item is not available on all the administrative files we are considering.
- *Address*—This is an excellent variable for confirming otherwise questionable links. Disagreements are hard to interpret, however, because of address changes; address variations (e.g., 21st and Pennsylvania Avenue for 2122 Pennsylvania Avenue); and, of course, differences between mailing addresses (usually all that are available in administrative files) and physical addresses (generally all that are obtained in a household survey). Recent research on this variable has been done by Childers and Hogan (1984).

Still other linkage variables could have been discussed, for example, race and telephone number. Race is a variable that is similar to sex except not nearly as well reported, unless it is recoded as black and nonblack (e.g., U.S. Bureau of the Census, 1973). Telephone numbers have problems similar to those of addresses and, while potentially of enormous value eventually, are not now widely available in administrative files.

Preprocessing steps—In general, any method of standardization of identifier labels, such as names and addresses, will improve the chances of linking two records that should be linked during the actual matching process. However, it will also, to an unknown degree, result in some distortion and loss of information in the identifying data and may even increase the likelihood of designating some pairs of records as a positive link when, in fact, the pair is not a match.

Typically, for person matches to SSA or IRS information, two preprocessing steps have been undertaken: (1) to validate reported social security numbers; and (2) if missing or unusable, to search for SSN's using surname and other secondary linking variables. Both of these steps have had to be conducted largely within the existing administrative arrangements. The cost of mounting a wholly separate effort has been judged to be prohibitive. (The data sets involved are simply enormous. Social Security has roughly 300 million SSN's now issued. In recent years IRS has been processing about 100 million individual income tax returns annually, containing well over 150 million taxpayer social security account numbers.)

The "validation step" itself consists of two parts: first, a simple match on SSN alone is attempted; and, if an SSN is found, then secondary information from Social Security or Internal Revenue records is made available on the output computer file. Further processing then takes place so that the confirmatory matching information (names, etc.) can be examined and coded as to the extent of agreement. It is possible that this part of the current administrative procedure can be readily modified to accord with modern matching ideas. What is needed is to institute probability-based weights for the agreements (disagreements) found. At present administrators and statisticians alike simply employ a series of ad hoc rules to separate what will be considered a link from cases that have questionable SSN's (e.g., Scheuren and Oh, 1975; Jabine, 1985).

The "search step" is an elaborate and fairly sophisticated computerized procedure (which differs in detail at SSA and IRS). The files used are in sort; and, for the most part, the only possible links that can be looked at are cases that agree on surname. Since other blocking variables are used as well, the current administrative methods tend to be very sensitive to small reporting errors. This is believed to be true despite the fact that the computer linkage procedures go to great lengths to protect against more common reporting errors (such as those mentioned earlier). At Social Security they do this by systematically varying the linking information on the record for which an SSN is being searched. An extensive set of manual procedures also exists for cases where computer methods prove unsuccessful.

Unlike the "validation step," it may not be possible to bring the "search step" into full accord with modern practice. First of all, we would need to reexamine the decisions about what blocking variables to use (Kelley, 1985). Ideally we want variables that are without error themselves, or nearly so, in both sources (Fellegi, 1985) and that divide the files into blocks or "packets" of reasonably small size, within which we can look at all possible linkage combinations (e.g., Smith, 1982). Research is now underway in both agencies to find ways of improving the blocking variables, but it is unlikely that the current deterministic methods will ever be replaced by probability-based ones, and for good reason. Linkage techniques for administrative purposes must be employed with high frequency in a great variety of situations and hence be extremely efficient in the use of computer time, since the basic files involved are so large.

A compromise that naturally arises within the world of large computer files is to employ some form of multiple, albeit still deterministic, scheme. This is the approach taken with the National Death Index (NDI). The NDI currently employs over a dozen different combinations of matching variables. Some give a primary role to the social security number, some to the surname; still others place primary emphasis on the given name or on date of birth (Patterson and Bilgrad, 1985). Adopting the NDI approach at SSA or IRS, if feasible, might be one way to make a real advance.

Match rules—Usually the computerized matching phase in a data linkage system consists of three steps: (1) comparisons between the linkage variables on the files being matched; (2) generation of codes which indicate the extent to which agreements exist or disagreements are present; and (3) decisions regarding the status of each comparison pair. This structure is the same, whether probability-based methods are being implemented (e.g., Howe and Lindsay, 1981) or heuristic approaches are taken (e.g., Scheuren and Oh, 1975).

- *Comparison step*—In a sense, we have already discussed this step earlier. It depends heavily on what linkage variables are present; the reformatting, etc., done of those variables to facilitate comparisons; and the degree to which blocking is required because of resource or other considerations. What is desired here conceptually is to compare every record on each file with every record on the other. Blocking, of course, limits (sometimes severely) the extent to which such comparisons can be carried out. Any recoding of the linkage variables (say SOUNDEX for surname) may possibly, as we have noted, reduce the utility of this step. Generally, if resources permit, all the linking variables should be used in the computer comparisons. When this is not possible, they can still be employed later in manually settling cases where the outcome might otherwise be indeterminate. However, it almost goes without saying that manual intervention needs to be carefully limited and closely controlled. Manual matching is extremely costly and, while individual manual decisions can sometimes be better than computer matching, usually humans lack consistency of judgment and can be distracted by extraneous information, such that they act more decisively than the facts would warrant.

- *Coding step*—As a result of the comparison step, a series of codes can be generated indicating the degree of agreement which has been achieved. These agreement outcomes may be defined quite specifically, e.g., "Agrees on Surname and the value is GILFORD." They might be defined more generally: agree, disagree, or unknown (the last arising because of missing information, perhaps).

  It becomes very difficult to talk about the coding step without looking ahead to the decision step and the specific approach that will be taken there. Nonetheless, some general observations can be made. Obviously, when we have, in fact, brought together records for the same person, we would like the agreement coding structure not to obscure this point. For example, to protect against trivial spelling errors, we might use the same agreement code even though there are transposition or single-character differences in the name. (The preprocessing of the files should have taken care of some of this but it may, again, be a consideration in the agreement coding itself.)

  In most applications of the Fellegi-Sunter approach, the assumption is made that agreement (or disagreement) on one linking variable is independent from that on any other, conditional only on whether or not the records brought together are, in fact, for the same person. To aid in making this assumption plausible, special care needs to be taken in structuring agreement codes for such variables as sex and first name, which are inherently related (Fellegi, 1985).

- *Decision step*—An assessment can now be made as to the extent to which an agreement on any particular linking variable, or set of variables, constitutes evidence that the records brought together represent the same person. Conversely, an assessment can be made as to the extent to which disagreements are due to processing or reporting errors or are evidence that the records do not represent information for the same person. Typically, the records are divided into those (1) where a positive link is deemed to have been "definitely" established, (2) where a "possible" link may exist but the evidence is inconclusive, and (3) where it can "definitely" be said that no link exists.

  In probability-based methods a statistical weight function is calculated to order the comparison pairs. The weights are developed by examining the probability ratio—

  $$\frac{\text{Prob (result of comparison, given match)}}{\text{Prob (result of comparison, given nonmatch)}}$$

  The numerator represents the probability that comparison of two records for the same person would produce the observed result. The denominator represents the probability that comparison of records for two different persons, selected at random, would produce the observed result. In general, the larger the ratio, the greater our confidence that the two records match, i.e., are for the same person.

  Let us consider a particular example in which we are matching on both sex and race, where sex is always represented as either male or female and where race has been recoded black or nonblack. Further suppose that the proportion of males and females is each 50 percent and that black persons constitute 10 percent of the population and nonblack persons 90 percent. Also suppose that the chances of a reporting error on race are 1/100 and for sex 1/1,000. Finally, we will assume that sex and race are independently distributed in the population and that reporting errors are independent as well.

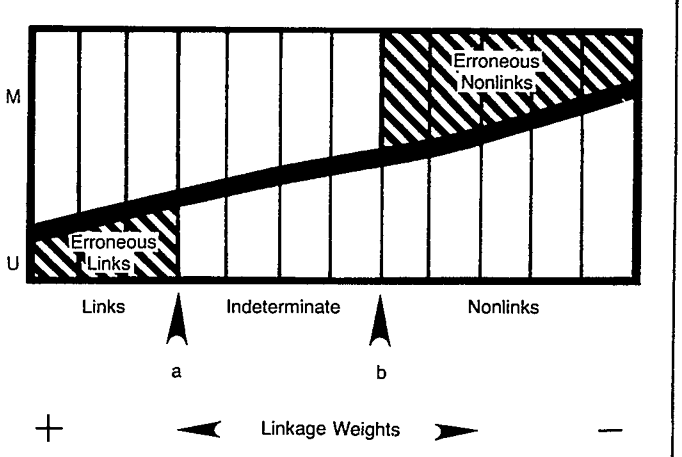
With these stipulations and assumptions, we have the following table of possible probability or "odds" ratios, say for black persons. Usually, given the independence assumption, the probability ratio is broken up into a series of ratios, one for each agreement or disagreement, and logs are taken (to the base 2). One is now working with simple sums, such that the larger (more positive) the total, the more likely that the pair is a match; conversely, the more negative the sum, the greater the likelihood that the two records are not for the same person.

Outcome	*Probability ratio*	*Base 2 log of ratio*
Race and sex agree:		
Race is black	167.7369	7.3901
Race is nonblack	2.4589	1.2980
Race agrees, sex does not:		
Race is black	0.3358	− 1.5743
Race is nonblack	0.0049	− 7.6730
Sex agrees, race does not . . .	0.2051	− 2.2856
Neither agrees	0.0004	− 11.2877

NOTE: See computational note at end of paper.

In our particular example, it is only when both sex and race agree that the sum of the logs is positive. If the race is black, the log is between +7 and +8, moderately strong evidence in favor of a match. If the race is nonblack, however, the log is only slightly more than +1. As one would expect, the strongest evidence in favor of a nonmatch occurs when both race and sex disagree; for this outcome, the log of the probability is about −13. (Parenthetically, it might be noted that this example illustrates nicely the fact that outcomes that are frequent in the population do not add very much to one's ability to decide if the pair should be treated as a link; but if there are disagreements on such variables and reporting is reasonably accurate, then the variable may have a great deal of power in identifying comparison pairs that represent nonlinks.)

Now it can be shown in general, as by Fellegi and Sunter (1969) or by Kirkendall (1985), that we can divide the weight distribution into three parts, as seen in figure 1. The points "a" and "b" optimally divide the distribution of weights so that we can simultaneously minimize the error of accepting as a positive link cases that we should not have matched, plus minimize the error of rejecting as nonlinks cases that we should have kept. Assumptions such as independence must be made, as a rule, and formidable computational problems exist. Nonetheless, the approach is entirely workable, especially since the development of the Generalized Iterative Record Linkage System (GIRLS), which provides a state-of-the-art solution to the major computational problems (Howe and Lindsay, 1981). Other notable approaches in advanced linkage software include the work of Jaro and his collaborators (Jaro, 1985).



SOURCE: Adapted from Fellegi, 1985.
NOTE: Comparison pairs above the line are matched (M), those below unmatched (U).

Figure 1. Hypothetical distribution of linkage weights

Indeterminate outcomes—Virtually all computerized record linkage schemes may leave at least some cases where the status is indeterminate. Three kinds of indeterminacy might be distinguished:

- *Nonlinks*—Cases that were "definitely" determined by the method to have no suitable match, given the approach taken, but which might have been matched if another technique had been used (e.g., if we had employed a different set of blocking variables). The difficulty here is that, while all the potential links that get looked at may have proved inadequate, not all possible links are examined, and we cannot necessarily tell the difference between a case that should have been a link and one that should not. The only way this issue can be dealt with is in the implausible situation when the probability of a match between blocks is zero. (An indirect "solution" to this problem can be developed using contingency table ideas, as will be discussed later.)
- *Multiple links*—These can occur in the Fellegi-Sunter formulation; that is, there may be more than one comparison pair for a unit whose match weight or score exceeded the threshold for acceptance. In some cases, these many-to-one links might be appropriate, but usually a further step has to be taken to select "the best" one. This problem also can occur with some frequency in administrative contexts and with the National Death Index. Manual resolution is usually the approach taken, especially if further information is going to be sought or is available to help make the selection. Jaro (1985) offers a computerized transportation algorithm to solve multiple linkage problems. His approach is most effective when all the linking information has already been computerized and when there are contention problems in the linkages, that is, n records on one file are matching m records on another. Smith and Scheuren (1985a) suggest ways of carrying through the statistical analysis using all the links.
- *Potential links*—This type may be the largest form of

indeterminacy. These are the cases that fall in the middle area in figure 1. The usual advice, resources permitting, is to collect more information to resolve the match status. If statistical estimates are to be made and the resources needed to seek further information are not available, the potential links may be treated as nonlinks and a survey-type nonresponse adjustment may be made (Scheuren, 1980). It is possible, also, to consider keeping some of the potential links and then conducting the analysis, with an adjustment being made for mismatching (Scheuren and Oh, 1975).

Often, the difficulty with indeterminate cases can be traced back to a design flaw in the data linkage system. For example, not enough linking information may have been obtained on one or both files to assure uniqueness. Maybe the degree of redundancy in the identifiers was insufficient to compensate completely for the reporting errors. In an administrative context, the linkage process may be so constrained for operational reasons that, even if there are sufficient linkage items, they cannot be brought fully to bear.

Analysis issues

Statements about the nature of the matching errors are typically provided in data linkage studies; generally, however, there is no real attempt to *quantify* the implications of matching errors for the specific inferences being drawn. Data linkage systems, like other survey-based or sample-based techniques, need to be "measurable" and to be structured to be as robust as possible in the face of departures from underlying assumptions. What can be done to achieve this is a separate and sizable subject (Smith and Scheuren, 1985a). For our present purposes, it may be enough to sketch some of the issues and indicate general lines of attack.

- *Linkage documentation*—Documentation should routinely be provided which tabulates the results of the match effort along dimensions that turned out to be important in the analysis. A distribution of the weights would be one example, perhaps shown for major subgroups. If a public use file is being created, then the match weight might be placed in the file along with summary agreement codes so that secondary analysts can "second-guess" some of the decisions made. Providing potential links, at least near the cutoff point, is another example of good practice. Most of the foregoing information, by the way, was part of the documentation and computer files made available from the 1973 Exact Match Study (Aziz et al., 1978).
- *Adjusting for nonlinks*—It is generally worthwhile to consider reweighting the linked record pairs actually obtained to adjust for failures to completely link all the proper records to each other (Scheuren, 1980). Conventional nonresponse procedures can be followed (Oh and Scheuren, 1983). Imputation strategies are also possible, but may be less desirable because they tend to disturb the estimated relationships across the two files being brought together (Oh and Scheuren, 1980; Rodgers, 1984). An important problem in this adjustment process, however conducted, is in being able to estimate whether a link should have occurred. Sometimes, by the nature of the problem, we know that all the records should have been linked. In other cases (Rogot et al., 1983), one of the key things we are interested in is, in fact, the linkage rate. Elsewhere (Scheuren, 1983; Smith and Scheuren, 1985a), we have advocated a capture-recapture approach to this estimation problem. Such an approach, in the presence of blocking, will actually allow us to improve the links obtained, as well as make it possible to measure the extent to which our best efforts still lead to erroneous nonlinks. Capture-recapture ideas are well described in the literature (e.g., Bishop et al., 1975; Marks et al., 1974). Here we will only indicate the application.

  If we employ more than one set of blocks and, for each blocking procedure, keep track of whether we would have found (and linked) the case in every other blocking scheme, then for any subpopulation of linked records we can construct the usual 2^n table, where we look at the link/nonlink status for each blocking (with n being the number of separate blocking schemes). To estimate the number of records not caught by any scheme, three or more sets of blocks are recommended; otherwise, the assumptions made may be unrealistically strong. (The National Death Index, or NDI, already employs many more than this, as we have noted earlier.) For best results the blocks need to be as independent functionally and statistically as is possible, given the linkage information. (Improvements in the current NDI would be recommended here, but these seem to be coming in any case.) Application of these ideas in an IRS or SSA context seems worthy of study (Scheuren, 1983), although the expense of developing such an approach, say at SSA, may never be incurred unless there were a compelling administrative need.
- *Adjusting for mismatches*—In most linkage systems, practitioners have operated in what they considered to be a conservative manner with regard to the links they would accept. Sometimes this may have meant heavy additional expense in obtaining more information or the risk of seriously biasing results by leaving out a large number of the potential links. In any event, further research is needed on how to apply more complex analytic techniques that take explicit account of the mismatch rate, possibly by use of errors-in-variable approaches where the mismatch rate is estimated, e.g., as in Scheuren and Oh (1975), so that a correction factor can be derived. We must also attempt to find ways of estimating the mismatch rate that make weaker assumptions than those made in most Fellegi-Sunter applications. (Some further ideas on this are found in Smith and Scheuren, 1985a.)

In summary, the main issues in the analysis of linked data sets are that, at a minimum, we need to examine the sensitivity of the results to the assumptions made in the linkage process. Where possible, we need to quantify uncertainties in the results; specifically, indeterminacies in the linkages should translate into wider confidence intervals in the estimates. To achieve these goals we need to bring in techniques from other areas of statistics and apply them creatively to linked data sets. Examples here include information theory, error-in-variable approaches, and contingency table (capture-recapture) ideas.

3. Some conclusions and areas for future study

In this paper we have dealt with the topic of data linkage in a broad conceptual framework, using examples from recent practice. It is appropriate now to draw out the implications of the point of view expressed for studies of aging and to use that summary as a basis for recommending further research.

Overall perspective

We have argued elsewhere that the potential for the statistical use of data linkage systems is truly enormous (e.g., Kilss and Scheuren, 1980; Jabine and Scheuren, 1985). The suggestion has even been made that data linkages among administrative records (with some supplementation) might eventually replace conventional censuses in the United States (Alvey and Scheuren, 1982). Such ideas are not new, certainly not in Europe, where many developed nations have been rapidly moving in this direction (e.g., Redfern, 1983). Indeed some countries, like Denmark (Jensen, 1983), may have "already arrived."

In the United States there has been some reluctance and resistance to accepting the inevitability of such a future. Grave concerns have been expressed (Butz, 1985) about moving too fast or in the wrong way. After all, while Denmark has succeeded in its efforts, other countries (notably West Germany) have encountered major problems which did grave damage to their statistical programs.

In view of what has happened elsewhere and, especially, given the current state of public opinion, we would caution that any planned use of data linkage systems be grounded firmly in existing practice and not be based on new legislation designed to expand on what it is currently possible to do. On the other hand, it is important to conceptually integrate what is now possible with what might be possible 10 or 20 years from now. Some further observations are—

- First, if a data linkage approach is going to be taken, it should be a necessary means, not just a sufficient one, for achieving some required specific purpose. It is simply not enough to argue the need for data linkage on efficiency grounds.
- Second, the linkage should be seen as important by all the cooperating agencies and part of their mission. It is simply not enough that the law can be interpreted to permit such linkages. Positive law, and indeed social custom, must exist which encourages the research, at least in broad outline (Cox and Boruch, 1985).
- Third, strong continuing user support is essential if a long-term basic research effort is to be successful. Program agencies cannot be relied on for really long-run undertakings without this support. Opportunity costs are simply too high. If the linkage system is to be placed in a statistical agency, user involvement is, again, essential (from the outset, if possible). Without strong user involvement, statistical agencies will tend to emphasize continuity of measurement over relevance (while program agencies tend to the reverse).
- Fourth, cost considerations suggest that most data linkage systems should be based on, or augment, an existing survey or administrative system. Further, maintenance costs should be low so that in the long run most of the resources can be focused on exploiting the analytic potential of the system.
- Fifth, access to the results of the linkage system must be basically open not only to the primary user(s), but to secondary users as well. Ways to solve the "reidentification" problem must be built into the undertaking from the beginning and firmly rooted in the best statistical practice.

Still other considerations come to mind, such as adequate physical security during the linkage operation and minimizing the risks by removing identifiers from working files as soon as possible (Kilss and Scheuren, 1978; Steinberg and Pritzker, 1967; Cox and Boruch, 1985; and Flaherty, 1978).

Many ad hoc efforts have succeeded without strictly adhering to one or more of these points. Nonetheless, if one is working toward a future which encompasses still more data linkages, it is essential that the strategy taken be absolutely sound and above reasonable reproach.

Potential data systems deserving further study

Within the framework just given, there seems to be a clear need to intensively examine the potential of particular data linkage systems to answer certain questions. We will illustrate this point by looking at one of the most pressing areas in the United States where better data are needed—this is on our rapidly growing aged population. Even if we confine ourselves to this single area, many subsidiary issues must be addressed. For example, where are the greatest gaps: in data on health, general demographic information, financial data, or the extent to which Federal programs provide support? In what follows, there has been no attempt to answer this question. To do so, we would go well beyond the scope of the present paper. Instead, there is a discussion of four data linkage environments that, depending on the answer to the question, may warrant further study. Special emphasis has been placed on the limitations of working in each of these settings and of the role that a strong outside user might play in overcoming those limitations.

Social Security and Health Care Financing Administrations—The Social Security and Health Care Financing Administrations are unlikely to take the lead in building and maintaining *general purpose* statistical data linkage systems, in part because of a reduced emphasis on basic and applied research. Nevertheless, the program-oriented statistical activities of these agencies will continue to give them an important role in data linkage efforts which are consistent with agency missions. The potential at SSA and HCFA for providing improved sources of statistics on the aging population depends on the extent to which they are able to: (1) maintain major in-house data linkage efforts, like the Continuous Work History Sample (e.g., Buckler and Smith, 1980) and the Medicare Statistical System (Health Care Financing Administration, 1983); (2) continue to sponsor or cosponsor periodic or ad hoc surveys; and (3) cooperate in linkage studies sponsored elsewhere (for example, in the Survey of Income and Program Participation or in the Health Interview Survey) if they are in support of the agencies' missions.

However, these efforts would need to be coupled with strong outside user support. At SSA and HCFA, there may be a particularly pressing need for outside users to aid in the resumption of some form of public release of subsets, at least, of the administrative samples now being employed almost solely for in-house purposes.

Internal Revenue Service—It seems pointless to speculate upon the degree to which interagency data linkages involving Internal Revenue Service data can or should take place. Formidable statutory barriers narrowly limit access to tax records and, even when the legal requirements can be met, many other agencies, notably the Census Bureau, feel they would be unable to engage in a cooperative study because of concerns about public perception. American social customs, particularly concerns about "Big Brother," stand as nearly insurmountable obstacles in the short run.

It is possible, though, to use IRS records essentially all by themselves as a basis for studying the aged population. This may seem surprising because the statistical program of the Internal Revenue Service is not looked at typically as a source of such information. Certainly the *Statistics of Income* publication series has focused very little on the aged, and then mainly through the use of the age exemption to identify taxpayers 65 years or older (e.g., Holik and Kozielec, 1984). Broader based research has been possible through occasional linkages between the IRS's Individual Income Tax Model File and Social Security information. In a few cases, these linkages have resulted in public use files (DelBene, 1979). What has not been done is to look at the aging population longitudinally, although this is fairly straightforward, at least back to 1972. Furthermore, with the recent addition of complete SSA year-of-birth information to IRS files, it will be possible to routinely study age cohorts by means other than the age exemption. It is also worthy of mention that linkages between IRS files and the recently instituted National Death Index have just been successfully instituted (Bentz, 1985).

Tax returns probably represent the single best source of financial information and could, therefore, prove of value in studying the aging process. There are, however, three main limitations to their use:

- First, the income data, while of exceedingly high quality (relative to surveys), are incomplete since certain nontaxable incomes have been omitted (e.g., tax-exempt bond interest and welfare payments). Until recently, data on social security benefits were unavailable, but they are now potentially taxable (beginning with 1984).
- Second, the population coverage of income tax returns is incomplete. In fact, only about one-half of the population ages 65 years or older show up as taxpayers on income tax returns. Again, recent changes have a bearing here, since information documents, notably Forms 1099 from Social Security, are filed with the Internal Revenue Service for all social security beneficiaries. This change permits an expanded population concept that could be essentially complete for the aged population.
- Third, the tax return is exceedingly awkward as a unit of analysis for some purposes since it does not always conform to conventional family and household concepts (Irwin and Herriot, 1982). It is possible, though, using information documents like Forms W-2 (for wages), Forms W-2P (for private pensions), and Forms 1099 (for social security payments, dividend, interest, etc.), to develop approximate financial profiles of virtually all individuals aged 65 or older. (Major gaps would exist, of course, for Supplemental Security Income recipients and recipients of veterans' disability benefits.) There does not appear to be much hope for inferring changes in lifestyles directly from the current IRS information, although the proposed addition of dependent social security numbers could lead to real progress (Alvey and Scheuren, 1982).

Depending on its extent, the cost of maintaining an IRS data linkage system to study aging could be quite modest. Public-use files are possible; but, as with the Social Security and Health Care Financing Administrations, strong outside support would be needed.

National Center for Health Statistics—Recent changes (Sirken and Greenberg, 1983) at the National Center for Health Statistics suggest that the Center may be assuming a leading role in sponsoring data linkage systems. Naturally and appropriately, the focus of these systems will be quite narrow, looking almost solely at health concerns. The National Health Interview Survey (NHIS), involving about 40,000 households annually, appears to be the Center's main survey vehicle for the approach it is planning to take. Continued periodic matching to Medicare records seems planned (Cox and Folsom, 1984) and, of course, the National Death Index can be expected to be fully exploited (Patterson and Bilgrad, 1985). Still other linkage efforts are underway (e.g., Johnston et al., 1984) which, taken together, suggest that the Center is pursuing a coherent, fully integrated approach, both among its surveys and toward needed vital record systems.

When the social security number question was added to NHIS a few years ago, it was largely for matching to the National Death Index. Great care initially was given to securing informed consent from respondents *before* obtaining the information. This approach proved tedious and expensive. Now the social security number question is simply asked without much explanation; and only if requested are reasons given for why the information needs to be obtained. (See appendix C.) Response rates are quite high, about 90 percent, and it appears that NHIS may constitute a major vehicle for a successful data linkage approach to studying aging. Concerns exist about the reidentification problem, but exactly how the Center will deal with this factor is unclear.

Bureau of the Census—Historically, the Census Bureau has played a major role in Federal data linkage systems involving surveys, sometimes as the sole sponsor (e.g., Childers and Hogan, 1984), but often as a partner in conducting a particular study, e.g., as with Social Security (Bixby, 1970). Much of this work has focused on the Current Population Survey (Kilss and Scheuren, 1978). Of more promise in future studies of aging has been the development of the Survey of Income and Program Participation (SIPP), which has as one of its design elements the notion that data linkages would be attempted, at least to Social Security information (Kasprzyk, 1983). SIPP, which may settle down to a sample size of about 30,000 households annually, is certainly of sufficient size and scope to look at many general demographic, financial, and program-related questions concerning aging. The SSN reporting rate is on the order of 90 percent; hence, the needed resources to "perfect" the linkage (and the analysis problems resulting from faulty or incomplete linkage) should be entirely manageable. Oversampling is possible for particular subgroups (e.g., those aged 65 or older); however, unfortunately, SIPP, like the NHIS, is confined to the noninstitutionalized population, and for studies of the very old, it may not be suitable alone.

Two difficulties exist with SIPP that further research may resolve. First is the extent to which informed consent is being obtained when the social security number is being secured. (SIPP's approach is similar to that in NHIS; see appendix D.) Related to this concern, of course, is the extent to which such consent is felt to be needed. The second issue, and one that seems exceedingly troublesome to the Census Bureau, is the "reidentification" problem. (Briefly stated, the reidentification problem is particularly acute where linkage is concerned, because the cooperating agencies might have enough data on the linked file to reidentify virtually all of the individuals linked.)

The Census Bureau appears to be searching for a solution that involves either simply not releasing public use files of linked data or releasing public use files where only very limited linked data have been provided and some kind of masking technique has been employed to prevent reidentification. Given these restrictions, it must be said, there seem to be real difficulties in concluding that there are sufficient benefits to outside users of a SIPP-based data linkage system. Some further comments on this dilemma and ways a general research program could address it are given next.

General issues deserving further study

Further research is needed on a wide range of data linkage issues, both structural and technical. Four, in particular, stand out from the rest and deserve special attention: ethical and legal concerns, public perception questions, finding solutions to the reidentification problem, and finally, analysis issues in the presence of matching errors.

Ethical concerns such as those raised by Gastwirth (1986) seem to need a more specific answer than they have been given so far (as by Dalenius, 1983). What might be done is to obtain some data directly bearing on how respondents actually think about data linkage. We could approach this in a way similar to the earlier study by the Committee on National Statistics concerning confidentiality guarantees (Committee on National Statistics, 1979). Within the context of current survey efforts in NHIS and SIPP, it might be extremely valuable to know how often respondents ask for clarification before providing social security numbers and to code the cases accordingly so we can look at differential refusal rates, for example. Again, exactly what is said typically (by respondents and interviewers) when respondents do ask? Legal and procedural issues abound here, too. For example, how long, even assuming informed consent, can the consent be treated as binding? Social Security practices with outside researchers (when they obtain consent to gain access to individual records) is to treat the consent as binding potentially only once; thus, requests for information on the same subjects may require a renewal of the consent. Signed consent agreements are also required of outside researchers. Such a requirement has never been imposed, say, in Census Bureau surveys, but should it be? If it were, what would be the costs of such a practice in interview time, reduced response, and cooperation generally?

Public perception concerns deserve to be examined in depth. To what extent are we already violating the public's sense of the social customs within which statisticians are supposed to work? The public opinion polling results reported in Gonzalez and Scheuren (1985) need to be followed up. It does not seem defensible simply to speculate about whether this or that approach to data linkage would be acceptable to the public. While we can never use opinion polling to answer all the many specific issues that exist here, much can be done. Of particular interest may be the extent to which the public knows or assumes that such linkages take place now and for what purposes; the perceived legitimacy of actual and perceived purposes; whether statutory or contractual prohibitions against efforts at reidentification would be seen to be adequate; and so on.

We do not believe that an entirely satisfactory technical solution to the reidentification problem is possible; but a great deal more can be done to allow for at least limited release of linked information. The work of Paass (1985) and Smith and Scheuren (1985a) is suggestive here. The line of attack that appears most promising is what might be termed a three-step process. First, "slice" the data up into small enough bits so that each of the "bits" can be adequately masked. (The data, for example, might be divided up into disjoint subsets and for each subset of observations, say, only 2 to 4 different items of administrative data would be provided.) Second, if the slices are chosen appropriately, then one can "splice" back together the complete data set using statistical matching; but in a setting where the conventional—and usually false conditional—independence assumption (e.g., Rodgers, 1984) does not have to be made. Finally, the masking step can add "noise" to the data set in such a way that either certain analytic results are invariant under the noise transformation or correction factors can be calculated and readily applied.

There are some serious losses in this approach. For example, the effective sample size of the linked data items may have shrunk considerably. In any case, more research on this problem is definitely warranted (maybe even if contractual and legal solutions turn out to be eventually possible). Either way, public access to the linked data sets must be seen as a key objective when such studies are undertaken and, to the extent possible, release practices should be as open as with any other data set (Committee on National Statistics, 1985).

Finally, a number of analysis issues have been mentioned which deserve further research, especially in measuring matching errors and adjusting the matched results accordingly. In particular, we need to find a way to escape the historical dilemma that the dissemination and growth of sound theory and practice have been retarded by the perceived uniqueness of many linkage problems (and the customized solutions this perception has led to). The profound nature of the common sense principles upon which good practice is based are not widely enough appreciated. Insufficient attention has been paid to the analysis issues in data linkage systems, perhaps because so much creative energy and financial resources typically go into the linkage steps (Smith and Scheuren, 1985a). It may be too optimistic to suppose that things are now changing, but there is some evidence to this effect in the success of the 1985 Washington Statistical Society Workshop on Exact Matching Methodologies (Kilss and Alvey, 1985). In any case, it is time to stop treating matching as a necessary but dirty business, isolated from other parts of statistical theory and practice.

Acknowledgments and afterwords

The ideas in this paper owe much to my associations with other professionals in the field of matching. Particular thanks are due to Dan Kasprzyk for his useful remarks, and, especially, Tom Jabine, whose insightful comments were much appreciated, even though I was unable to incorporate them all in the present version. Tom also acted as a discussant when this paper was originally given and, among other things, corrected a computational error in the calculation of the probability ratios shown in the example. All the remaining errors are, of course, my responsibility.

Computational note

The probability ratios shown in the table were calculated as follows:

Race and sex agree (race is black)

$$[(.99)^2+(.01)^2][(.999)^2+(.001)^2]/[(.1)^2(.99)^2+(.9)^2(.01)^2+2(.1)(.9)(.99)(.01)][.5]=167.7369$$

Race and sex agree (race is nonblack)

$$[(.99)^2+(.01)^2][(.999)^2+(.001)^2]/[(.9)^2(.99)^2+(.1)^2(.01)^2+2(.9)(.1)(.99)(.01)[.5]=2.4589$$

Race agrees, sex does not (race is black)

$$[(.99)^2+(.01)^2][2(.999)(.001)]/[(.1)^2(.99)^2+(.9)^2(.01)^2+2(.1)(.9)(.99)(.01)][.5]=0.3358$$

Race agrees, sex does not (race is nonblack)

$$[(.99)^2+(.01)^2][2(.999)(.001)]/[(.9)^2(.99)^2+(.1)^2(.01)^2+2(.9)(.1)(.99)(.01)][.5]=0.0049$$

Sex agrees, race does not

$$[2(.99)(.01)][(.999)^2+(.001)^2]/[2(.1)^2(.99)(.01)+2(.9)^2(.99)(.01)+2(.9)(.1)(.99^2+.01^2)][.5]=0.2051$$

Neither agrees

$$[2(.99)(.01)][2(.999)(.001)]/[2(.1)^2(.99)(.01)+2(.9)^2(.99)(.01)+2(.9)(.1)(.99^2+.01^2)][.5]=0.0004$$

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Appendix A
Supplemental bibliographic sources

In this paper we have cited some of the literature on exact and statistical matching when the discussion warranted. Further bibliographic material can be found in the following publications:

- *Record Linkage Techniques—1985* (1985), U.S. Internal Revenue Service. (Edited by Beth Kilss and Wendy Alvey.) Many of the citations in the present paper come from this volume, which contains the proceedings of the Workshop on Exact Matching Methodologies, held May 9–10, 1985, in Arlington, Virginia.
- *Statistical Working Paper Series* (1977–85), Federal Committee on Statistical Methodology. (Produced under the general editorial guidance of Maria Elena Gonzalez.) See especially No. 5, on "Exact and Statistical Matching," and No. 6, on the "Statistical Uses of Administrative Records." Some of the publications in the series were prepared by the U.S. Department of Commerce; more recently the publications have been issued by the U.S. Office of Management and Budget.
- *Statistics of Income and Related Administrative Record Research* (1981–84), U.S. Internal Revenue Service. (Edited by Beth Kilss and Wendy Alvey.) This annual publication series contains numerous papers on record linkage topics and is a successor to the Social Security publications: *Statistical Uses of Administrative Records With Emphasis on Mortality and Disability Research* (1979) and *Economic and Demographic Statistics* (1980), which also may be useful.
- *Statistical Uses of Administrative Records: Recent Research and Present Prospects* (1984), U.S. Internal Revenue Service. (Edited by Thomas Jabine, Beth Kilss, and Wendy Alvey.) This handbook of recent work includes many papers on data linkage, most of which are also found in the series listed previously.
- *Studies From Interagency Data Linkages* (1973–80), U.S. Social Security Administration. (Produced under the general editorial supervision of Fritz Scheuren.) Of special interest may be the bibliography by F. Scheuren and W. Alvey (1975), "Selected Bibliography on the Matching of Person Records From Different Sources," which will be found in Report No. 4 in the series, pages 127–136.
- *Policy Analysis with Social Security Research Files* (1978), U.S. Social Security Administration. (Edited by Wendy Alvey and Fritz Scheuren.) Most of the research files described are based on data linkage methodologies.
- *Accessing Individual Records from Personal Data Using Non-Unique Identifiers*, National Bureau of Standards, NBS Special Publication 500–2.

Additional citations to the recent literature on disclosure which may be of value are given below. Some of these are of interest as general background; others focus specifically on disclosure barriers to data linkage.

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Appendix B
Taxpayer opinion question on sharing Internal Revenue Service data

Yankelovich, Skelly and White, Inc. (1984)
1984 General Purpose Taxpayer Opinion Survey

60a. As you may know, the IRS has been required by law to keep all of their records confidential. However, some people feel the IRS should share this information with other government departments in order to save money and reduce bureaucratic waste since those departments also need this information to do their work. Others feel that the taxpayer's right to privacy is more important. For which, if any, of these departments or purposes do you think it would be all right for the IRS to provide information?

a. The Census Bureau	24%
b. Major criminal investigations (such as drugs and organized crime)	43%
c. Investigations of illegal aliens	34%
d. Welfare fraud investigations	48%
e. Draft Boards or Selective Service	17%
f. Other U.S. Federal departments	12%
g. State governments	13%
h. Child support investigations	38%
i. Fraud and embezzlement investigations	43%
j. Other	1%
k. None (should keep records private)	31%
l. Don't know/no answer	4%

Appendix C
Record matching information for the National Health Interview Survey 1984 Supplement on Aging

Question 16

▶ *Read to respondent* – **In order to determine how health practices and conditions are related to how long people live, we would like to refer to statistical records maintained by the National Center for Health Statistics.**		RT 69 3–4
16a. I have your date of birth as *(birthdate from item 3 on HIS-1 Household Composition page).* **Is that correct?**	Date of birth Month | Date | Year	5–11
b. In what State or country were you born? *Write in the full name of the State or mark the appropriate box if the sample person was not born in the United States.*	99 ☐ DK ____________________ State 01 ☐ Puerto Rico 02 ☐ Virgin Islands 03 ☐ Guam 04 ☐ Canada 05 ☐ Cuba 06 ☐ Mexico 98 ☐ All other countries	12–13
c. To verify the spelling, what is your full name, including middle initial?	Last	14–33
	First	34–48
	Middle initial	49
Verify for males; ask for females. **d. What was your father's LAST name?** *Verify spelling. DO NOT write "Same."*	____________________ Father's LAST name	50–69
▶ *Read to respondent* – **We also need your Social Security Number. This information is voluntary and collected under the authority of the Public Health Service Act. There will be no effect on your benefits and no information will be given to any other government or nongovernment agency.** *Read if necessary* – **The Public Health Service Act is title 42, United States Code, section 242k.**	999999999 ☐ DK ☐☐☐-☐☐-☐☐☐☐ Social Security Number	70–78
e. What is your Social Security Number?	*Mark if number obtained from* → 1 ☐ Memory 2 ☐ Records	79

Instructions

1. Read the introductory statement above item 16 to explain the purpose of obtaining the information.
2.[1] When asking 16a, insert the birth date from the HIS-1, Household Composition Page. If the birth date recorded in the HIS-1 is in error, make no changes to the HIS-1 entry, but enter the correct birth date in the answer space in 16a and note "Date verified." If you determine that the person is actually under 55 years of age, footnote the situation and continue the interview. Do not make any changes to the HIS-1(D16-2) or to the supplement. Mark Check Item S2 in Section S based on the original HIS-1 age.
3. Enter the full State name on the line in 16b; do not use abbreviations. If the sample person was not born in one of the 50 States or the District of Columbia, mark the appropriate box in 16b, leaving the State line blank.

4a. If questions arise in 16c, we want the name the sample person is legally known by. If the person has more than one middle name, enter the initial of the first one given. Some women use their maiden name as a middle name; accept the response as given. Be sure to verify the spelling and record the last name first in this item.

4b.[1] It is acceptable to record an initial as the first name in 16c if this is how the person is legally known. Even if such a person uses their full middle name, only the

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[1] Revised February 1984.

middle initial is necessary. For example, G. Watson Levi would be recorded as Levi, G., W. in 16c. Do not record name suffixes such as "Sr.," "Jr.," "III," etc.

5a. When verifying 16d for males, ask "Was your father's last name ______?" Always ask the question for females, regardless of their marital status. Be sure to verify the spelling.

5b. Enter the last name of the sample person's father in the answer space, whether it is the same as the person's name or not. Always verify the spelling, even if the names sound alike. If it is volunteered that the person was legally adopted, record the name of the adoptive father.

NOTE: Take special care to make the entries in 16b-d legible. Printing is preferred.

6. Read the introduction to 16e to all respondents. If you are asked for the legal authority for collecting social security numbers, cite the title and section of the United States Code, as printed below the introduction. If you are given more than one number, record the first 9-digit number the respondent mentions, not the first one issued. If the number has more than 9 digits, record the first 9-digits. Do not record alphabetic prefixes or suffixes.
7. After recording the social security number, mark the appropriate box indicating whether the number was obtained from memory or records.

Sensitive questions in the 1984 Supplement on Aging

There are no questions considered to be sensitive on either the core series of items or the supplement. However, certain information may be considered sensitive and the following explanation of the need for the data is provided regarding social security number and the subject of incontinence.

- Social Security Number and National Death Index Match

So that in the future the National Center for Health Statistics (NCHS) may investigate the relationship between the results of the "Supplement on Aging" data and causes of death, the supplement collects the appropriate information (items 11a-11e of questionnaire Section 3, Occupation/Retirement), particularly the social security number, that will enable monitoring the National Death Index records for sample persons.

The cost-effectiveness of this supplement is enhanced by the availability of the National Death Index (NDI). Data on the future mortality of the survey population will be available with minimum expenditures by means of a computer search of the NDI. Information on age at death, cause of death, residence at time of death, and place of death can be easily ascertained from a copy of the death certificate obtained from the appropriate vital records office. This additional information can be integrated with data from the original survey to greatly enrich the scope of the analysis. Extensive information on the health status of the elderly is being collected on the original survey. Information obtained from death certificates will allow investigators to relate these health status measures to longevity and cause of death. It will also be possible to determine whether selected behavioral and socioeconomic factors collected at the time of the original survey, such as living arrangements, affect the relationship between health characteristics and mortality.

Several years after the data collection and preparation are completed, a list of all survey respondents will be submitted to the NDI and a search made to determine which respondents had died during the interim period. Additional searches of the NDI will be carried out on a periodic basis. In order to optimize the successfulness and reduce the cost associated with these searches, the following information must be collected as part of the original survey: social security number, full (legal) name, date of birth, State of birth, race, sex, and marital status. Ascertainment of social security number is most essential. A search of the NDI which uses social security number should produce only one match if the subject is deceased. The other information is then used to verify the match. The result of such a match identifies a death certificate which can be obtained from the State with reasonable certainty that it is in fact for the subject. If a social security number is not available, multiple matches within the age range established will occur, especially for common names. This would necessitate obtaining death certificates from several States and attempting to determine whether any of them is for the subject. These false positives would add both acquisition costs and staff costs to the death search process, as well as introducing error.

Interviewers will verify the person's name and birth date (which may have been provided by the household respondent on the core questionnaire), and obtain the last name of the person's father. The social security number will also be requested and if the person is unable to recall the number, he or she will be asked to check the card. This information is not thought to be sensitive; however, respondents will be reminded of the voluntary and confidential nature of the survey, the purpose of the data collection, the legislative authority under which the information is being collected, and the absence of any penalty for refusal. Nonresponse to any of these items will not affect most of the analyses planned for the supplement; however, provision of social security numbers allows for future epidemiologic research for this population without the necessity of conducting a separate longitudinal or followback survey.

- Incontinence

NCHS's and the National Institute on Aging's interests in general physical problems of older people, which relate directly to their quality of life, include questions on urination and bowel control (Pretest Questionnaire Section V, Items 6a–6e, 7a–7e). One issue is the relationship of incontinence to the aging process. In this case, incontinence can be viewed as a health problem, independent of other illnesses. In order to examine this issue, it will be necessary to collect data from all persons in the 55-and-over age group (so that their effects can be examined) and from people both with and without other illnesses.

In addition, a substantial part of the interest in the problem of incontinence results from the relationship between incontinence and institutionalization. It is the view of some experts consulted that incontinence is one of the main reasons for the decision to institutionalize an older person.

Considerable effort went into wording these questions both to minimize sensitivity and to assure comparability with similar items proposed for the 1985 National Nursing Home Survey. Analysis of comparable data for both the institutionalized and noninstitutionalized populations from the two surveys is planned.

Appendix D
Record matching information for the Survey of Income and Program Participation

Question 33

CARD B—Continued
COMMON QUESTIONS AND SUGGESTED ANSWERS

I thought that the Bureau of the Census operated only every 10 years, when they counted people. What is the Bureau of the Census doing now?

In addition to the decennial census, which is conducted every 10 years, the Bureau collects many different kinds of statistics. Other censuses required by law are conducted on a regular basis including the Census of Agriculture, the Censuses of Business and Manufactures, and the Census of State and Local Governments. In addition, we collect data on a monthly basis to provide current information on such topics as labor force participation, retail and wholesale trade, various manufacturing activities, trade statistics, as well as yearly surveys of business, manufacturing, governments, family income, and education.

Why does the Census Bureau want to know my social security number?

We need to know your social security number so we can add information from administrative records to the survey data. This will help us avoid asking questions for which information is already available and help to ensure the completeness of the survey results. The information we obtain from the Social Security Administration and other government agencies will be protected from unauthorized use just as the survey responses are protected.

PGM 2

O M B No 0607-0425 Approval Expires June 30 1984

FORM **SIPP-4001**
(6 25 83)

U S DEPARTMENT OF COMMERCE
BUREAU OF THE CENSUS

CONTROL CARD

SURVEY OF INCOME AND PROGRAM PARTICIPATION

NOTICE – Your report to the Census Bureau is confidential by law (title 13 U S Code). It may be seen only by sworn Census employees and may be used only for statistical purposes

1 REGIONAL OFFICE CODE

2 CONTROL NUMBER — PSU | Segment | Segment suffix | Serial | Sample S 8 4

3 ADDRESS I D

4 SEGMENT TYPE
1 ☐ Address
2 ☐ Unit
3 ☐ Permit
4 ☐ Area
5 ☐ Special place

	WAVE 1	2	3	4	5	6	7	8	9
5a Interviewer code									
5b Letter sent	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No

6a EXTRA UNIT Original unit serial number

6b Sheet ____ Line ____

6c OFFICE USE ONLY

7 Wave for which Control Card first prepared

HOUSEHOLD RECORD (Card ____ of ____)

FILL ITEMS 17 - 20 FOR ALL PERSONS LIVING OR STAYING HERE

17 ENTRY ADDRESS I D
PGM 3

18 PERSON NUMBER
Assign 101, 102, etc for wave 1, 201, 202, etc for wave 2

19a HOUSEHOLD ROSTER
FIRST INTERVIEW AT ORIGINAL ADDRESS
What are the names of all persons living or staying here? Start with the name of the person or one of the persons who (owns, rents) this home. Please include middle and maiden names.
Last, first, middle, maiden
FIRST INTERVIEW AT MOVER'S NEW ADDRESS for mover's new address – Fill items 17 - 19a, 24 - 33c before the interview

* **19b** RELATIONSHIP TO REFERENCE PERSON (RP)
Ask if not apparent
What is . . .'s relationship to *(Read name of RP)*?
Example Reference person, wife or husband son, daughter, son in law, sister, foster son, partner, lodger, lodger's wife
See codes in Information Booklet
Code | Update

20 HOUSE HOLD MEMBER
Does . . . usually live here?
1 Yes
2 No *Probe for URE*
Yes 1 ☐ | No 2 ☐

FILL (OR UPDATE AS APPROPRIATE) ITEMS 23 - 33 FOR HOUSEHOLD MEMBERS ONLY *Ask each item for entire household before asking next item*

* **23** DATE ENTERED OR LEFT
Complete if instructed by item 21 enter code and date
See codes below
First occurrence: Code | Mo | Day
Update: Code | Mo | Day

* **24** BIRTH DATE/AGE
a. What is . . .'s date of birth?
example 01 20 1963
12 01 1924
Verify age using flashcard
b . . . is now *(Read age)* **years old, is that correct?**
Mo | Day | Year | Age | Age update

* **25** PERSON NUMBER OF PARENT
Refer to 18 and 19b If none enter "999"

ASK IF 15 OR OLDER

* **26a** MARITAL STATUS
Is . . . now –
Married
1-Sp. Pres
2-Sp. Abs.
3-Widowed
4-Divorced
5-Separated OR
6-Never married?
Code | Update

* **26b** PERSON NUMBER OF SPOUSE
Refer to 18, 19b and 26a If none enter "999"

* **27** DESIGNATED PARENT OR GUARDIAN
Fill for "Never married" persons under 18 If no parent, ask **Who in this household is responsible for . . .?**
Enter person number

28 SEX
Ask if not apparent
Is . . .
1 Male or
2 Female?
M 1 ☐ | F 2 ☐

29 RACE
SHOW FLASH CARD
What is the race of each person in this household?
See codes below

30 ORIGIN
SHOW FLASH CARD
What is the origin or descent of each person in this household?
See codes below

ASK IF 15 OR OLDER

EDUCATION

* **31a** **What is the highest grade or year of regular school . . . has ever attended?**
See codes below
Code | Update

* **31b** **Did . . . complete that grade (year)?**
1 Yes
2 No
Yes 1 ☐ | No 2 ☐

ARMED FORCES

32a **Did . . . ever serve on active duty in the U.S. Armed Forces?**
1 Yes
2 No
Yes 1 ☐ | No 2 ☐

If "Yes" in 32a ask

32b **When did . . . serve?**
See codes below

32c **Is . . . now in the Armed Forces?**
1 Yes
2 No
Yes 1 ☐ | No 2 ☐

GO TO ITEM 33a

21 HOUSEHOLD ROSTER COVERAGE

• FIRST INTERVIEW

21a **I have listed** *(Read names from item 19a)*, **have I missed** – *If "Yes," to any of the following, ask name and complete items 17 – 20 above* PGM 4

		Yes	No
– **Any babies or small children?**	0010	1 ☐	2 ☐
– **Any lodgers, boarders, or persons you employ who live here?**	0012	1 ☐	2 ☐
– **Anyone who usually lives here but is away now – traveling, at school, or in a hospital?**	0014	1 ☐	2 ☐
– **Anyone else staying here?**	0016	1 ☐	2 ☐

• FIRST INTERVIEW AT MOVER'S NEW ADDRESS

		Yes	No
21b **I have listed . . .** *(Read names from item 19a)*. **as now living at this address. Is this correct?** *If NO, ask* – **Which person did not move here?**	0018	1 ☐	2 ☐
21c **When did . . . move in here?** *Enter appropriate code and date in item 23*			
21d **Is there anyone else living or staying here now?** *If YES, ask name and complete items 17 - 19a, then ask* **When did . . begin living here?** *If moved in before sample person(s), enter code "4" in item 23 and omit date* *If moved in at the same time or after sample person(s), enter appropriate code and date in item 23*	0020	1 ☐	2 ☐
21e **Which of these persons (owns/rents) this home?** *Assign as reference person in item 19b*			

22 HOUSING UNIT COVERAGE

• FIRST INTERVIEW

22a INTERVIEWER CHECK ITEM
Unit is ☐ In a special place *SKIP to 24 above*
☐ Not in a special place *ASK 22b*

Ask if not apparent

22b **Do all persons in this household live OR eat together?**
☐ Yes - *ASK 22c*
☐ No, neither live nor eat together - *Fill Table X for the person or group of persons not living or eating with RP*

Ask if not apparent

22c **Does any other household on the property live OR eat with this household?**
☐ Yes *Redefine the unit to include space occupied by all persons who live or eat together Apply merged unit procedures if appropriate*
☐ No
GO TO ITEM 24 ABOVE

• SUBSEQUENT INTERVIEWS

	W2	W3	W4	W5	W6	W7	W8	W9
21f **I have listed . . .** *(Read names from item 19a)*. **Are all of these person still living or staying here?** *If NO, ask* **Who no longer lives here? When did . . . leave?** *Enter appropriate code and date left in item 23 Probe, if necessary, for reason left If entire household moved complete item 23 determine new address (item 34) and end interview*	0022 1 ☐ Y 2 ☐ N	0026 1 ☐ Y 2 ☐ N	0030 1 ☐ Y 2 ☐ N	0034 1 ☐ Y 2 ☐ N	0038 1 ☐ Y 2 ☐ N	0042 1 ☐ Y 2 ☐ N	0046 1 ☐ Y 2 ☐ N	0050 1 ☐ Y 2 ☐ N
21g **Is anyone else living or staying here, including new born babies?** *If YES, ask name and complete items 17 - 20 above, then ask* **When did . . . begin living here?** *Enter appropriate code and date in item 23* **Anyone else?**	0024 1 ☐ Y 2 ☐ N	0028 1 ☐ Y 2 ☐ N	0032 1 ☐ Y 2 ☐ N	0036 1 ☐ Y 2 ☐ N	0040 1 ☐ Y 2 ☐ N	0044 1 ☐ Y 2 ☐ N	0048 1 ☐ Y 2 ☐ N	0052 1 ☐ Y 2 ☐ N

CODES FOR 23

Entered
1 Birth
2 Marriage
3 Other
4 (Use only with item 21d)

Left
5 Deceased
6 Institutionalized
7 Living in Armed Forces barracks
8 Moved outside of country
9 Separation or divorce
10 Person number 201 no longer living with sample person
11 Other

CODES FOR 30

01	German	10	Norwegian	19	Central or South American (Spanish speaking)
02	English	11	Russian	20	Other Spanish
03	Irish	12	Ukrainian	21	Afro Amer (Black or Negro)
04	French	13	Welsh	30	Another group not listed
05	Italian	14	Mexican American	39	Don't know
06	Scottish	15	Chicano		
07	Polish	16	Mexican		
08	Dutch	17	Puerto Rican		
09	Swedish	18	Cuban		

CODES FOR 31a

00	Never attended or kindergarten
01 08	Elementary
09 12	High school
21 26	College (Academic)

CODES FOR 29

1 White
2 Black
3 American Indian Eskimo or Aleut
4 Asian or Pacific Islander
5 Other *Specify below*

Person No	*Specify race*

CODES FOR 32b

Enter code in descending order of priority Thus if person served in Vietnam and in Korea enter "1"

1 Vietnam Era (Aug 64 April 75)
2 Korean Conflict (June 50 Jan 55)
3 World War II (Sept 40 July 47)
4 World War I (Apr 17 Nov 18)
5 May 1975 or later
6 Other Service (All other periods)

SOCIAL SECURITY

33a Person number
Enter person No from item 18

★ **33b** **What is . . .'s Social Security (or Railroad Retirement) number?**
If don't know ask
If I call back, would . . . be able to provide this information?
If "Yes," mark reminder card

33c Nonresponse
Mark the appropriate box
1 Don't know
2 Refusal
3 None
1 ☐ 2 ☐ 3 ☐

INTERVIEWER [illegible]

Statistics for an aging population, dealing with uncertainty[a,b]

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Policymakers often ask questions that are hard for statisticians to answer. Someone concerned with policy for an aging population, for instance, might ask: "In 2015, what will be the health needs of the population 65 and over in the United States?" Because of uncertainties that arise from definitions, from data sources, and from the difficulty of extrapolation into the future, it is difficult to answer any such question with a high degree of confidence. Uncertainties matter, however. In 1982 the *possibility* that the deficit in the Social Security Trust Funds could average more than $91 billion over the next 75 years helped to convince Congress to make major changes in the system.

This paper describes the kinds of uncertainties that appear in statistical data used to guide policy and discusses some methods that statisticians and policy analysts can use to deal with uncertainty. The first section lays out common sources of uncertainty and, in the process, illustrates the broad meaning of the term. The next section discusses ways to reduce the uncertainty from these sources. The third section discusses the importance of recognizing and explicitly dealing with the uncertainty that is inherent in policy problems. The next section explores four approaches for measuring and expressing uncertainty in quantitative terms. The paper closes with four recommendations for improving our ability to deal with uncertainty. Throughout, the paper uses statistics on aging populations as examples, but the issues and methods are more general.

Sources of uncertainty

"Uncertainty" in policy data comes from a number of sources. For the purpose of discussion, let us consider them in four groups:

1. Definitions. Uncertainties arise in reconciling multiple data sources, each employing different definitions, and in using data for policy problems that do not exactly correspond to the original definitions.
2. Sampling errors in surveys.
3. Nonsampling errors. Sometimes known as "bias," this kind of uncertainty includes problems such as age misstatement and reporting errors.
4. Scientific uncertainty. This arises from the use of scientific theory, whether simple or sophisticated, to fill in the gaps left by missing data or to use data for policy purposes for which they were not originally intended. It includes errors due to extrapolation, especially into the future, and the use of models.

The remainder of this section illustrates the different kinds of statistical uncertainty by reviewing a series of policy issues that exemplify the different sources. Although not exhaustive, the list does identify most of the major sources of uncertainty in statistics for an aging population. There is overlap among the categories, but the list should serve well as a vehicle for discussing approaches to reducing and dealing with uncertainty.

Question 1. In 1980, how many people 65 and over were there in the United States?

Two kinds of uncertainty arise in the answer to this question: problems with definitions and two kinds of nonsampling errors.

Place of residence—What does "in the United States" mean? The decennial census uses a concept of "usual residence" to answer this question. Although the precise definition is complex, the goal is to include everyone residing in the country on the day of the census, including U.S. residents temporarily abroad on business or vacation travel and excluding foreign residents temporarily in the United States. This definition does not involve citizenship or legal or tax residence. Depending on their purposes, the Social Security Administration, the Internal Revenue Service, and the Republican National Party, for instance, employ different definitions and come up with different population figures. As an example, in 1979 the population covered by the Social Security system (which includes U.S. citizens living abroad, residents of U.S. territories, and an estimate for census undercount) was 2 percent larger than the resident population (Faber and Wilkin, 1981).

The same uncertainty takes on even more significance for smaller geographic areas. In recent years, it has become common for retired people to winter in places with warm climates. The concept of "place of usual residence" used in the decennial census, however, was developed before such regular migration became common. Because of uncertainty about how these people should answer the census question about where they live, and because the census date, April 1,

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[a] Contents are the opinions of the author and not those of the Department of Health and Human Services or the organization he works for.

is close to the time that many of them move back north, the census contains substantial uncertainty about the size of the aged population in places with high seasonal migration.

Age misstatement—In most data sources, including the decennial census, age data come from the individuals involved or other informants. Ages are not verified against independent sources. Comparison of individual records from different sources shows that the inconsistency in age data increases with age, and that age tends to be overstated (Siegel and Davidson, 1984). The amount of age misstatement varies in an unknown way from one data source to another and contributes a major source of uncertainty. In 1970, for instance, perhaps 2 percent of the total population reported to be 65 or older was actually under 65 and the proportion for males of races other than white was 9 percent (Siegel and Davidson, 1984).

Population undercount—In the decennial census an unknown proportion of the population fails to be enumerated. Based on comparisons with other statistical records, such as Medicare enrollment, past censuses, and independent surveys, the Census Bureau has estimated that 1.4 percent of the population 65 and over was not counted in the 1980 census. This estimate, however, is itself subject to error. Furthermore, the proportion not counted varies substantially with age, race, and sex. For the population aged 75 and older, for example, the estimate ranges from a 0.6-percent undercount for white males to a 4.7-percent overcount for black females (Siegel and Davidson, 1984).

Question 2. In 1985, how many people 65 and over are there in the United States?

It is substantially harder to estimate the population in a noncensus year than in a census year. Such estimates must depend either on data (often vital statistics) to fill in the time gap, or on mathematical assumptions about how to extrapolate the available data, or both. Each of these brings additional sources of uncertainty.

Intermediate estimates—If births, deaths, and immigration figures are to be used to bring population estimates forward from a census to a current year, they must be timely. In fact, final versions of vital statistics are often delayed a few years, and intermediate estimates involve substantial uncertainties. Immigration and emigration data are even more problematical. Since the 1950's, the United States has not kept statistics on the number of residents leaving the country to live abroad. Passel (1985) has estimated that more than 133,000 former immigrants leave the country every year. Moreover, 1 to 4 million Mexicans alone entered the country illegally each year during the 1970's (Warren and Passel, 1983; Bean, King, and Passel, 1983).

Extrapolation—If timely vital statistics or other data are not available, demographers must resort to extrapolating trends from past years. This could mean simply extrapolating the total population 65 and over; extrapolating the population by age, sex, and race components; or extrapolating past trends in vital statistics and migration and applying them to the last census population figures. Different extrapolation methods often lead to quite different estimates, and it is usually not clear which of the many possible methods is most appropriate.

Question 3. In 2015, how many people 65 and over will there be in the United States?

Extrapolation—The problems associated with extrapolating population data from a census year to the current year are compounded when making population forecasts. The data must be extrapolated over a longer period so that the specification of the functional form and interrelationships of the variables becomes more important.

Unknown future—All projections rely on (sometimes hidden) assumptions about what remains constant. In forecasts of the population 65 and over, for instance, assumptions about future mortality rates are crucial. Various analysts have assumed that age-specific mortality rates would remain constant, that the rate of change in the mortality rates (over the last so many years) would remain constant, that the rate of change in age-specific mortality rates would remain constant, and so on. In making short-term extrapolations from a past census to the present, even when we cannot get accurate data on death rates, sometimes we can assess through indirect nonsystematic means whether the trends are holding. When projecting into the future, obviously we cannot.

Question 4. In 2015, what will be the health needs of the people 65 and over in the United States?

Definition of health needs—"Health needs" are neither easily nor well defined. First, they include many dimensions. Need can be measured by the number of people with various types of health problems; by demands on health care providers for various sorts of hospital, outpatient, and nursing home care; or in other ways. Second, the needs themselves can be defined by absolute level of care deemed medically desirable, by comparison with the needs of presumably well served populations, or by other means. Each definition leads to different estimates of health demands. In projecting health needs from 1980 to 2040, Rice and Feldman (1983) have found that the number of elderly (65 years and over) with limited ability to perform the "activities of daily living" will increase by 233 percent, the number of elderly nursing home residents will increase by 319 percent, and nursing home expenditures for this same group will increase by 160 percent.

Conceptual problems with definitions arise in other areas as well: we tend to think of retirement, for instance, as a binary choice, but many intermediate steps lie between fully employed and totally unemployed.

Survey error—Sample surveys of individuals provide many measures of health status and health needs. These data have two types of uncertainty. The first, and simplest to deal with, is *sampling error*, which arises because the selected random sample might differ from another that might have been selected. An important determinant of sampling error is sample size. Because the aged population makes up a relatively small proportion of the overall population, nationally representative samples that provide a reasonably small sampling error overall may have an unacceptably high sampling error for questions asked of the aged population. Second, the other sources of error are known collectively as *nonsampling error* (Mosteller, 1978). This category includes, for instance, differential nonresponse by particular subpopulations and errors due to self-reporting. Measures of absolute health needs often rely on individuals' self-reports of their health status, which may be more difficult to interpret than more expensive measures based on physician examinations.

Interactions—Estimates of future health needs are often obtained by multiplying estimates of future population by per capita utilization rates. The work by Rice and Feldman (1983) mentioned previously is a prominent example. These utilization rates (the average number of hospital days per year for a 70-year-old man, for example) are based on current values or extrapolation of current trends. But complex interactions may cause utilization rates to change. For instance, because of their increased political influence, the per capita level of services provided or demanded may be higher in places where there is a large concentration of elderly. Additionally, the definition of need may change with the introduction of new services. Many health policymakers are concerned, for instance, that the introduction of home health care as a substitute for nursing homes will drastically increase the demand for such services (General Accounting Office, 1982).

Reduction of uncertainty

One way, and in some respects the best way, to deal with uncertainty is to get better data. Gathering more data, taking more care in its collection, or more thorough analysis can help reduce uncertainty from each source mentioned previously. For some problems it is relatively feasible and inexpensive to gather more data or perform more analyses, and this is a reasonable short-term solution. For other problems, however, such responses are at best long-term solutions; often little can be done in the short term. The next section describes methods for living with uncertainty that cannot be removed.

Definitions—If uncertainty arises from differing definitions, our first response is to seek agreement on a single definition. In practice, however, this is very difficult. First, in most policy questions the relevant data come from a variety of different organizations, each with its own data needs. Regarding the definition of the U.S. population discussed earlier, the Social Security Administration and the Internal Revenue Service will not be easily convinced to redesign their statistical systems to accommodate health planners. Second, even if agreement on a common definition were achieved, it often is not possible to readjust data for past periods.

Some problems with definitions are conceptual and hence difficult to resolve by any means. The different definitions of health needs, for instance, reflect truly different concepts, and a single answer would be misleading. Two major Census Bureau surveys, the Current Population Survey (CPS) and the Survey of Income and Program Participation (SIPP), use different definitions of personal income—SIPP includes income from government programs that CPS excludes—because they have different purposes. Furthermore, statisticians and policymakers must choose between relatively simple definitions that are easy to operationalize and more complex definitions that may be more relevant but more difficult to implement.

Sampling errors—In theory, uncertainty due to sampling errors can be resolved very simply by increasing sample size. In order to get better statistics on the aged population, it may be necessary to oversample the aged in nationally representative surveys or to arrange for special surveys of the elderly. In 1980, 17 percent of the adult population of the United States was 65 or older. These numbers alone suggest that, to equal the sampling error of the population as a whole, the elderly must be oversampled by a factor of about 6. In some instances, sampling error can also be reduced by using more complex sampling procedures.

Nonsampling errors—This residual category of sources of uncertainty in survey and census data, which includes problems of nonresponse and self-reporting, offers no easy solutions. In particular, these errors do not decrease as sample sizes increase. Furthermore, there is a tradeoff between sample size and nonsampling error. In larger samples, especially if they involve more personnel and data from multiple institutions, coordination problems often lead to greater nonsampling errors. In the long run the development of better survey instruments and more careful collection of statistical data are necessary. (See, for instance, Kruskal, 1981.) A large-scale national longitudinal survey of the elderly population suggested by Branch et al. ("Health indicators for an aging population" in Chapter II of this report) would go a long way toward reducing nonsampling error. In addition, as with the problem of definitions, relevancy often competes with simplicity of operation.

In the short run, statisticians can sometimes adjust data by building a model to describe nonresponse or self-reporting problems or by using ancillary data. However, such approaches usually depend on unverifiable assumptions about the structure of the data or the problem. For instance, statisticians sometimes address nonresponse problems by assuming that the people who did not respond are the same as the respondents, are similar to some other group, or have a particular reason for not responding. In some problems, the assumptions in the adjustment method may introduce more uncertainty than is removed by the adjustment itself. The estimates of census undercount mentioned previously may be an example (Stoto, 1983b).

Scientific uncertainty—Social scientists often try to reduce uncertainty by building formal models or by carrying out social experiments. In estimating future health needs, demographers disaggregate by age, race, and sex, as well as by components of change such as cause-specific mortality rates, and look for simpler trends than are present in the aggregate data. Econometricians build regression-based models and bring in variables that they think determine health behaviors and the supply and demand of medical care. Biometricians build models that attempt to realistically represent disease processes. Social experiments, in which individuals or entire groups are actually exposed to an innovation, are more difficult to perform but may give more realistic answers (Rivlin, 1974; Gilbert, Light, and Mosteller, 1975; Fienberg, Singer, and Tanur, 1985).

Formal models are essential for both forecasting and interpreting the results of social experiments. All forecasts require some theory about what remains constant. Social programs are complex and change quickly; experiments based on one version of the program need some theory for translating their findings to a new situation. Formal models, however, have intrinsic limitations. All models involve difficult to check judgments and assumptions about theory and data. Important interactions, resulting from complicated social and political accommodations, are often unforeseen. Investigations have shown that more complex models do not necessarily result in more accurate forecasts of aggregate measures (Armstrong, 1978; Stoto, 1982, 1983a). These factors suggest that formal models offer only a limited potential for reducing uncertainty.

Living with uncertainty

In most important policy questions, decisionmakers press for quick answers. Once the policy options are on the table, it is rare for a statistician or policy analyst to have a year or more to study a problem before a decision is made; more frequently, answers must be available in a matter of months, weeks, or even days. In such short timeframes, the techniques for reducing uncertainty described in the previous section cannot be employed; policy analysts and decisionmakers must somehow live with the information that is available. Most decisions, however, are subject to revision as more facts develop. Living with uncertainty involves making the most of available data and being conscious of the opportunities for getting better data and revising policies.

The situation facing the Social Security Administration, the President, and the Congress in 1982 illustrates the potential contribution of being specific about uncertainty. The actuaries of the Social Security Administration had prepared three projections of the income and costs of the Old Age and Survivors Insurance and Disability Insurance (OASDI) Trust Funds under alternative sets of demographic assumptions shown in figure 1. In monetary terms, the difference between them was great, more than 50 percent of outlays in some years (Congressional Budget Office, 1982). Over the 75-year period, the shortfall could average as much as 6.5 percent of the taxable payroll (Koitz, 1982). In 1982, 1 percent of payroll equaled $14 billion, so the average annual deficit under the pessimistic assumption would have been $91 billion.

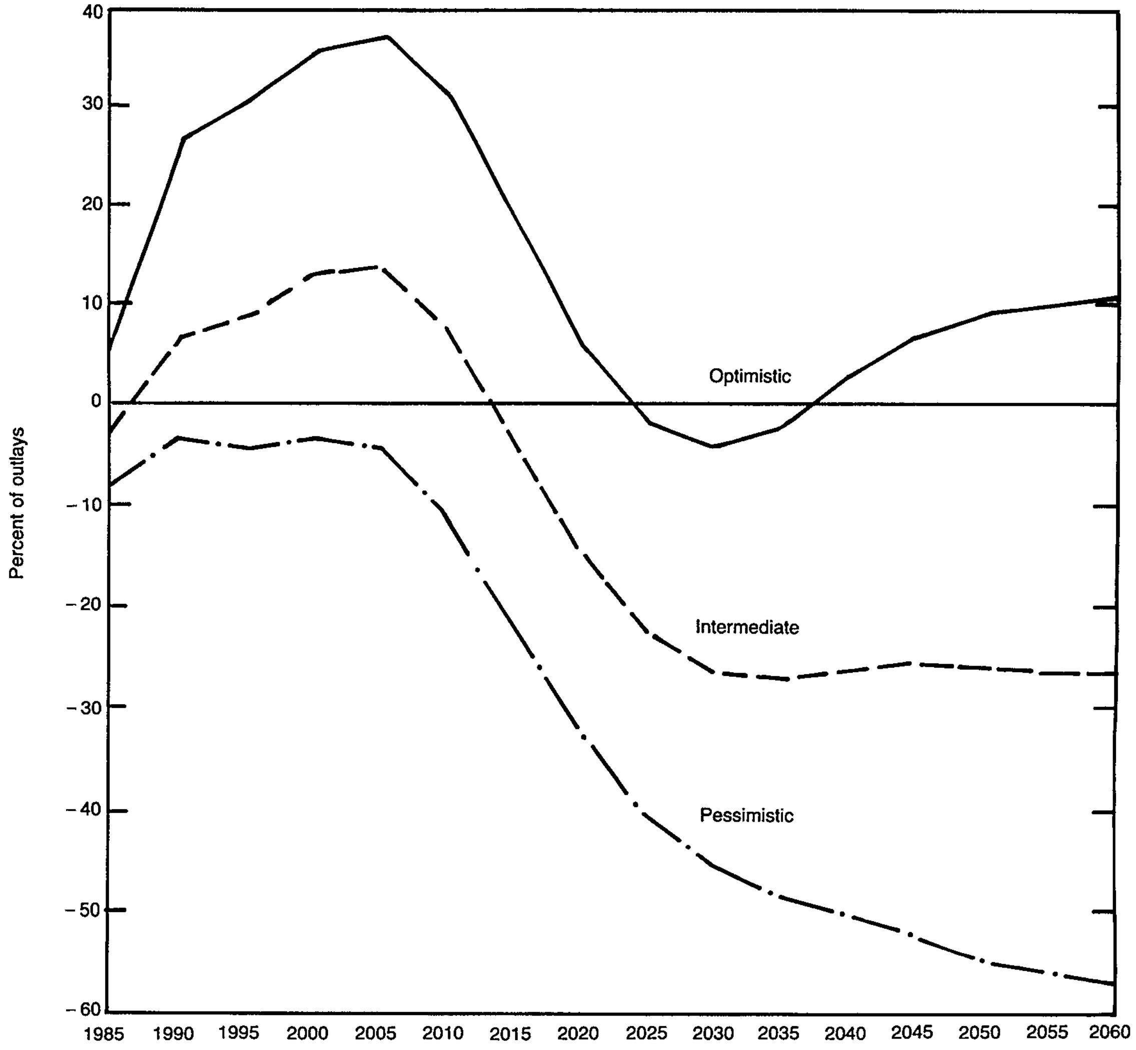
A proponent of the status quo, relying on the optimistic assumption, could argue that no changes were needed. But the lesson of the figure is that there is a good chance that action is needed now. If we wait until the next century to decide whether to increase payroll taxes or reduce retirement benefits, we will have missed the opportunity to build up a surplus in the trust funds in the intervening years. Projections like the one summarized in figure 1 played a large part in convincing the Congress in 1982 to make major changes in future Social Security taxes and benefits.

The simplest and most common way that decisionmakers deal with uncertainty is to ignore it (Fischhoff, Slovik, and Lichtenstein, 1977). In the game of bureaucratic politics, "he who hesitates loses his chance to play at that point and he who is uncertain about his recommendation is overpowered by others who are sure" (Allison, 1971, p. 171). Ignoring uncertainty takes a variety of forms. At one extreme, an advocate for a particular course of action could seize upon the most extreme projection that favors his or her approach regardless of the plausibility of the projection's assumptions. At the other extreme, a decisionmaker could consider the range of forecasts of population growth, employment and retirement patterns, and so on, and make his or her best honest judgment about future needs. Neither approach leads to good policymaking.

The Social Security example illustrates the danger in selecting the most favorable projection for a particular policy approach. Policymakers regularly consult demographic and economic forecasts in determining the Social Security payroll tax, benefit levels, and other matters. The 1982 projections suggested that the next few decades offered an opportunity to build up the Social Security Trust Fund to help support the retirement benefits of the Baby Boom population in the next century. But since increasing payroll taxes and building up the trust fund have implications for today's economy and individual welfare, too much investment also has serious costs. Selecting an extreme estimate may be convincing to an analytically unsophisticated audience, but it is bound to lead to too much or too little current investment. Unfortunately, the adversary system of decisionmaking common in many policy areas fosters such extreme estimates. The Social Security Commission that was established by President Reagan in 1982 was fortunately able to deal with the inherent uncertainty and forge a compromise (May and Neustadt, 1986).

Relying on an individual expert's single best judgment, even if an unbiased expert can be found, is still problematical. For example, retirement policies have differential costs and benefits for individuals through time. Furthermore, individuals differ in their aversion to risk, the amount they are willing to pay now to reduce uncertainty in the future. Decision theory tells us that if individuals are to make informed decisions, they need information on the range of possible outcomes and their relative likelihood (Raiffa, 1968; Stokey and Zeckhauser, 1978; Behn and Vaupel, 1982). A single best estimate, no matter how thoughtful and honest, is not enough. Faced with the uncertainty in future income and outlays of the OASDI Trust Funds, highly risk averse policymakers would increase payroll taxes now to ensure against the "pessimistic" forecast, even if the "intermediate" forecast were thought to be more likely.

Another problem with basing a policy decision on a single best estimate is that it ignores the possibility of gathering more information. In spite of the short timeframe for policy decisions discussed earlier, it is always possible to decide to delay or to review and revise in the future. Retirement security policy decisions, for instance, have a long time horizon and their major source of uncertainty is the extrapolation of demographic and economic trends into the future. In such situations, knowledge of the nature and magnitude of



SOURCE: Congressional Budget Office, based on 1982 Annual Report of the Board of Trustees, Federal Old Age and Survivors Insurance and Disability Insurance Trust Funds, Table 29, pp. 67–68.

NOTES: Optimistic assumptions = Alternative I. Intermediate assumptions = Alternative II–B. Pessimistic assumptions = Alternative III.

Figure shows the difference between revenues and costs in each year, rather than OASDI balances. Differences are on an annual basis, and are not cumulative from year to year.

Figure 1. OASDI surplus or deficit as a percentage of outlays under three alternative sets of assumptions, 1985–2060

forecasting uncertainty should help determine the need for and the frequency of periodic scheduled policy reviews.

If short-term consequences are dominant, it may be advisable to delay a decision if a critical piece of information can be made available shortly. With an accurate assessment of the nature and magnitude of the uncertainty and the feasibility and cost of gathering new information, decision theory can help determine whether the benefits of more information exceed the costs of delay and the additional expense of data gathering (Raiffa, 1968; Behn and Vaupel, 1982).

Thus, the way that statistical estimates and forecasts are used in the policy arena has two implications for statisticians and decisionmakers in dealing with uncertainty. First, we need to understand the sources of uncertainty so we can determine the possibility of reducing it in the long run or estimating it in the short run. Second, in order to employ formal or informal decision theory, we need quantitative measures of the amount of uncertainty in our estimates in terms of subjective probability.

Estimating and reporting on uncertainty

Many people regard uncertainty either as a quality that is present or absent ("these data are uncertain") or a matter of degree ("these data are highly uncertain"). But the language of subjective probability can and should be used to convey a clear and precise message to policymakers about the degree of uncertainty in a statistical estimate.

For instance, suppose the problem involves estimating the proportion of the U.S. population that will be 65 or over in the year 2015. In the most recent Census Bureau projections, the "middle" assumptions of mortality, fertility, and migration lead to an estimate of 15.4 percent, but everyone would regard this as "uncertain." A simple measure of uncertainty is a range of estimates. For instance, the Bureau has constructed a "high population growth" estimate of 14.9 percent and a "low population growth" estimate of 15.7 percent. Without knowing something about the likelihood of the assumptions, it is hard to know what to make of this range. It would be more informative to have a statement such as:

> "There is a 50 percent chance that the proportion will be between 14.7 and 15.8 percent, and a 90 percent chance that the proportion will be within 14.2 and 16.4 percent."

At the end of this section, I will return to this example and describe how I calculated these figures.

One alternative to quantitative estimates is to use words like "very likely," "probably," and "rarely." Research has shown, however, that these "probability words" mean different things to different people. Behn and Vaupel (1982), for instance, found that in a group of 163 students, the numerical interpretations of the phrase "It is probable that..." ranged from 20 to 98 percent. One-fourth of the students interpreted it to be less than 61 percent, and another one-fourth interpreted it to be greater than 80 percent.

Explicit quantification of uncertainty is important for two reasons. First, in order to employ the kind of formal decision analysis described in the previous section, quantitative estimates of subjective probabilities are needed. Formal decision analyses are rarely the deciding factor in a complex public policy decision. Such methods are, however, employed by policy analysts in synthesizing background information and making recommendations to decisionmakers. Second, even if there is to be no formal decision analysis, decisionmakers still need an accurate picture of the amount and nature of uncertainty.

Some people object to the use of numerical probabilities to express uncertainty. They say that using any numbers at all implies a false sense of precision. But the point is accurate communication. An expert who makes a statement about percentiles such as the one in the example above may or may not be correct, but at least we know what he or she intends.

The remainder of this section describes approaches for making formal or informal estimates of the amount of uncertainty associated with statistical estimates. None is completely satisfactory and some are controversial, but they offer a start.

1. Sampling theory

Of all sources of uncertainty, sampling error is the simplest to quantify and communicate. Introductory statistics books describe methods for calculating confidence intervals, and they need not be repeated here. The interpretation of these intervals is simple in theory, but in practice there is sometimes confusion.

One problem with using confidence intervals to measure and communicate uncertainty arises from their relative simplicity. Sampling error frequently contributes only a small part of the total uncertainty in statistical estimates. In good surveys, sampling error is often less than 10 percent of the quantity being estimated; there is often more uncertainty associated with differences in definitions, nonsampling error, and scientific uncertainty. But since there are no equally simple and objective measures of other sources of uncertainty, some analysts only report confidence intervals based on sampling error. Even if these analysts make it clear that these confidence intervals are lower bounds on the true uncertainty, the numerical results tend to be remembered and repeated by others and their limitations ignored or forgotten.

Statistical measures sometimes contain more uncertainty than sampling theory would suggest because of hidden heterogeneity. For instance, if individuals differ in mortality risks, the variance formulas for the binomial distribution ($p(1-p)/N$) will understate the true variance because of the formula's assumption that p is the same for all individuals. More realistic estimates can be obtained by examining the variation in p across different subgroups of the population (Mosteller and Tukey, 1977, Chapter 7) or by modeling the distribution of p in the population and estimating its parameters (Manton, Stallard, and Vaupel, 1981).

Some statistical estimation problems are too complex to allow the mathematical derivation of standard errors, and many analysts in this situation do not report any confidence intervals at all. A relatively new set of statistical techniques known as resampling plans provides a means for calculating variances in this situation. Suppose X is the statistic that is to be estimated from the available data. One technique, the jackknife, works by dividing the available data into groups and examining how X varies as each group is sequentially left out of the calculation (Mosteller and Tukey, 1977). Another technique, the bootstrap, draws samples with replacement from the available data and recalculates X a large number of times (Efron, 1982). In each method, the observed variability in the recalculated X values yields an estimate of the sampling variability and can be used to calculate confidence intervals. Like traditional confidence intervals, these methods estimate only sampling variability and not the other sources of uncertainty discussed in this paper.

2. Assessment of experts' subjective distributions

Statisticians have developed techniques for assessing and quantifying the uncertainty in expert estimates in the form of a subjective probability distribution (Raiffa, 1968; Spetzler and Stael von Holstein, 1975). These techniques, based on Bayesian updating and decision theory, have been used extensively in business problems, weather forecasting, and other areas. In essence, the methods offer the experts a series of choices between lotteries with known probabilities and lotteries dependent on the subjective distribution that is being elicited.

The difficulty with these methods lies not so much in the techniques but in the experts themselves. Investigations in a wide range of fields show that experts tend to be overconfident in their own estimates or predictions; that is, they tend to have subjective distributions that are too narrow (Behn and Vaupel, 1982; Tversky and Kahneman, 1974). A review of population projections made by the U.S. Census Bureau and the United Nations since World War II, for instance, shows that actual population growth often falls outside of the low-to-high range given by the forecasters. The traditional range corresponds, roughly, to a two-thirds confidence interval (Stoto, 1983a). Furthermore, because experts' views are really opinions (though perhaps based on extensive experience) rather than hard scientific data, the results are often controversial.

3. Sensitivity analysis

Sensitivity analyses are commonly used to assess the amount of uncertainty due to different definitions and different methods of extrapolating into the future. The Census Bureau's presentation of its population projections provides a good example of the strengths and weaknesses of the approach. For concreteness, let us focus on the proportion of the population that will be 65 years or older in 2015.

In the latest set of national projections, the Bureau presents 27 separate projections of the U.S. population by age, race, and sex (Spencer, 1984). These correspond to the conjunction of three fertility assumptions (ultimate number of births per woman equal to 1.6, 1.9, or 2.3 births), three mortality assumptions (life expectancy in the year 2000 equal to 71, 73, or 75 years for men and 78, 80, or 82 years for women), and three immigration assumptions (total net immigration of 250,000, 450,000, or 750,000 people).

Traditionally, the Bureau has presented "high," "medium," and "low" population projections. In 2015, for instance, the population aged 65 and over is projected to be 14.9 (high), 15.4 (medium), or 15.7 (low) percent. In these projections, "high" corresponds to high population growth, that is, the high assumptions for fertility and immigration and the low assumption for mortality (high assumption for life expectancy); and "low" is the opposite. But as Siegel and Davidson (1984) have pointed out, this approach gives an unrealistically narrow range for the proportion of the population aged 65 or older. The highest proportion results from a combination of low fertility, low mortality, and low immigration, and the lowest proportion results from the opposite combination. Taking this approach, the proportion ranges from 13.5 to 17.5 percent.

A range alone is not enough; users need to know the probability that the quantity projected will be within the range given. For instance, the "traditional" range (14.9 to 15.7 percent) is probably too small. Similarly, if the assumptions about the range of uncertainty in the components are reasonable, the alternative range (13.5 to 17.5 percent) may be too large. For either of the extremes to be achieved, each of three variables (fertility, mortality, and immigration) has to take on its own extreme value.

One solution is to have the experts who prepare the forecasts give a range and their best estimates of the probability associated with it. The Census Bureau does not do this but instead takes "the longstanding projections approach of showing a 'reasonable high' and a 'reasonable low' selected on a judgmental basis" (Spencer, 1984). They are "reasonable" only in the sense that their assumptions are clearly presented. To the Bureau's credit, the latest report presents a table comparing the differences between the highest, middle, and lowest series (in terms of population growth) with errors in past projections.

Making quantitative statements about the likelihood that the projected value will fall within a given range need not be difficult. The proportion of the population 65 and over in 2015 provides a simple example. As a start, assume that the future courses of fertility, mortality, and immigration are independent of one another. Further assume that there is a 50-percent chance that the middle value of each will turn out to be true, and a 25-percent chance that each of the extreme values will turn out.[1] These two assumptions allow us to calculate a probability, ranging from 1/64 to 1/8, for each of the 27 projections. The results are shown in table 1; for each scenario there is both a projected value and an associated probability. The next step, shown in table 2, is to sort the scenarios by their projected values and cumulate the probabilities. The calculations result in an empirical cumulative distribution that reflects the probabilistic assumptions about the input values. Interpolating in this table gives the following quantiles:

Percentile	*Proportion of population 65 and over (in percent)*
5	13.9
10	14.2
25	14.7
50	15.4
75	15.8
90	16.4
95	16.7

In actuality, the confidence intervals based on these calculations may be too narrow. First, they reflect only the uncertainty covered in the Bureau's sensitivity analysis. There are many assumptions about the age-specific rates that add up to the aggregate fertility, mortality, and immigration figures and the time pattern of change that are not reflected in the sensitivity analysis. Second, this calculation neglects the possibility that actual fertility, mortality, and immigration may go beyond the assumed range. Although it is not possible to adjust formally for these factors without running different projections, the distribution provides a good base for judgmental adjustments.

Other analyses offer opportunities for sensitivity analyses expressed in quantitative terms. According to Scheuren

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[1] Donald Shepard (personal communication) has calculated that if a normal distribution is divided into three segments at the 25th and 75th percentiles, the means of the outer two segments are approximately equal to the 10th and 90th percent points of the distributions. Thus, a normal distribution can be roughly approximated by a three-point distribution with probability 1/4 on the 10th percentile, 1/2 on the mean, and 1/4 on the 90th percentile. If the uncertainty about the Bureau's mortality, fertility, and migration assumptions can be represented by a normal distribution with 10th and 90th percentiles at the "low" and "high" values, the calculation in the text may be a reasonable approximation of the uncertainty in the proportion of the population aged 65 and over.

Table 1. Results of a sensitivity analysis of mortality, immigration, and fertility on the proportion of the population 65 and over in 2015, with associated subjective probabilities

Series	*Mortality*	*Immigration*	*Fertility*	*Probability*	*Percent 65 and over*
1	Low	Low	Low	1/64	17.5
2	Low	Low	Middle	2/64	16.5
3	Low	Low	High	1/64	15.5
4	Low	Middle	Low	2/64	17.3
5	Low	Middle	Middle	4/64	16.3
6	Low	Middle	High	2/64	15.4
7	Low	High	Low	1/64	16.7
8	Low	High	Middle	2/64	15.8
9	Low	High	High	1/64	14.9
10	Middle	Low	Low	2/64	16.5
11	Middle	Low	Middle	4/64	15.6
12	Middle	Low	High	2/64	14.7
13	Middle	Middle	Low	4/64	16.3
14	Middle	Middle	Middle	8/64	15.4
15	Middle	Middle	High	4/64	14.6
16	Middle	High	Low	2/64	15.8
17	Middle	High	Middle	4/64	15.0
18	Middle	High	High	2/64	14.2
19	High	Low	Low	1/64	15.7
20	High	Low	Middle	2/64	14.9
21	High	Low	High	1/64	14.0
22	High	Middle	Low	2/64	15.6
23	High	Middle	Middle	4/64	14.7
24	High	Middle	High	2/64	13.9
25	High	High	Low	1/64	15.1
26	High	High	Middle	2/64	14.3
27	High	High	High	1/64	13.5

Table 2. Calculation of the subjective probability distribution for the proportion of the population 65 and over in 2015, based on the sensitivity analysis in table 1

Percent 65 and over	*Series*	*Probability*	*Cumulative probability*
13.5	27	.0156	.0156
13.9	24	.0313	.0469
14.0	21	.0156	.0625
14.2	18	.0313	.0938
14.3	26	.0313	.1250
14.6	15	.0625	.1875
14.7	12	.0313	.2188
14.7	23	.0625	.2813
14.9	9	.0156	.2969
14.9	20	.0313	.3281
15.0	17	.0625	.3906
15.1	25	.0156	.4063
15.4	6	.0313	.4375
15.4	14	.1250	.5625
15.5	3	.0156	.5781
15.6	11	.0625	.6406
15.6	22	.0313	.6719
15.7	19	.0156	.6875
15.8	8	.0313	.7188
15.8	16	.0313	.7500
16.3	5	.0625	.8125
16.3	13	.0625	.8750
16.5	2	.0313	.9063
16.5	10	.0313	.9375
16.7	7	.0156	.9531
17.3	4	.0313	.9844
17.5	1	.0156	1.0000

("Methodologic issues in linkage of multiple data bases" in Chapter II of this report), for instance, statistical ideas such as information theory, contingency tables, and error-in-variable approaches could help quantify uncertainties due to assumptions in the analysis of linked data sets.

4. Multiple estimates

In many policy problems, statistical estimates are the result of a complex process and involve numerous extrapolations, adjustments, assumptions, and other judgment calls. In such situations, a large part of the uncertainty comes from the fact that analysts take different approaches and make different assumptions. One way to measure the uncertainty in this process is to have a group of analysts make estimates independently and examine the distribution of results.

The sensitivity analysis described previously comes close to this approach. The difference is that most sensitivity analyses use a common model and vary its parameters. When the model itself is uncertain, we need to go beyond it to measure the inherent uncertainty (Stoto, 1982).

One more general method, described by Mosteller (1977), is "triangulation." In making order of magnitude calculations, he recommends making two or three different estimates of the same quantity, using different data and methods. If the resulting estimates are close to one another, we can be confident in the results. If not, we have some idea of the magnitude of the uncertainty.

In this respect, Rice and Feldman's (1983) estimates of nursing home needs for the elderly, mentioned earlier, shed some light on the uncertainty of the estimates. Two of the estimates, for the growth in nursing home residents and nursing home expenditures, ought to be parallel. In fact they are, respectively, 319 and 160 percent. The difference might reflect a projected decrease in cost per resident, but this seems unlikely. The first estimate was based on utilization rate data from the National Center for Health Statistics, the second on financial estimates from the Health Care Financing

Administration. The difference in the estimates probably arises from differences in the data used for the projections, and thus reflects the uncertainty in the projection.

Light and Pillemer (1984) discuss the importance in policy analysis of combining evidence from separate evaluation studies. They stress the fact that the various approaches taken by different investigators result in different answers. Upon closer analysis, however, the results often turn out to be estimates of different targets: variations of the programs are being tested on various subpopulations. Rather than being confused by the range of answers, Light and Pillemer recommend that analysts take the opportunity to learn something about the influence effect of the program variations and subpopulations that might lead to more efficient policies.

The approaches discussed so far tend to be informal and thus do not lead to explicit measures of uncertainty in terms of subjective probabilities. In certain circumstances, however, quantitative measures are available, including the "empirical Bayes" methods developed by Efron and Morris (1975). In comparing a group of independent studies of different surgical innovations, Gilbert, McPeek, and Mosteller (1977) developed a method for measuring the distribution of likely success of future innovations. Similarly DerSimonian and Laird (1983) studied a group of independent studies of the effect of coaching on Scholastic Aptitude Test scores and developed a subjective measure of the likely gain from coaching.

Stoto (1982) describes a less formal method for quantifying the uncertainty reflected in a small number of estimates made by experts working independently on estimating the same quantity. The idea is that if the estimates can be regarded as a random sample from a distribution of expert opinion, the mean and variance of the sample reflects the mean and variance of the underlying distribution.

Suppose that two demographers independently make projections of the proportion of the U.S. population that will be 65 or older in 2015, and that their results are 14.2 and 15.4 percent. We might be tempted to think of the range defined by these two estimates as an extreme, but if we regard the two estimates as a sample of two chosen at random from the distribution of possible estimates, there would be a two-thirds chance that the next estimate chosen from that same distribution will be outside the range defined by the first two. For a sample of size two from a normal distribution, the standard deviation can be estimated as 0.886 times the range, in this example 1.06, and the mean is 14.8. This calculation suggests the following distribution:

Percentile	*Proportion of population 65 and over (in percent)*
5	13.1
10	13.4
25	14.1
50	14.8
75	15.5
90	16.2
95	16.5

This method leans heavily on the assumption that the estimates are independent. Advocates for different sides of a policy debate, for example, would not make independent estimates but would tend to bias their estimates in opposing directions. If the method were applied to two estimates made by opposing advocates, the resulting confidence intervals would be too wide. At best, the method provides a rough estimate that can be modified by informed judgment. The method also relies on the assumption that the distribution is normal, but can be modified for other distributional assumptions.

Bayesian analysis provides more formal methods for constructing subjective probability distributions based on the estimates of one or more experts (Morris, 1974, 1977; Winkler, 1967; Agnew, 1985). All these methods begin with the decisionmaker's a priori subjective distribution and also subjective distributions about what the experts will say conditional on the true state of the world, both expressed in quantitative terms. These methods will be difficult to use in public policy matters, however, because (1) decisionmakers are not likely to be able to develop the relevant subjective distributions in quantitative terms, and (2) there is frequently more than one decisionmaker.

Recommendations

1. Pay more attention to uncertainty.

All statistical measures have some degree of uncertainty, and efforts to reduce that uncertainty can have only limited success. In developing public policy, this uncertainty must be taken into consideration. Statisticians, however, for different reasons, tend to shy away from considering it. These facts suggest that both statisticians and policymakers should pay more attention to measuring and communicating uncertainty, perhaps as much attention as they pay to getting better estimates.

2. Develop uncertainty profiles for major statistical data series.

As a first step, statisticians ought to give serious attention to developing uncertainty profiles of some of the most important data series on aging. This should include comparisons of different definitions and the implications for analysis, and studying the magnitude of nonsampling errors and scientific uncertainty. With the current state of the art, sensitivity analyses and multiple independent estimates offer the most hope for quantifying uncertainty.

3. Develop more sophisticated methods for quantifying uncertainty from all sources.

Because statisticians have paid so little attention to quantifying uncertainty, the methods described in this paper are still relatively primitive. They all involve a considerable amount of judgment and tend to be controversial in policy settings. Further statistical research is necessary to advance the state of the art.

Progress can be made in a number of areas. Better formal models of heterogeneity, more disaggregation of data to learn about hidden heterogeneity, and more use of resampling plans could improve estimates of uncertainty due to sampling and heterogeneity among individuals and population subgroups. Experts in various areas can be trained to be better probability assessors. Methods for representing sensitivity analyses in quantitative terms, and Empirical Bayes and other methods for representing multiple estimates, are in their infancy but offer great potential.

4. Develop more effective methods for communicating uncertainty to policymakers.

Part of the reason that policymakers have difficulty dealing with uncertainty is that scientists do not have good methods for communicating it. We need to know more about how policymakers use statistical information. Drawing upon this, we need to develop better techniques for graphical and numerical presentation of uncertainty, both general and developed for specific policy issues. To the extent that the uncertainty is presented in terms that are familiar to policymakers (payroll taxes and deficits, not birth rates and death rates), the more likely it is to be understood.

Conclusion

Uncertainty in statistical data for policy is a difficult problem to resolve. Policymakers would rather ignore it. Statisticians, who are comfortable with precise methods for dealing with the simple problem of sampling errors, are reluctant to deal with the messier, and often larger, problems of nonsampling errors. As the initial discussion shows, statistical data for an aging society are not immune to broader kinds of errors and uncertainties.

Once we understand the sources of uncertainty, there are two ways to deal with it: reduce it or live with it.

In most situations, decisionmakers must learn to live with uncertainty. Statisticians, however, have not yet developed simple, reliable, and objective methods for the measurement and reporting of uncertainty. Except for methods for measuring sampling errors, those methods that do exist tend to be subjective and often controversial. Statisticians must develop better ways to measure and express the full range of uncertainty in quantitative terms. The methods described in the last section of the paper are a modest start, but much more work is necessary.

As this paper shows, reducing uncertainty is not easy, even in the long run. Unfortunately, the sources of uncertainty that are the hardest to measure and discuss quantitatively are the ones that are the hardest to reduce. But in many situations some reduction in uncertainty is possible and may well be worth the cost and effort. Being precise about the extent and sources of uncertainty is the first step in targeting efforts to reduce it.

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Health indicators for an aging population[a,b]

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It was the best of times,
It was the worst of times, . . .
—Charles Dickens, *A Tale of Two Cities*

I. Introduction

Are the closing years of the 20th century the best of times for elderly people in the United States? Or the worst of times? Or perhaps a bit of both? Unfortunately, the existing Federal statistical base will not help us with the answer.

The fundamental problem is that, although life expectancy continues to increase in the United States and people who survive to age 65 can expect more additional years of life than at any other time in the history of the world, no one knows to what extent these additional years of life are years of independence and vigor, or years of dependency and frailty.

One of the perennial challenges facing health professionals is to define a yardstick against which one can measure the health of the population (in this instance, the health of the elderly population). Is it improving, staying the same, or failing? Few of us disagree with the goal of improving the health of older citizens, but many might disagree about how to measure it, or, more practically, how to recognize improvement if we in fact achieve it.

One response to the challenge of finding the appropriate measures is to throw up one's hands in defeat. *The New York Times* recently reported that the Administration has proposed a sharp reduction in the Federal Government's efforts to gather and distribute statistics about all aspects of American life (March 31, 1985). However, wholesale reductions might be shortsighted (Committee on Government Operations, 1984).

Another response is to evaluate critically the current statistics for an aging population, consider what additional information might be necessary for assessing advances or declines in the health of older Americans, and offer recommendations for improving the accuracy and appropriateness of health indicators for an aging population in the United States.

The goal of this paper is to suggest constructive approaches to measuring the health of older Americans. To this end, we first reconsider the importance of the topic; second, review the strengths and weaknesses of traditional indicators of health; third, suggest criteria for appropriate health indicators for older Americans; and fourth, propose specific alternative health indicators for older people during the remaining years of the 20th century.

II. The importance of the topic

Demographics—Changes in demographics and longevity in the United States have converged to force a reexamination of the measurement of the health status of older Americans. The demographic facts are well known (Rice and Feldman, 1983; Soldo, 1980; American Council of Life Insurance, 1982). At the turn of the 20th century, there were only 75 million Americans, and one out of 25 was aged 65 or older. By 1980, one out of nine Americans was aged 65 or over, and the population had expanded more than threefold to over 225 million. By the year 2000, it is estimated, there will be over 36 million people aged 65 years or older; they will represent over 13 percent of the U.S. population (Rice and Feldman, 1983). In addition to the sheer numbers, it is helpful to recognize that since the beginning of time, one-half of all the people who have ever survived to age 65 are alive today.

The challenges for both older individuals and society at large are different now, during the closing years of the 20th century, than they were during the previous decades. At the turn of the century, few older people entered a stage of life we could call "healthy retirement," a stage characterized by complete or near complete disengagement from one's life work, good health and functional robustness, and anticipation of a steady (if not substantial) pension for the duration of one's lifetime. By the latter part of the 20th century, most people aged 65 years or older have been able to enter this state of healthy retirement. However, for the robust pensioner the glamour of a leisurely retirement loses its luster when income or health fails. At an individual level, it is still easier to assume responsibility for one's financial future than for one's future health. Notwithstanding the laments of brokers concerning the uncertainty of financial planning and the boasts by medical researchers about the near certainty of preventing certain diseases, the fact is that maintaining the buying power of one's retirement funds is still more predictable than maintaining one's health and vigor.

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[a] Contents are the opinions of the authors and not those of the Department of Health and Human Services or the organizations they work for.

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Longevity—The longevity statistics are as compelling as the demographics (Rice and Feldman, 1983; Soldo, 1980; American Council of Life Insurance, 1982). In 1900, a man who reached the age of 65 could expect to live 11 more years, and a woman aged 65 could expect to live 12 more years. By 1980, men turning 65 enjoyed a 3-year increase in life expectancy on the average, to 14 additional years. Women turning 65 in 1980 could anticipate an average of 6 additional years of life expectancy, as compared with the 1900 cohort, for a total of 18 additional years. The important issue, however, is the quality of the additional years of life expectancy for the elders of the 1980's. Are the additional years ones of vigor and independence, or of frailty and dependence? The debate among health professionals has begun, but with a conspicuous lack of data on both sides.

Katz, Branch, and their colleagues (Katz et al., 1983) provided a conceptual basis for assessing the quality of life during the later years of life and presented preliminary findings based on small-scale demonstration data. Adapting the concepts and methods developed for quantifying life expectancy that measure the age at which one-half of a group or cohort will experience mortality, Katz and colleagues measured the age at which one-half of the initially independent older people subsequently lost their independence in one of three ways: by death, by entering a nursing home, or by relying on another person for help in performing activities of daily living (e.g., bathing, dressing, eating, transferring from a bed to a chair) while remaining at home. Figure 1 shows how one can subtract the estimate of active life expectancy from total life expectancy to obtain an estimate of the average number of years of dependency prior to death that a person of a given age is likely to experience. Based on the pilot data, people aged 65–69 years could expect that 6.5 (approximately 40 percent) of their remaining 16.5 years would be in a state of dependency. People aged 85 years or older could expect 4.4 (approximately 60 percent) of their remaining 7.3 years to be spent in a state of dependency.

Federal statistics have documented the changes in life expectancy during the 20th century. Unfortunately, there are no national data showing whether the active life expectancy has also changed. Therefore, we do not know whether either the actual number or the proportion of the later years spent in a state of dependency has increased, stayed the same, or decreased during the period when the number of additional years of life has increased.

III. Review of traditional public health indicators

Mortality—For many years mortality statistics have carried the burden as the major indicator of health. How people die tells us something about how they live. Mortality statistics have helped to establish public health priorities. The reliance on mortality as an indicator of a population's health status is warranted for a variety of reasons.

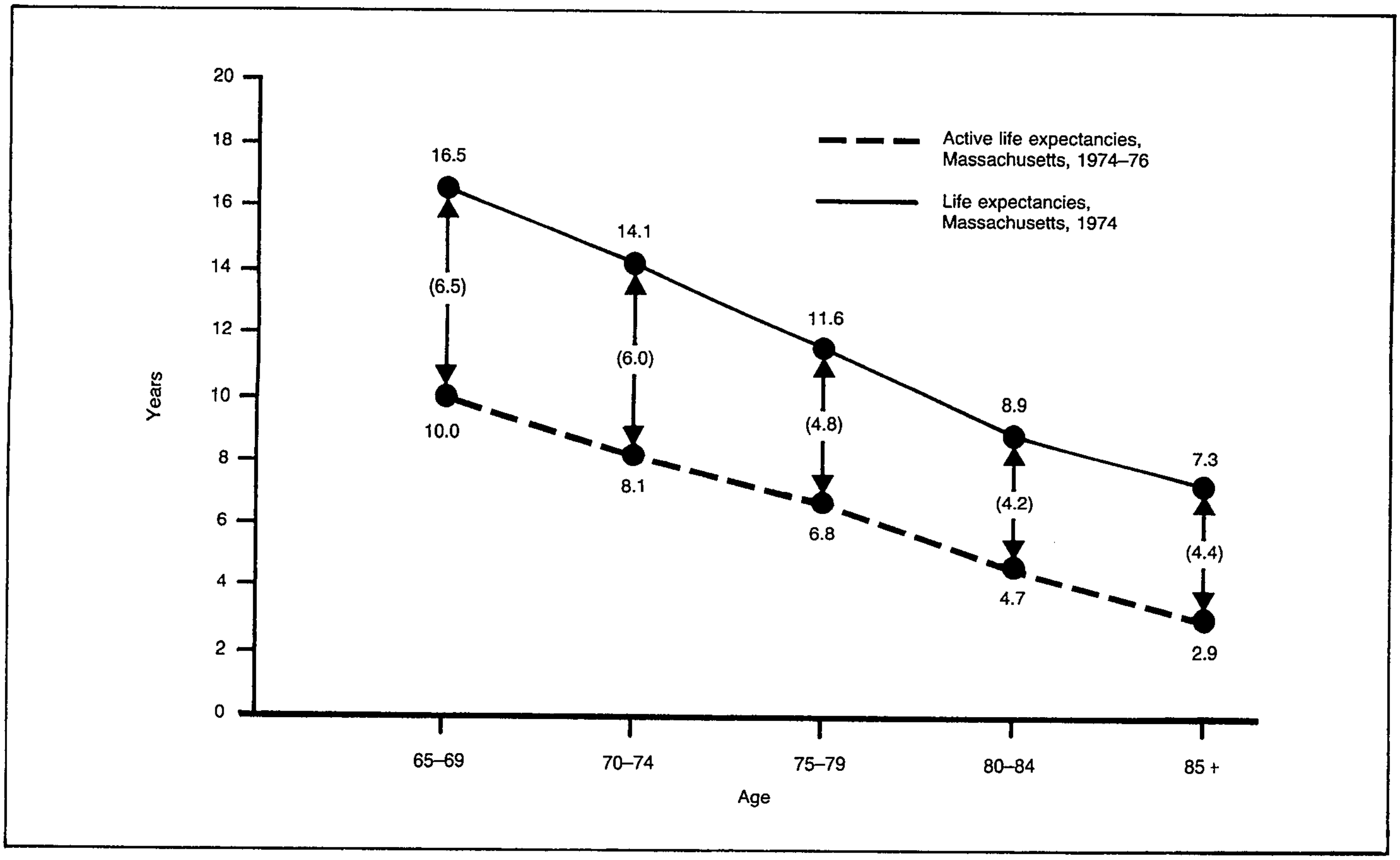

Figure 1. Life expectancies and active life expectancies in Massachusetts

First, the fact of death is certified by a licensed physician and uniformly recorded. This record-based system benefits from nearly 100 percent compliance. National fact-of-death mortality statistics are readily available and have provided an invaluable base for the assessment of the health status of the population.

Second, mortality statistics have an extremely valuable inherent quality that is often unrecognized: they provide individually based information at two points in time. Each person who dies during a specific interval of time was by definition alive during the previous interval, and the individual's age indicates exactly how many previous intervals the individual's life encompassed. The ability to measure change for the individual is an extremely important component of health status indicators, one which we will discuss in greater detail at a later point.

Third, death is irreversible. Thus each person can be counted as dead once and only once. There are no interpretive difficulties, such as whether one person getting pneumonia twice during a year is better, the same, or worse than two people getting pneumonia once a year.

Fourth, mortality statistics reflect a clear dichotomy. An individual is either dead or alive at any instant; there is no grey area of judgment in between. In some circumstances there are benefits to having graded outcomes (such as high, medium, and low). However, monitoring the health status of the population has been facilitated in the past by the reliability resulting from the unambiguous dichotomous measure of "dead" or "not dead."

Fifth, in addition to fact of death, cause of death is provided on the death certificate. Cause of death is based on a uniform and well-established classification system, the *International Classification of Diseases*, which is periodically updated, most recently in 1979 (Public Health Service and Health Care Financing Administration, 1980). Consequently, both all-cause mortality (i.e., all mortality regardless of cause) and cause-specific mortality (i.e., mortality attributable to a specific cause such as heart disease, cancer by various sites, and so forth) can be monitored over time. For example, in 1980 in the United States the suicide rate for men rose sharply after age 74, and for men aged 85 years and over it was alarmingly high at 52.5 deaths per 100,000. For persons aged 85 and over, neither white women nor men or women of other racial groups had suicide rates anywhere near that of white men, who thus contribute disproportionately to the overall rate. In fact, motor vehicle accidents ranked only slightly ahead of suicide as a cause of death for white men aged 85 or older; data for 1980 show that motor vehicle accidents claimed the lives of 356 men in this age group and that 328 were victims of suicide. Without knowing that suicide was the cause of death for these white males 85 and over, some of us might have assumed that their deaths represented a triumph of the health system because they died after attaining the age of 85, after reaching a point many consider to coincide with the end of the lifespan for humans. The specific cause-of-death information, however, suggests that it is not a triumph but a tragedy, perhaps resulting either from the loss of social role and social contacts that is often experienced by very old men in our society or from an individual decision to escape the ultimate consequence of a fatal disease.

Sixth, all-cause mortality in general and cause-specific mortality in particular have undeniable associations with the health status of the population. For young and middle-aged individuals, we have assumed that most deaths are preventable. Consequently, many statements of public health goals for the Nation have been expressed in terms of reduced mortality (usually cause specific) for specified age groups (usually the young and middle-aged). For example, table 1 indicates a summary of the health goals for the six age groups as articulated by the Surgeon General in the 1979 report *Healthy People* (Office of the Assistant Secretary for Health and the Surgeon General, 1979). Notice that the goals for healthy infants, healthy children, healthy adolescents and young adults, and healthy adults were each stated in terms of reduced all-cause mortality. Notice also that the goal for healthy older adults was the only one not stated in terms of reduced mortality, a point to which we will return later. For older adults, some might argue that substantial reductions in age-specific, all-cause mortality rates are probably unattainable because older adults by definition are reaching the end of the lifespan. The underlying logic of such arguments is often based on a variant of the logic of competing risk, which would contend that mortality at the end of the lifespan is inevitable, and any success in reducing one type of cause-specific mortality would be offset by an increase in another. A critical assumption within this argument is that the end of the lifespan is not

Table I. The 1990 health goals for the United States

Group	Goal
Healthy infants	To continue to improve infant health, and, by 1990, to reduce infant mortality by at least 35 percent, to fewer than 9 deaths per 1,000 live births.
Healthy children	To improve child health, foster optimal childhood development, and, by 1990, reduce deaths among children aged 1–14 years by at least 20 percent, to fewer than 34 per 100,000.
Healthy adolescents and young adults	To improve the health and health habits of adolescents and young adults, and, by 1990, to reduce deaths among people aged 15–24 by at least 20 percent, to fewer than 93 per 100,000.
Healthy adults	To improve the health of adults, and, by 1990, to reduce deaths among people aged 25–64 by at least 25 percent, to fewer than 400 per 100,000.
Healthy older adults	To improve the health and quality of life for older adults, and, by 1990, to reduce the average annual number of days of restricted activity due to acute and chronic conditions by 20 percent, to fewer than 30 days per year for people aged 65 and older.

SOURCE: Office of the Assistant Secretary for Health and the Surgeon General: *Healthy People, The Surgeon General's Report on Health Promotion and Disease Prevention, 1979.* DHEW Pub. No. (PHS) 79–5507. Public Health Service. Washington. U.S. Government Printing Office, July 1979.

many years away for those who have reached the age of 65. For centuries the consensus usual end of the lifespan for humans was declared to be approximately 70 to 80 years. In the 10th century before Christ, King David stated that "the days of our years are threescore and ten, and if by reason of strength they be fourscore years ..." in Verse 10 of Psalm 90. Zoology texts also suggested that "the Biblical 'threescore years and ten' is still a fair approximation" of length of life for humans (Storer, 1943). Fries has suggested the mid-eighties for average lifespan under normal circumstances (Fries, 1980).

However, some have begun to challenge this consensus and point out that insufficient information exists on the issue. By definition, mortality at the end of the lifespan would have to occur in the absence of a preventable cause of death. Present conventional medical wisdom suggests that major portions of the second through sixth leading causes of death for people aged 65 years and over are eminently preventable (some cancers, stroke, influenza and pneumonia, some arteriosclerosis, and diabetes mellitus). Furthermore, many types of heart disease, the leading cause of death, are also preventable. Although the vast majority of deaths among this age group may be due to preventable causes, we have insufficient information to speculate on the average age at death due to nonpreventable causes. Furthermore, recent years have witnessed substantial reductions in all-cause mortality in two age groups: those aged 75–84 years and those aged 85 years and older. From 1980 to 1982, all-cause mortality for those aged 75–84 years decreased by 5 percent, and it declined by 4 percent for those aged 85 and older. These rates support the claim that lifespan for humans is not limited to "threescore and ten."

We have discussed the strengths of the mortality statistic: record based, 100-percent coverage, an individual longitudinal indicator, an irreversible state, a judgment-free dichotomy, augmented by specific cause-of-death information, and undeniably associated with a fundamental dimension of health. What are the liabilities of the mortality statistic? The fundamental liability is that the absence of death is not all there is to health. Therefore, mortality indicators are necessary and helpful, but not exhaustive, indicators of the health status of an aging population.

Morbidity—Morbidity patterns (i.e., the distribution of diseases in a population) historically have been useful adjuncts to mortality statistics and have proved to be another sensitive gauge of the health of certain populations.

Implicit in the monitoring of the incidence of disease (new cases during some time interval) and prevalence (total number of cases at any time within the population) is the assumption that these rates can be reduced with certain interventions. Interventions can include primary prevention (avoiding the disease completely), secondary prevention (reducing the duration and intensity of the disease), and tertiary prevention (reducing the consequences of the disease).

Some diseases are more amenable to counting than others. The more easily counted include acute conditions of serious nature, illnesses with rapid onset, diseases with classical presentations—all those whose identification is necessary for the available effective treatments. These are more accurately counted than chronic conditions for which most treatments are ineffective (e.g., chronic lower back pain), illnesses with insidious onset (e.g., glaucoma, cataracts, or senile dementia), or diseases with atypical presentations (e.g., myocardial infarctions among the elderly). Consequently, procedures for monitoring changes in patterns of disease among populations have emphasized rapid-onset, classically presenting, life-threatening acute conditions over insidious-onset, atypically presenting chronic conditions that are debilitating but not fatal. It is these chronic conditions that actually may influence the day-to-day lives of the elderly more than the acute conditions. However, methods of reliably, validly, and accurately measuring these chronic conditions are underdeveloped. Current morbidity statistics often reflect the same choice as that made by the drunk looking for lost keys under the street lamp where the light is better rather than in the alley where he lost them. It is easier to monitor reliably and validly the rates of those conditions with recognizable onset and predictable progression than other conditions, even though some of the latter might be more important to the individual and to the health status of the population.

Also germane to the reconsideration of health indicators for an aging population is this question: To what degree should contact of individuals with the medical health care system be necessary for the accurate counting of their morbid conditions? Recall that mortality data are uniformly available for virtually 100 percent of all decedents. The same claim of virtually 100-percent counting cannot be made for most diseases; one of the few exceptions would be tuberculosis, for which mandatory reporting to a State registry is required. Consequently, record-based morbidity information is often an undercount. Self-reported morbidity information (for example, the kind reported in the National Health Interview Survey) is thought generally to be an underestimate also. Some people may hesitate to report specific illnesses or conditions if not confirmed (and labeled) by a physician. However, access to physicians is not uniform. Furthermore, even elders in regular contact with physicians often have unrecognized (either by the patients or by the physicians) conditions, many of which are treatable. The accurate reporting of morbid conditions is necessary but difficult to achieve.

The interpretation of measured rates and changes in rates over time is complicated further by improvements in diagnostic methods, improvements in interviewing techniques, and increases in public awareness and understanding which influence changes in reported rates of disease.

The weaknesses of morbidity statistics as indicators of the health status of a population are similar to the weaknesses of mortality statistics. First of all, there is more to health than the absence of disease. Second, the connection between current health status and the history of a specific condition at a point in time is sometimes tenuous, particularly when the condition is no longer of consequence (e.g., a successfully repaired hernia). Furthermore, the hope that the average number of reported conditions can serve as an indicator of function and/or as a harbinger of premature mortality is unwarranted. Morbidity status, health status, and functional status simply are different concepts (largely overlapping, perhaps, but nevertheless not interchangeable).

Disability—The third traditional health indicator is disability. For the older person, the presence of a disease or condition is not nearly as important as its consequences. Some diseases cause disability only during the acute phase and have no lasting influence on the long-term functioning of the individual (e.g., influenza). Other diseases vary not only in the degree of disability that they cause during the acute phase, but also in their contribution to the long-term decrease in functional ability. A cerebral vascular accident, or stroke, is an example of a disease with a substantial compromise of function during the acute phase and significant declines in the long-term functional ability of the victim relative to levels of function before the stroke. On the other hand, arthritis is an example of a disease with minimal disruption of function during an identifiable acute phase, but it causes long-term functional limitations among its victims.

Compromised physical function is a final common pathway for many of the diseases affecting older people. Compromised physical function also is assumed by some to be a consequence of aging that is independent of specific diseases. The importance of physical function in understanding the health status both of individuals and of populations is readily agreed upon, but its measurement is not.

Two common measures of self-reported disability incorporated into the National Health Interview Survey (NHIS) are days of disability and limitations of activity. Days of disability are measured in four ways: (1) bed disability (days spent in bed for all or most of the day for reasons of health); (2) work loss (days lost from work); (3) school loss (days lost from school); and (4) restricted activity (days during which a person reduces normal activities for all or most of the day because of an illness or injury). Bed-disability, work-loss, and school-loss days each would be included in the fourth category. Statistics on days of disability per person per year are further refined by the percentages attributable to acute versus chronic conditions.

The concept of limitation of activity in NHIS refers to the long-term reduction in activity attributable to chronic disease and impairment. The measurement of this concept in NHIS permits four distinctions: (1) those unable to carry on their usual major activity, (2) those limited in the amount or kind of their usual major activity, (3) those limited but not in their usual major activity, and (4) those not limited at all. Before 1982 the major activity of an individual was defined by the usual activity for each age-sex group, for example, ordinary play for preschool-aged children, going to school for people of school age, keeping house for females who are not in the paid labor force, and working for all others including retired males. An obvious defect in the measurement of limitations in major activities prior to 1982 was the undefined nature of major activity for males who were retired from the paid labor force. How was a retired individual to respond to the question of whether he is unable to work for reasons of health when his company enforced a mandatory retirement policy predicated on an assumption of reduced work capacity among older workers, but the retiree thinks he is still capable? Since 1982, limitations in major activities were measured among all people aged 60 or older by independence or dependence in activities of daily living (such as eating, dressing, bathing, shopping, or everyday household chores); all individuals aged 18–69 were asked also about possible limitations in their ability to work for pay. Usual activities remained the same for preschool children, school-age children, and those keeping house (up to age 70). The 1982 revisions are a definite improvement.

The primary strength of the use of disability as a health indicator for an aging population is its focus on function—the person's capacity or ability to perform appropriate activities—which presumably is closely related both to the individual's quality of life and the aggregate health status of the population.

In general, the limitations of disability status as a health indicator for an aging population are weaknesses of application, not limitations of the concept. Specifically, additional improvements in the measurement of the concept of disability are necessary, as is a consistent approach to measurement in those areas that reflect consensus. The refinement of the concept of "major activity" for retirees not keeping house is an example of a recent advance in measurement.

One nonobvious implication of advances in measurement deserves mention. What do we do with the less accurate data? The temptation is strong, and not resisted by all researchers, to disregard the inherent unreliability of the undefined concept as it existed prior to 1982 and to present the age-specific rates of limitations in major activity over time as an indicator of a changing health status of the elderly population. Professionals differ on whether compromised data are better than no data at all.

IV. Five criteria for appropriate health indicators for an aging population

The criteria for generating appropriate indicators of health status for an aging population are discussed in the context of the following five issues: (1) study design, (2) sample selection, (3) instrument development, (4) data merging, and (5) data analysis.

Study design—A longitudinal panel study design is essential (that is, a design calling for repeated interviews with the same individuals over an interval of many years). Repeated cross-sectional data (that is, data from different individuals interviewed at different times) invite difficulties in interpretation because observed changes over time can be attributed either to real changes in the population or to selective mortality in the population. For example, consider the hypothetical (and quite impossible) case of a country with a total population of 1,000 elders, 750 of whom thought their health was great and 250 of whom thought their health was terrible. Suppose we did an accurate sample survey last year, and found the correct proportion of 75 percent in great health and 25 percent in terrible health. Suppose further that during the course of the following year, the 250 who thought they had terrible health in fact did, and they all died. Then we do a new sample survey, it is accurate, and we estimate that 100 percent of the population has terrific health. The simplest interpretation—that the health of the elderly population in this country has improved this year compared to last year—is misleading; none of the individuals with initial poor health experienced improved health status.

This example is used to demonstrate at an intuitive level that repeated cross-sectional data can be misleading in certain circumstances, and the aging population frequently embodies those circumstances.

Consider another hypothetical situation in the country with 1,000 elders, 600 of whom demonstrate independent physical function and 400 of whom demonstrate compromised function. Suppose further that one-half (200) of those with compromised function regain independence during the following year, and the other one-half (200) remain dependent. Suppose further that 200 who were initially independent become dependent. Our second sample survey would then estimate that 60 percent of the population was independent in physical function at the second year, and 40 percent had compromised function, just as we found at the first year. Would the public health czar of this country suggest different programs if he realized there is one group who continues with physical disabilities, a second group whose function improved, and a third group whose function recently deteriorated? Would the czar recommend still different services if there were only one group of disabled individuals: those who once became disabled and remained disabled?

Sample selection—A second criterion of appropriate health indicators for an aging population is that the participants in the longitudinal panel study design must be both a large and a representative sample. The aspect of sample size is important because public policy discussions about options for the health care delivery system frequently require specific information on relatively small subgroups of the population. For example, in the context of capitated prospective payment systems in which the provider of health care shares in the financial risk that a group of enrollees might require more health care services than initially budgeted, health planners are frustrated by the lack of national representative data which specify the probabilities with which subgroups of older people historically have entered long-term care institutions. Does hospitalization history alter the probability that a person over age 70 will enter a nursing home within 5 years? Do those with functional deficits which produce dependency in basic activities of daily living require longer lengths of stays in acute care hospitals compared to their agemates without the physical disabilities? Are those who usually use walkers and/or wheelchairs more prone to use home care services than their agemates? What characteristics distinguish those who will use the less expensive home-based long-term care services from those who will use the more expensive institutional long-term care support?

The most rudimentary information concerning issues like these requires a longitudinal panel design with a sufficiently large number of people to have adequate numbers of those with the relatively infrequent characteristics of concern (in these examples, dependency in activities of daily living or using ambulatory aids).

Our national health statistics system has been unable to provide data on these fundamental issues of health policy. In 1983 the national health expenditures of $355 billion approached 11 percent of the gross national product (Gibson et al., 1984). Perhaps it finally will seem reasonable to devote a most modest fraction of that amount to obtaining an appropriate repository of national health indicators for an aging population. The right health indicators can clarify and thereby rationalize the over $100 billion business of health care for the elderly by providing the basic descriptive and actuarial information that is currently unavailable.

Concerning the issue of representativeness of the large sample participating in a longitudinal panel study, it is important to recognize the need to generalize the information obtained from the sample to the population as a whole. The issue of representativeness is intertwined with both the previous issue of sample size and the subsequent issue concerning the type of information collected. Concerning the interacting issues of sample size and representativeness, the sample should adequately represent important subgroups such as black elders, rural elders, Hispanic elders, and Native American elders, and these subgroups of elders do not live in approximately equal proportions throughout the United States. Therefore, samples clustered in one geographic area or even a few geographic areas run the risk of inappropriate representation of important minorities. Consequently, the large representative sample should be drawn from many diverse places across the Nation.

Instrument development—The third criterion for appropriate health indicators deals with the type of information obtained during the interview. Self-reported information has had a useful history in research on health indicators. Methodological studies have demonstrated the reliability and validity of most types of self-reported health information, including the utilization of health services; functional status (physical, cognitive, emotional, and social); the knowledge, attitude, and practices of individuals relative to their own health care; and, to a lesser degree, their own medical histories. Obviously, self-reported information would be a part of the information collected.

In addition to self-reported information, other studies have demonstrated the utility of physical examination and laboratory data as health indicators. The merits of examinations such as blood tests, measurements of lung function and blood pressure, oral health examinations, and a variety of others have been demonstrated repeatedly. The incorporation of any of these kinds of examinations or tests would be a valuable addition to the health indicators information base. However, their inclusion would preclude conducting the interview by telephone and likewise would be very difficult to perform in the participant's home without appropriate portable equipment.

Actual performance testing of physical function would be another valuable addition to the health indicators information base. The concordance between self-reported capacities and actual performance abilities has been an issue of recurring professional debate. A battery of performance tests should be developed as part of the health indicators for an aging population. Among the candidates for inclusion would be stair climbing, walking one-half of a mile on a treadmill, tests of the range of motion of the arms and legs, grip strength, torque strength as measured by removing the cover from a jar, manipulatory ability as measured by opening the current "safe" medicine containers, and a variety of other tests.

Any consideration of a large, nationally representative sample undergoing performance tests and selected examinations emphasizes the need for sophisticated mobile equipment to support the collection of the type of information necessary for health indicators for an aging population. A group of interviewers with long-distance telephone lines is insufficient.

Data merging—The fourth criterion of health indicators for an aging population is the availability of refined mechanisms for merging appropriate information from other record sources for the large representative national sample participating in the longitudinal panel study. The ability to merge the individual's Medicare utilization history with data from his or her self-reports, performance, and examinations is necessary. If record-based information of reasonable accuracy already exists, it is less reliable to ask the individual to duplicate or summarize the existing information. Merger of panel study information with information on decedents from the National Death Index is also appropriate.

Other papers commissioned by this panel of the National Academy of Sciences address the issues involved in merging dispersed data files.

Data analysis—A fifth criterion of health indicators for an aging population concerns the analytic capability to develop composite indicators that would supplement single items and to examine an individual's patterns over time rather than just a snapshot at one point in time. In some instances, single-item measures from one point in time on some aspects of the health of the elderly are certainly appropriate indicators of health. For example, cross-sectional prevalence rates for certain things like disability days or the post-1982 limitations in major activities are valuable. In other instances, composite indicators from cross-sectional surveys are useful. For example, some investigators have tried to develop composite indices of physical disability by combining information from Katz's activities of daily living items (Katz and Akpom, 1976), some items from Rosow and Breslau's functional health scale (Rosow and Breslau, 1966), and some items from Nagi's disability surveys (Nagi, 1976) into a cumulative disability score (Pinsky et al., 1985). In still other instances, accurate representations of the functional histories of individuals are critical, and these historical patterns require longitudinal information. In the case of the example repeatedly used in this paper, any increase in the years of life without a delay in the onset of disability would yield an increase in the proportion of dependent years at the end of life, a dubious public health goal. The longitudinal history of physical function among individuals is necessary in order to examine this phenomenon.

V. Recommendations for specific health indicators for an aging population from 1988 to 2000

The context of the following recommendations is that health care is second only to defense in its proportional contribution to the gross national product of the United States. In 1983, $355 billion were spent on health care in the United States; this sum represented 10.8 percent of the gross national product in that year. In light of this magnitude of health care expenditures, it is surprising that basic information necessary to clarify some of the most fundamental issues of health policy is still lacking. For example, the national statistical base does not have the data that would tell us whether the years that have been added to life expectancy in the United States during the 20th century are additional years of independence and vigor, or additional years of dependency and frailty. The national statistical base is insufficient to implement rationally what has been described as the most significant change in the health care system since the introduction of Medicare and Medicaid in 1965, namely, the conversion of Federal Medicare reimbursements for acute hospital stays for older people from a retrospective cost-reimbursable basis to a prospective payment system based on uniform payments for diagnostically related groups of illnesses requiring hospitalization. Within the context of this type of prospective payment system, the Federal Government is trying to entice providers of health services to share the financial risk of care for Medicare beneficiaries. Appropriately, the providers have requested some elementary information, such as whether those with greater physical disabilities are more likely to be hospitalized regardless of the diagnosis. This basic information is simply unavailable. A rational and planned health care system would require information about the characteristics distinguishing those who need institutional long-term care from those who need long-term care or support services provided in their homes. This information is also unavailable.

At this time, our national health statistics system cannot answer these kinds of basic questions. Unfortunately, our present national health statistics system will not be able to answer those kinds of questions in the 1990's either.

How the absence of such fundamental information might have contributed to the inefficiencies of the health care system in the past is not our concern now. Rather, our present concern is to ensure that such essential information concerning health indicators for an aging population will be available in the future.

We recommend that the National Center for Health Statistics participate in a joint public and private effort to establish a longitudinal panel study, with a large representative national sample, which would provide self-reported information as well as data from performance tests and physical examinations, collected on a biannual basis. The reasons for recommending that the National Center for Health Statistics coordinate the public participation stem from its long and laudatory history of ensuring precision and rigor within national data files. The reasons for recommending private foundation participation in this effort stem from a desire to increase support and funding stability for a project of indefinite duration and to facilitate a public/private partnership in analyzing the data and charting national health goals.

Furthermore, we recommend that mechanisms for merging the information from the panel study with existing recorded information for the participants be developed and become part of a national system for health statistics. Specifically, the National Death Index and Social Security files should be merged with information from survey participants. Legislative initiatives will be required to overcome certain existing obstacles to record linkage.

In order to collect information about the transition to retirement and to capture an accurate assessment of the knowledge, attitudes, and practices of late middle-aged individuals, we recommend that the age of eligibility for the participants in the national longitudinal panel study be 55 years. Furthermore, both institutionalized and noninstitutionalized participants should be enrolled. In addition, new cohorts should be enrolled periodically into this panel study of indefinite duration.

The mechanisms of data collection should incorporate self-reported information, performance tests, and data from health examinations. Accordingly, mobile testing and laboratory equipment would be needed to support this longitudinal panel study of health indicators among an aging population.

The feasibility of employing students from schools of medicine, nursing, social work, and other allied health professions to assist in data collection should be explored. It would be a valuable experience for these students to participate in the collection of a national statistical data base that provides the health indicators for an aging population, and which in turn is used to modify our approach to delivery of health services. In addition, these students would soon become the professionals whose fields would benefit from the information obtained. The overall goal of a national system of health indicators for an aging population would be to assess our progress toward our targets and to modify our health care system. This goal would be facilitated by an informed cadre of health service providers, the nucleus of which could be formed by these student participants.

These recommendations build on the accomplishments of other successful cross-sectional and longitudinal studies. Among the cross-sectional studies which have successfully implemented parts of our recommendations are the National Health Interview Surveys, the National Health and Nutrition Examination Survey (NHANES), and medical expenditure surveys including the National Medical Care Expenditure Survey, the National Medical Care Utilization and Expenditure Survey, and the National Expenditures Survey. NHIS has pioneered work on self-reported health indicators for older people. NHANES has developed portable examination equipment suitable for older respondents. The several expenditure surveys have demonstrated the abilities of respondents to provide complex information to interviewers.

Successful longitudinal studies which have demonstrated the feasibility of parts of our recommendations include the Framingham Heart Study (FHS), the Longitudinal Study of Aging (LSOA), and the Health and Nutrition Examination Survey I Epidemiological Followup (HANES I EFS). FHS has demonstrated an ability to maintain high participation rates for over 30 years among a panel of community participants subjected to laboratory tests, interviews, and examinations on a biannual basis. LSOA has demonstrated the ability to enroll and maintain a national sample of elderly participants over a series of interviews. HANES I EFS has demonstrated the ability to enroll and maintain a national sample of elderly participants in an examination and performance testing study.

The feasibility of merging data files from dispersed record sources has been demonstrated by some small-scale projects.

In summary, our recommendations for improving the health statistics for an aging population require the establishment of a new national statistical effort with the following characteristics:

- A continuous longitudinal panel study, with precision and rigor comparable to current surveys of the National Center for Health Statistics.
- A large representative national sample of institutionalized and noninstitutionalized adults aged 55 and over.
- Periodic enrollment of new cohorts.
- Obtaining self-reported, performance, and examination information on a biannual basis.
- Ability to merge the study data with existing record information for the participants.
- Use of students of medicine, nursing, social work, and other allied health professions to assist in data collection.
- Data available for public use in a timely fashion.

The information from this national statistical effort can enable the Nation to monitor the health status of our aging population, to set health goals for our elders, and to chart our progress toward those goals.

The monetary costs of mounting this kind of national statistical effort are considerable, but the human costs of not undertaking this challenge are even greater. For the sake of current older people and future groups, we cannot afford *not* to undertake this national statistical effort.

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Chapter III

Issues in improving data resources

Research for tomorrow's elderly[a,b]

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Introduction

The purpose of this report is to review the state of current efforts to forecast the nature of our future aging population and some major issues that are likely to emerge from these developments. Recent reviews of substantive findings from existing projections of the aged population and some of its compositional characteristics have recently been made (U.S. Bureau of the Census, 1984; Myers, Manton, and Bacellar, 1985; Manton and Soldo, 1984). In addition, an examination of computer data bases was completed in 1982 by the U.S. General Accounting Office for the Senate Special Committee on Aging. The scope of this report will not duplicate these efforts, but rather will assess the methodological aspects of various forecasting activities and raise issues intended to make these endeavors more meaningful.

The major areas of concern for policy decisionmaking relate to demographic factors, health, family structure, and economics. In this report particular attention is given to the first two factors. An emphasis on various dimensions of health is justifiable not only because of the significant impact that population aging has upon this dimension, but also in recognition of the importance that health and its endpoint, mortality, have upon the growth and changing composition of the aged population. Therefore, it is both an *input* to and an *outcome* of projection efforts.

The aged population is a dynamic segment of the population that is constantly being modified by both new entrants reaching the older ages (e.g., age 65) and exits through dying. The "natural increase" between these two forces modifies not only the size of the aged population, but also its composition. At the same time, there may be changes among the population of older persons that occur through the normal aging process and other changes that result from behavioral factors (remarriage, movement, etc.). Thus, the aged population is altered both in size and composition by the new cohorts entering the older ages and the internal dynamics taking place during this period of life. The high rates of turnover in the aged population (nearly 60 percent of the persons in the population 65 years of age and over are not found among this subpopulation 10 years earlier) give support to this view. In this report, attention is really being given to the population 45–64 years of age, who will become the new aged in the next 20 years—up to the year 2005. While subsequent cohorts of the new aged after the year 2005 will be larger in size, reflecting the Baby Boom generation, those persons currently 45–64 years of age represent cohorts which are very different in educational, marital, income, and perhaps health characteristics from cohorts of persons who are presently aged. They merit, therefore, special research attention.

The dynamic aspects of population change among the older population must be viewed within the context of an aging society whose social and economic structures are also undergoing change. To assess major issues arising from these demographic and societal developments requires forethought along multiple dimensions. Demographic projections per se provide only one facet for our consideration. We also are interested in examining how other societal structures and policies would be affected and, in turn, how various policy options can influence the projections. Thus, the aim of projection activities can be viewed as at least threefold. *One*, they can create a new awareness of emerging issues, as in the case of the growth of the aged population. *Two*, they enable us to assess the relative importance of different parameters; for example, how the relative health status of the population relates to mortality, which also affects the growth and structure of population. *Three*, projection models enable us to examine existing policies, their implications, and how alternatives may be needed to address emerging issues.

In this report, we will attempt to examine the basic national population projections, focused projections that often rely directly on these efforts, and other types of projection modeling that are intended either to probe in greater depth input or outcome dimensions or to incorporate different models into integrative frameworks.

Projecting the aged population

Most projections of the aged population are derived as simply one age segment in a total population projection. While this should not cause any problems from a theoretical point of view, it does raise some practical issues that have arisen in many of these projection efforts. *One*, inadequate attention is given to age detail at older ages, i.e., truncation at ages 75, 80, or 85. *Two*, the absence of detailed data at the extreme older ages limits the attention that can be given to many of the factors that may be of particular interest to the policy analyst (e.g., institutionalization). *Three*, little consideration is given to problems that may arise with respect to the quality

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[a] Contents are the opinions of the author and not those of the Department of Health and Human Services or the organization he works for.

of data at older ages. These problems can involve age misstatement, underenumeration, inaccurate reporting of characteristics, etc.

Perhaps a greater concern derives from the fact that the rates of transition between relevant states at older ages are often much greater than at younger ages. Therefore, greater sensitivity is implied for purposes of adequate estimation. For example, mortality rates after age 1 tend to increase throughout life and reach much higher levels at extreme ages. The 1982 death rate for males was 546.1 per 100,000 at ages 45–49 but nearly 20 times greater at ages 80–84. Thus, the margins of error in estimation are often greater at older ages, and unless special care is given to these issues, inappropriate findings for the aged population can result. High transition rates among the aged also apply to morbidity, hospitalization, retirement from full-time employment, and the like. In contrast, the fact that some transition rates are much lower, as for geographic migration, marriage and divorce, and housing mobility, should make the estimation task relatively easier for older persons.

In short, there are a number of particular issues that are raised in dealing with the aged population which suggest that specific efforts are called for in projecting their future states.

Projection shortfalls

The past record with respect to the accuracy of projections of the aged population has not been an enviable one for the most part. An examination of 23 major sets of projections made by the U.S. Bureau of the Census since 1947 shows the projections (more recently, the medium variant set) to have consistently underestimated the subsequent census enumerations, even over the short term (Myers, 1981). This is true for the aged population as a whole (65 years of age and over) and for both sexes, both white persons and persons of other races, and even for different age groups within this subpopulation.

The main reason for these shortfalls primarily concerns the mortality component and specifically the survival ratios that have been used, both at adult ages under age 65 and at the later ages. It also should be pointed out that some of the inadequacy rests on the apparently inadequate base populations that are used, as well as unexpectedly more complete enumerations, such as in 1980, in which much larger numbers of older persons than expected were reported. These are due to highly technical matters involved in the projection procedures followed, which will not be discussed in this paper. Yet another part of the problem can be traced to the ad hoc basis on which projections are prepared.

In reviewing these forecasts, one becomes aware of the lack of regularity in issuing official sets of productions. The 23 different sets prepared by the Bureau of the Census since 1947 have been issued at many different time points (e.g., only years ending in 6 and 9 are apparently omitted). So too, the series have beginning dates that are not systematic. Surprisingly, few begin with census dates, although clearly base populations for these dates (or estimates for July of census years) would seem most reliable, especially after post-enumeration adjustments are made. One is tempted to conclude that the use of varied beginning dates offers a hedge against subsequent questions of accuracy (Myers, 1983). In addition, the periods covered by the projections have tended to vary widely, with more recent sets extending farther into the future. For example, the most recent Census Bureau projections extend to the year 2080. It might be suggested that this lack of regularity simply implies that new sets (or additional series) are prepared only when they are needed, but the recent gap between 1977 and 1984, when the last official version was issued, belies this assertion. Certainly there was strong evidence that the 1977 forecasts were deficient in many respects, particularly in the mortality assumptions. A delay in preparing a new set of forecasts was no doubt due to the decision to wait until the 1980 census figures were available.

With respect to the single-factor projections of other characteristics, a similar situation exists as with the basic demographic forecasts. They are issued at irregular intervals, have varied beginning dates, and cover different time horizons. However, very few of these projections extend for more than 25 years. In addition, while the projections of social and economic characteristics are generally based on the so-called official demographic forecasts, these specialized forecasts often use selective series and, at times, somewhat divergent methodological approaches (Long, 1981). As Long notes, "Perhaps the most striking results of this overview of projections methodologies are the lack of a mechanism for assuring consistency among projected variables and the apparent arbitrariness of many of the assumptions used...." (1981, p. 317).

Types of projections

It is important at the outset to address the various ways in which the future states of the population can be examined.

(1) *Basic* population projections, such as those issued by the U.S. Bureau of the Census and often considered "official" because they are so widely used, are the most commonly available sources of information about the future age, sex, and race composition of the national population. Moreover, the set of Bureau of the Census State and regional projections is developed to be consistent with these basic projections. The Office of the Actuary of the Social Security Administration prepares long-term population projections with a comparable cohort-component approach (Social Security Administration, 1984b). In addition to age and sex characteristics, the projections also treat marital status in an endogenous manner. It should be noted that race is not treated in these projection series. These projections utilize cohort-component/demographic accounting procedures in which each of the components is independently estimated. Land (1986) and Long (1985) have recently reviewed the various methods that have been used to forecast components.

The basic national projections form the basis for a range of single-factor projections prepared by the Bureau of the Census and other Federal agencies (Long, 1981; U.S. Bureau of the Census, 1983, appendix). They relate to educational attainment, household and marital status, labor force status, etc. A characteristic feature of these national projections is that they employ fairly conventional ratio procedures by applying fixed ratios or ratios changing in some predetermined pattern to the disaggregated base figures found in the projection series (usually the middle variant, although sometimes with alternative sets or even special base distributions). So too, some range of ratio values may be introduced. In all cases, these projections are single-factor projections in the sense that they do not incorporate interactions between the outcome factor and the dynamic factors that "drive" the basic projections—fertility, mortality, and migration. For example, changes in educational levels would not affect fertility outcomes, although they might be expected to in reality.

(2) There are a number of more *global* models that attempt to integrate different submodels or modules into a common projection framework. In particular, there are numerous aggregate economic-demographic models that have mainly treated the demographic components as exogenous for purposes of short-term forecasting. Ahlburg (to be published) has reviewed recent attempts to incorporate a number of endogenously determined components. For example, the Brookings, Chase, and Wharton econometric models now have developed modules to accomplish this in a variety of ways. Although most of these models have not been used extensively to project specifically the aged population or economic outcomes related to the growth of the older population, a few models of this type have been developed or modified to provide longer term projections of the aged.

The National Institute on Aging Macroeconomic-Demographic Model is a global, long-term model that is intended to assess how the changing age structure of the population will affect the income level of the elderly population, as well as productivity, consumption, saving, and investment (National Institute on Aging, 1984). The model treats all population factors exogenously within the comprehensive, integrated model of long-term economic growth and labor market. These, in turn, are related to major features of national pension systems and transfer programs. This means that economic factors contained in the other modules have no impact on the population dimensions.

Another large-scale macroeconomic model developed by Data Resources, Inc., incorporated a Demographic-Economic Model of the Elderly for 25-year projections of the economic implications of an aging population (Olsen, Caton, and Duffy, 1981). The demographic variables are determined exogenously in this model also.

Yet another strategy of global modeling involves microsimulation rather than macrosimulation. Although models of this type seem to have fallen from favor somewhat, they still hold promise if adequate estimation procedures can be introduced. These types of models show probabilistic estimates (Monte Carlo procedures) of transitions for different parameters to operate on a sample population over time, thus changing their status distributions (e.g., marriage, childbearing, and employment). An early microsimulation model developed by the Research Triangle Institute, called POPSIM, was particularly useful in evaluating the effects of different patterns of childbearing and contraceptive regimes upon population growth. Another widely utilized microsimulation model, DYNASIM, was prepared by the Urban Institute (Wertheimer and Zedlewski, 1980). It has been used to examine labor force dynamics such as employment, hours worked, retirement, and the impact on these dimensions of various changes in Federal legislation (Hendricks and Storey, 1981; Anderson and McNaught, 1982). A preliminary research project using a microsimulation model to examine future health status was conducted by the Duke University Center for Demographic Studies (Myers et al., 1977). Exercises were conducted using the model based on transitions among 10 disease states and subsequent death for the elderly population to the year 2000 and for the population of U.S. male veterans. Although these efforts were successfully completed, some serious shortcomings in the parameter estimation, due mainly to insufficient and inadequate data, were encountered.

(3) A third type of projection can be identified that deals with more *focused* objectives. These endpoints often are intended to explore the implications of certain population changes on matters of potential national importance, such as service and facility demands, labor force requirements, and expenditures. Like the single-factor projections of population characteristics, they may be limited to simple application of fixed ratios to the population counts or may involve a chain of variables directed toward certain endpoints. For example, the Health Care Financing Administration has examined health expenditures through such procedures (Freeland and Schendler, 1983). The Social Security Administration (1984a) has used its projections to assess the future requirements of the Old Age, Survivors, and Disability Insurance (OASDI) system and its fiscal health. The income projections of the Bureau of the Census and several efforts at the National Center for Health Statistics to assess future levels of health status, utilization of services, and health expenditures also are of this type (National Center for Health Statistics, 1983). It should be noted that these focused projections may involve alternative series from a baseline population projection or alternative assumptions dealing with the factors to be estimated. Moreover, each of the outcomes may entail more complex modeling as well. Thus, on both the input side, in terms of components of change affecting the population characteristics, and on the outcome side, in terms of structural factors, there may be quite sophisticated treatment of estimation equations for forecasting.

This brief review of projection techniques is not intended to be exhaustive, but rather to be indicative of the variety of approaches that characterizes the field of forecasting. In the sections to follow, we will examine projection efforts applied to older persons that illustrate these approaches in terms of certain important demographic, health, social, and economic dimensions.

Data available

Population characteristics

The two most general and, no doubt, widely used projection series are those issued by the Bureau of the Census and the Office of the Actuary of the Social Security Administration. There are similarities between these two activities in at least three respects. *One*, they are issued on a recurring basis—the Census Bureau projections were last released in final form in May 1984 and the previous set was released in 1977, whereas the Social Security projections have been issued on an annual or biennial basis since 1974, the most recent being issued in May 1984. In both cases, the projections are long term, extending to the year 2080, with data for selected intermediate years reported. *Two*, the projections are made according to age and sex in both efforts, but race is included only in the Census projections. Since 1980, the Social Security projections also include marital status. *Three*, the projections involve conventional cohort component methods and even share alternative series assumptions. Thus, the Census Bureau utilizes the mortality forecast assumptions of Social Security as a starting point for their projections, while the reverse exchange between the agencies is true of fertility and net migration assumptions.

Nonetheless, there are important differences between the two agency efforts. The major difference is in the population coverage. In published reports, the Census Bureau projections cover the resident population of the 50 States and Washington, D.C., along with Armed Forces overseas. The so-called "Social Security Area" is broader and also includes the civilian residents of Puerto Rico, the Virgin Islands, American Samoa, and Guam; Federal employees and their dependents overseas; and other citizens overseas. The intent of the Social Security Area is to reflect those covered by the OASDI system. In 1982 it was estimated that an additional 9 million persons are found in this enlarged Social Security Area compared with the Census coverage, with 681,000 of these persons 65 years of age and over.

A second difference between the two projections relates to the fact that the Census Bureau reports results of 30 alternative series of projections, based on three alternative assumptions for fertility and mortality and four assumptions for net international migration. The Social Security published reports contain information on only three alternatives. The casual user of these alternative series must be made aware that the two extreme Census alternatives (called Highest and Lowest) do not correspond to Social Security Alternatives I and III. The Census extremes reflect highest population growth (low mortality and high fertility) and lowest growth (high mortality and low fertility); whereas the Social Security extremes reflect the lowest fiscal burden on the OASDI system (high mortality and high fertility) and the highest (low mortality, low fertility). Moreover, the middle series also differ in terms of fertility (completed fertility of 1.9 children in the Census projections and 2.0 in the Social Security series). Mortality assumptions also differ in the two series, as can be noted from the levels of life expectancy at birth forecast for the terminal year 2080:

	Male		Female	
Mortality	*Census*	*Social Security*	*Census*	*Social Security*
Low	80.83	83.8	90.98	91.8
Middle	76.75	77.6	85.22	85.5
High	74.46	74.4	81.22	81.9

These differences result from the assumptions, mainly those made for the low series, and the time trajectories of change adopted.

The general procedures involved in the mortality forecasts bear directly on our concern with the growth of the aged population and health status characteristics. The need for developing alternative assumptions for mortality evolved at Social Security in the 1970's along with the general procedures for forecasting this component. The adoption of alternative mortality assumptions by the Census Bureau in its latest projections reflects the fact that mortality forecast errors had become a significant proportion of overall error in the short as well as long term, especially for projected estimates of the older population. The U.S. Bureau of the Census report noted that: "Mortality accounted for more than 40 percent of the 6-year aggregate error in the last two projections" (1984, p. 17).

The general procedure followed by Social Security is to begin by examining past trends in cause-specific mortality by age and sex for 10 major cause-of-death groups. For the most recent Social Security projection (1984b), trends for ages under 65 were examined for the 1968–80 period. For data on ages 65 and over, Medicare program records are used to derive rates by age and sex. Age-sex-cause rates for this group are determined by the distribution of the number of deaths by cause from vital statistics sources. Average annual improvements in the rates are calculated over the period by age, sex, and cause. Judgmental procedures are then applied to determine ultimate annual percentage improvements that would apply to the year 2080 at three alternative levels for each sex. For 1983, the first year of the most recent projection, the 1968–80 annual improvements were arbitrarily assumed at 50, 100, and 150 percent of the change for the three alternatives I, II, III. They were then interpolated by logarithmic function to the ultimate annual improvements over the period 1983–2008. From 2008 to 2080, the ultimate annual improvements are applied on a constant basis. The result of these multiple procedures is the derivation of a gradually declining rate of improvement up to 2008 compared with the period 1968–80 (dampened extrapolations), and then a steady but lowered improvement through the rest of the forecast period. Thus, there is a combination of both extrapolation and judgmental procedures employed, with rather strong assumptions made about the pace of change for the different causes.

The latest U.S. Bureau of the Census projections (1984) are based on somewhat earlier Social Security forecasts, but they are generally based on the same procedures. An exception is the modification in the high improvement assumption to only 125 percent of the 1968–80 annual improvement. This more conservative assumption through the year 2005 produces lower life expectancy figures at subsequent points in time.

The Social Security forecasts also show greater divergence in the sex mortality differential than is true in the Census Bureau forecasts. In addition, forecasts of mortality by race were made independently by the Census Bureau using fairly arbitrary assumptions that black male mortality would reach white rates by 2080 and that black female levels would converge earlier with white rates.

The data for both major sets of basic population data are published for selected years to the year 2080. In the Census report, for the Middle Series, single year of age data are reported up to age 84 and 5-year data are reported to age 99 on an annual basis to the year 2000 and every 5 years from 2000 to 2080. Five-year age data are given for the Lowest and Highest Series for the same years. For the other series, 5-year age data are provided at 5-year intervals. In the Social Security report, 5-year age data up to age 95 are presented for 1985, 1990, 1995, and 2000, and then data are presented at 20-year intervals to 2080. Intermediate year data and more detailed information on the values for components are generally available from the agencies in unpublished form.

Family and household structure

There are a variety of different aspects of family and household structures that are of considerable importance for older persons and their social, economic, and health well-being. These include marital status, living relationships of older persons, kin networks (e.g., multigenerational families), and sources of support. The complexity involved in describing these structures at even a single point in time presents some major obstacles in the way of forecasting. It is not surprising that a number of different projection approaches have been applied to further our knowledge in what has come to be recognized as a crucial dimension of public policy for the aged.

The Census Bureau has periodically issued projections of marital status; households, families, and unrelated individuals; and families by type. The last projection report on these dimensions was issued in 1979 for the period 1979–95. These projections are of the fixed-ratio type, in that changes in the proportions of persons in each marital status who are heads of households or families are applied to projections by ever-married status. Multiple series were generated in the last projection to represent four patterns in the rates of change in marital status, and thereby household headship, as reflected in the changes between various periods over the years 1964 to 1978. No change in the four sets of rates was assumed over the projection period. All of these projection series used only the 1977 population Series II figures. The published tables include annual data to 1995 of households by 10-year age intervals and data for marital status in 1985, 1990, and 1995 by the same 10-year age intervals.

The projections of marital status prepared by the Social Security Administration also involve constant transition rates over the entire projection period derived from the 12-month period ending June 1983. Incorporated into their procedures, however, are differentials by previous marital status and mortality variations by marital status (the latter are based on data available only for the period 1959–61). No alternative series were developed. There are numerous comments in the 1984 report indicating the relative crudeness of these procedures and suggestions that further improvements will be made in future projections. The reporting detail is the same as for the age and sex characteristics.

Several projections are currently underway that adopt multistate demographic procedures to project future marital status distributions. Essentially, these involve the calculation of increment-decrement marital status life tables derived from data on either the retrospective experiences of cohorts over time or period information. At the Research Triangle Institute, Griffith and associates have prepared female marital status projections on successive birth cohorts from 1906–10 to 1946–50 through age 70 (Griffith, Suchindran, and Koo, 1985). For estimation of future cohort experience, four assumptions are made, including a static assumption based on period transitions in the period preceding 1980. Data are drawn from the June 1980 Current Population Survey, in which a sample of 66,000 females 15–75 years of age were asked about timing of past marital events for their first, second, and most recent marriage. Only limited data have been presented to date from this activity.

Espenshade at the Urban Institute has used the same data to project female marital status distributions for the period 1980 to the year 2080 (1985). Fixed-rate projections were made under two assumptions—the rate of transitions in the period 1975–80 (low family stability) and that of the 1950's (a high family stability scenario). It should be noted that these projections incorporate their own fertility and mortality assumptions relevant to the two periods. Sensitivity tests were run to assess the relevant effects of fertility, marital status transition rates, and mortality. Although the reported projections are not broken down by age, they illustrate the use of so-called integrated population systems that make use of disaggregated state transitions. For example, fertility levels may best be forecast in terms of the childbearing patterns for each marital class of females. In general, these approaches make considerable demands for suitable input data that contain age- and status-specific transition rates. Moreover, in nearly all applications of these procedures for projection purposes, fixed-rate transitions over time have been applied.

Wolf (1985a) at the Urban Institute has used a semi-Markov process model and microsimulation to examine life-cycle marital dynamics. Projections of marital status distributions by different birth cohorts to the year 2025 have been made under two simulation variants. This is an interesting exercise in that, unlike the multistate life table approaches, it explicitly treats duration of time or sojourn time in a given marital state in estimating the probabilities of moving between states. Although the tables published to date start only with cohorts of persons 40–45 in 1985, the analysis has been made for the earlier cohorts (Wolf, 1985b). The analysis is also based on the June 1980 Current Population Survey data set.

Housing

The projecting of future housing requirements relies quite heavily on household and marital status forecasts. At the

Joint Center for Urban Studies of the Massachusetts Institute of Technology and Harvard University (1982), projections of housing consumption have been prepared to the year 2000 under a set of assumptions relating to marital and household structures for different birth cohorts. (See also Pitkin and Masnick, 1980.) The reports of this research do not contain detailed age data, but certainly such materials are available inasmuch as age groups through 85 and over are examined. Furthermore, households are projected by owner and rental tenure and for regions of the United States. It should be noted that this projection effort is self-contained and not based on Bureau of the Census projections, although comparisons are made between the two efforts.

Although some attention is paid in these reports to type of housing (e.g., public housing, trailers), the specific demands arising from the growth of the older population are not addressed. The U.S. Senate Special Committee on Aging (1983) examined a range of such issues dealing with housing trends and programs concerned with the aged, but no projections are reported. The variety of different types of housing used by older persons and the marked changes in living arrangements would seem to be a research area in which projections are needed. At the same time, the potentially growing need for institutional facilities should command greater attention. (See, for instance, Rice and Feldman, 1983.)

Education

Projections of educational attainment have not been routinely prepared by Federal agencies or other groups. The last Census Bureau projections were released in 1972 and contain projections at 5-year time points from 1975 to 1990. They are fixed-ratio projections based on two sets of age and sex educational attainment rates determined by trends for prior periods applied to official projection figures. The procedures implied that rates would remain fixed after ages 30–34 and that mortality for a given age group is the same regardless of level of attainment. In spite of the relatively nontechnical procedures that would be required for this type of projection, official series have not been prepared by the Bureau of the Census in recent years. For the older population, at least 40 years into the future, educational attainment levels can be determined in a crude way by using existing data on attainment and simply carrying them forward (see, for example, Uhlenberg, 1977). Such an effort also has been reported as unpublished projections prepared by the Bureau of the Census up to the year 2000 and the year 2014 (chart presented in Federal Council on the Aging, 1981) for males and females aged 65 and over.

In light of the important changes that are anticipated in educational attainment levels for cohorts entering older ages up to at least the year 2000, it is surprising that more attention has not been paid to this issue. More sophisticated projections would need to include both differential survival by educational level (where differences are known to exist, but for which national data are sparse) and estimates to account for different forms of adult educational achievement, especially at older ages.

Health status and health care

Although health status, health care utilization, and costs emerging from these services constitute a matter of great national importance, it has been treated only sporadically by projection efforts. It is, of course, a complex and difficult area to examine, particularly at older ages, where chronic diseases and related conditions become more manifest. Chronic diseases are complex for a variety of reasons. One, they evolve over long periods of time; two, they tend to produce various symptoms related to the quality of life (e.g., varied types and levels of functional limitations); three, they are etiologically multifaceted, involving both specific risk factors and physiological changes due to the aging process; and, four, joint prevalence and interactions between these diseases frequently exist (Manton, 1985). Thus, in spite of clearly charted trends in causes of death and overall mortality, the underlying health dimensions present patterns of change that are only starting to be considered in forecasting efforts on a national scale.

In addition, the forecasting of various aspects of the health care system rests not only on patterns of health status for the population and its subgroups, but intrinsically on intervention strategies (e.g., primary prevention, surgical and medical treatment, and technological developments) and the degree of commitment taken to alter the course of disease processes and their related elements. We are dealing with a complex interplay, therefore, between what might be called natural processes and social, economic, and political factors. Let us examine some of the forecasting efforts that have been made to capture varied aspects of the situation.

The Social Security projections make use of several strategies to forecast mortality. As noted earlier, they involve empirical trend analyses of broad categories of causes of death to determine age- and sex-specific rates of change and judgments regarding the ultimate rates of change and the patterns of change over the projection period. Judgments also are made to create alternative series. While such procedures are certainly an improvement over earlier efforts at simply extrapolating age- and sex-specific mortality rates, they still involve rather arbitrary assumptions about the future course of terminal conditions rather than any profound consideration of the biological process involved (Manton, to be published). While these forecasts provide a basis for making general population projections, they do not enable us to examine in any great depth the underlying dimensions of health status.

The estimates of future mortality resulting from these efforts have served as a basis for the Social Security and Bureau of Census projections and a number of other forecasting efforts. In the way of aggregate forecasts, the Health Care Financing Administration has developed projections of national health care expenditures and types of expenditures to the year 1990 using the Social Security projections, Alternative II (Freeland and Schendler, 1983). No specific costs connected with the aged are reported, but clearly these demographic trends are involved in the projected figures on expenditures and their share of the gross national product.

The National Center for Health Statistics also has reported on projections of various aspects of health services utilization and health care expenditures for the year 2003 (National Center for Health Statistics, 1983). These projections involved assumptions for both a constant mortality (1976) and declining mortality extrapolated from the trend from 1953–78 to project the age structure of the population in 2003. Fixed ratios of limitations of activity, utilization of health services, and health care expenditures were then applied to determine the overall impact of the population change, the contribution attributable to specific age groups (including older persons), and the effect of the two mortality assumptions. Rice and Feldman (1983) updated these earlier projections by using the 1981 Social Security projections (Alternative II) and more recent health utilization and related data. Using the same fixed-ratio procedures, they carry projections out to the year 2040. These reports pointedly note the limited nature of these exercises, but emphasize that they do provide general indications of how population aging can affect various dimensions of health.

For the 1981 White House Conference on Aging, the Federal Council on the Aging also reported in graph form some fixed-ratio projections related to health care and needs for long-term care. Derived mainly from the current estimates of various agencies and the 1977 Bureau of the Census projections, estimates are made of the use of health services by the elderly in the year 2000. Estimates also are made of the percent of elderly who will be childless and average childbearing, by race, for those turning 65, and at ages 65 and over through the year 2008. Finally, the percent of persons in the labor force to the year 2000 is estimated by sex and ages 45–54, 55–64, and 65 and over in order to gain a perspective on persons potentially unavailable to serve as caregivers to the elderly. While these are fairly crude efforts at estimating future needs and currently are outdated, they do indicate some social dimensions that warrant further attention. It may be noted that the U.S. Senate Special Committee on Aging and the American Association of Retired Persons presented more current charts on various health utilization dimensions to the year 2050 using similar procedures (1984).

Manton and Soldo (1985) have prepared projections of the noninstitutionalized and institutionalized long-term care population for married and unmarried persons of both sexes for the years 2000 and 2040. Three groups of older persons are identified, those 65–74, 75–84, and 85 and over. In addition, four different levels of functional limitations are assessed for the noninstitutionalized—three activities of daily living levels and one instrumental activities of daily living level. Fixed ratios of rates that are age, sex, and marital status specific, estimated from the 1982 National Long Term Care Survey, were applied to the Social Security projected populations (adjusted to U.S. resident level). The 1977 National Nursing Home Survey provided ratio estimates of the institutionalized.

In addition, they derived further estimates of total hours per week spent in providing informal care for functionally limited persons 85 years of age and over where the helper was a spouse, offspring, relative, or nonrelative (Manton and Soldo, 1985). These ratios were derived from the National Long Term Care Survey and the National Opinion Research Center Survey of Caregivers. An alternative scenario was developed by examining the age- and sex-specific disability levels compared to the projected 1981 Social Security mortality rate declines. Thus, they have examined some interesting issues of both future forecasts of disabilities and certain kinds of service requirements that such levels would generate, drawing upon varied surveys for the fixed estimates. Finally, they determine the volume of informal services implied by current levels of care and the expenditures that would be involved.

A more focused effort at developing biomedically informed forecasting models has recently been prepared by Manton (1985). Incidence and prevalence of cancer morbidity by age groups to age 90 and over are projected to the year 2000 under assumptions of a changing population structure and one fixed from 1977. Projections for lung cancer deaths in 2000 under both assumptions also were made. What is interesting about these forecasts is that Manton employs stochastic compartment modeling techniques to estimate health state transitions for persons subject to specific diseases. Multiple sources of data are used to deal with age cohort differences in risk, changes in risk exposure over the lifespan, individual differences in risk, and both independent and dependent competing risk assumptions about interactions among diseases.

A second aspect of this research uses more complex random process modeling strategies that are particularly suitable for use with data from longitudinal studies of chronic diseases. These models are shown to have considerable use in assessing particular intervention strategies. In the application examined, lost future lifetime income is estimated for risk variable controls (e.g., smoking) at different ages. Prevalence costs for lung cancer to the year 2000 also were determined from the stochastic compartment model under different population structures.

Labor force

A variety of different projection approaches have been taken to forecast the participation of women and men in the labor force (i.e., employed or seeking work). The Bureau of Labor Statistics prepares a series of widely used projections, the most recent of which was issued in 1984 to cover the period to 1995 on an annual basis. Three series are included (high, medium, low economic growth) that are based on extrapolation of age- sex- and race-specific participation rates for the period 1962–81 or subperiods, and assumptions relating to change over the projection period in both demographic and economic conditions. The changing schedule of rates is then applied to the Bureau of the Census Middle Series projected populations. It should be noted that the scenarios are mainly determined judgmentally, but empirical trends and related modeling are also taken into account. One of these econometric models, which involves a marital status model, has been used to forecast labor force participation among older persons (Duggan, 1984). The U.S. Bureau of the Census (1984) also has published labor force participation ratio figures for the year 2000, but these are now superseded by the later modified set of projections by the Bureau of Labor Statistics.

The Social Security Administration, as noted earlier, prepares economic projections to assess the financial status of the OASDI system (1984). Estimates of labor force participation over the projection period enter into these efforts. Projections are made to the year 2060, by ages up to 70 and over and by sex, according to four long-range economic assumptions. The ratio estimates are based on previous trends with judgments made as to their future course.

Although the Bureau of Labor Statistics and Social Security projections do not consider part-time employment, an earlier study by Wertheimer and Zedlewski (1980), using the Urban Institute's DYNASIM microsimulation model, included detailed examination of work status by annual hours worked for various older age groups of males and females to the year 1990. Two alternative scenarios were examined, depending on early or late departure from the labor force. The DYNASIM model takes into account a variety of individual characteristics—age, sex, race, marital status, education, disability status, employment history, children of the elderly, etc. Mortality changes were also introduced into the model, for this application focused on an aging society. Another simulation model based on retirement decisions has been utilized by Hendricks and Storey (1981) at the Urban Institute to investigate the effects of alternative mandatory retirement policies on labor force participation of persons around retirement ages for the years 1990 and 2000.

A Macroeconomic-Demographic Model of the National Institute of Aging (1984) includes a labor force integrated supply and demand model, which produces labor force participation rates for each age-sex group. The MDM has mainly been used for economic policy analyses to date and, in this regard, three pension system models have been developed and two Federal transfer models. Some aggregated projections have been prepared to the year 2055 for employment, compensation, private pension benefits, and other economic dimensions (National Institute of Aging, 1984). Anderson and McNaught of ICF, Incorporated, the developers of the model, also report labor force participation rates to the year 2050 (1982). Interesting alternatives are provided for both high and low productivity growth in the economy.

Income

Estimates of income and sources of income for the aged population in the future have been the goals of a number of projection efforts using the MDM and other models. The 1984 volume describing the model provides some breakdowns of income by selected sources for older age and sex groups through the year 2055. Anderson and McNaught (1982) also provide aggregate compensation over the projection period to 2050. It is likely that more detailed age and sex information is available from the analyses reported for the MDM model.

The U.S. Bureau of the Census (1980) has published illustrative projections of income distributions for different types of households by broad age categories of householders for 1980 through 1995 at 5-year time points. Income levels from the 1978 Current Population Survey were applied to the two intermediate household projections to derive those estimates. Seven annual growth rates of income, ranging from 0 to 4.0 percent, were assumed to operate in a fixed manner over the projection period, thus yielding 14 series of projections.

The Data Resources, Inc., Macroeconomic Model and Demographic-Economic Model of the Elderly form the bases for the analyses reported by Olsen, Caton, and Duffy in their work *The Elderly and the Future Economy* (1981). Data for limited age categories for each sex are reported on the distribution of income through the year 2005 under a series of economic scenarios involving different government programs. These data are based on simulations involving increased labor force participation of older persons, income guarantees, increases in personal savings, and investment-oriented tax cuts. A baseline projection series provides a means of assessing the different program implications. The macroeconomic models are dynamic econometric formulations, but the population base used in each series is the 1977 Middle Series from the Bureau of the Census.

Evaluation and suggestions

Even the brief review of the projections that have been made about tomorrow's elderly indicates that a bewildering array of data exists from a variety of different sources. Dissemination of the results of these exercises has been in many different formats. It is clear that a wide range of projection strategies has been applied, but with little overall assessment of efficacy. There appears to be only limited coordination among these efforts, even among Federal agencies in which some common forecasting parameters are used. Although efforts have been made from time to time to bring some of the evidence together from these projections (e.g., U.S. Bureau of the Census, 1984; Myers, Manton, and Baceller, 1986; Siegel and Davidson, 1984), there has been a lack of systematic evaluation. The recently held Workshop on Forecasting Life Expectancy and Active Life Expectancy, sponsored by the National Institute on Aging and the American Council on Life Insurance, suggests that recognition of this situation is emerging. A fully developed program of evaluation of the theoretical, methodological, and data requirements for forecasting of the aging population seems in order, perhaps under the aegis of the National Research Council and the National Institute on Aging.

It should be emphasized that we are not suggesting that a rigid framework for projections should be introduced, for there are advantages in diversity, but rather that greater attention be given to a more coordinated effort. It also is clear that forecasts are intended for different purposes and therefore require varied approaches. Nonetheless, the independent efforts may lead to quite different conclusions that require systematic evaluation. With these thoughts in mind, a number of more specific suggestions can be made in terms of the organization of these efforts, areas of needed research, and data requirements.

Organization

(1) It would be desirable if the ad hoc timing of the basic set of projections prepared by the Bureau of the Census could be replaced by an integrated program effort made every 10 years, based on the decennial census results and related data sets. Perhaps a shorter term projection could also be prepared at the midcensal point as well. This would replace the sporadic efforts that have been undertaken in the past. These projections would ideally cover all the characteristics that have been included in the past—age, sex, race, marital status, households, educational attainment.

(2) The Office of the Actuary of the Social Security Administration has been issuing projection series on an annual or biennial basis for some time. There seems to be little advantage realized by making long-range projections so repeatedly—a greater range of alternatives would certainly accomplish the same end. The important contribution made by Social Security is to forecast mortality, the results of which are used in part by the Bureau of the Census. While these forecasts incorporate cause-of-death trends, this effort could profit from exposure to a wider range of expert judgments relating to variations in the future. Incorporation of more biomedically informed actuarial procedures also seems useful, especially in developing morbidity and disability forecasts. Cooperation with the Health Care Financing Administration and the National Center for Health Statistics in these efforts might prove beneficial. In addition, if mortality forecasts were made by race, this would relieve the Census Bureau of the need to prepare such estimates. Finally, the inclusion of marital status projections by Social Security since 1980 appears useful, but coordination of these efforts with other agencies in improving the projection procedures is desirable, especially in developing alternatives.

(3) The National Institute on Aging's Macroeconomic-Demographic Model would seem to be an excellent aggregate-integrated model for examining a whole range of economic issues relating to older persons. However, there is a need for developing more endogenous modules for the demographic component with respect to family formation and dissolution, fertility, and especially health status and mortality. In this regard the pioneering work performed by the Australian group working on the IMPACT model would seem to be particularly relevant, especially with respect to their endogenous population submodule (Sams, 1979). The MDM seems to have been used almost exclusively for assessment of employment decisions and income considerations. Research is currently under way for the development of modules to assess the demand for health insurance and services and another one on health expenditures, which seemingly would require further detail on health status of household members.

(4) Developments are called for that would lead to more sophisticated modeling of the components of population, particularly the mortality component that so affects projections of the aged population. In this regard, integrated efforts are necessary to forecast health status, functional limitations, and support systems available for older persons (Manton, 1984). These forecasts not only can have utility for probing important policy issues related to health care expenditures and welfare programs, but also can serve to inform improved mortality forecasts in general population projections. Projections in this area should be aided as data from the National Health and Nutrition Examination Survey I-Epidemiologic Followup Survey, the 1984 Supplement on Aging of the National Health Interview Survey, and the National Long Term Care Survey's 1984 round become available.

Needed research

(5) There are several areas of importance for increasing our understanding of the future elderly that have been relatively neglected as far as projections are concerned. *One* of these is ethnicity, both in terms of foreign-born persons of non-U.S. parents and foreign ancestry. Uhlenberg (1977) reported some changes in foreign-born older persons using static-component procedures, but we are unaware of any projections relating to American Indians, for example. There is a lack of data on mortality risk for different types of immigrants, but this perhaps could be overcome with existing information on records. Of course, estimation would be difficult to assess for groups in which undocumented migration is extensive. A *second* area is living arrangements. This is a particularly difficult dimension to forecast in view of the strong economic, health, and value determinants that operate in conjunction with demographic factors such as age, sex, and race. Some exploratory work has been undertaken in this area, but more vigorous efforts would seem desirable.

(6) Another dimension that has been largely omitted in the discussion to this point concerns the lack of geographic detail in many of the national projections. The Bureau of the Census provides periodic State projections that agree in aggregate with the national figures, but these are limited to only age, sex, and race. Long and McMillen (to be published) have reviewed recently various demographic-economic models for projecting State and metropolitan area populations. Masnick and Pitkin (1982), at the Joint Center for Urban Studies of the Massachusetts Institute of Technology and Harvard, have prepared projections for States and regions for 1970 through 2000, but the data are limited at older ages. Of course, States often issue their own projections, often for counties, county groupings, and metropolitan areas, but these are not prepared on a periodic basis and the procedures may be quite variable from State to State. This is particularly true for migration estimates. There are currently underway several programs of research on the migration of the elderly, but these have not led to projection efforts as yet. Clearly, there is a need for greater attention to forecasting of migratory flows, perhaps the major elements of uncertainty in State and local area migration.

(7) There is a continuing need to develop approaches for presenting estimates of uncertainty associated with projections. It is often suggested that confidence limits should be a built-in feature of projections, just as in the case of sampling error estimates with different types of surveys. Several approaches have been suggested for determining confidence limits. They include estimates based on post facto empirical evaluations of previous projections (Keyfitz, 1981); systematic use of alternative series for this purpose; techniques dealing

with assumed likelihoods of certain alternative combinations, as suggested by Stoto ("Statistics for an aging population, dealing with uncertainty" in Chapter II of this report); and Delphi approaches.

(8) Dissemination of data from projections has tended to be mainly in the form of published tables showing limited age and characteristic information for only a few points in time. Detailed information for alternative series is often omitted. Moreover, the input schedules for the change components are seldom presented in published reports in adequate detail. One means of overcoming such shortcomings is to release information in tape form or through interactive computer systems. The Bureau of the Census has been moving ahead in making dissemination in this form possible, but it should be more widely encouraged. In this regard, it is likely that future projection developments may involve more user involvement, in which standard methods programs and input data can be used by those interested in order to prepare their own alternative projections. There is an effort underway by the American Council of Life Insurance that would create a computer program that is interactive and allows changing mortality assumptions for specific diseases to be introduced. This appears to be a most interesting communication development.

Data requirements

(9) A sound fundamental premise of forecasting is that the issues to be addressed and the methodological strategies adopted should dictate data requirements. Although data are seldom gathered or processed with the intent of forecasting in mind, it is clear that certain types of data are particularly valuable in promoting more sophisticated forecast modeling. In general, data that capture the process nature of change are more useful than static measurements, or even retrospective historical data, for estimating transition values. Data of this type can come from longitudinal studies that are based on repeated surveys and/or record linkages (Migdal, Abeles, and Sherrod, 1982). The latter sources may prove to be more effective in that larger numbers of cases and more representative samples are possible, although the intensity of the behavioral or underlying conditions for state transitions may be lacking. The recent development of methodologies for analyzing life history events suggests that steps are underway to utilize data that can be quite effective in forecasting efforts. In addition, the developments in multistate demography should lead toward more disaggregated efforts for estimation of transitions between states, such as in the case of marital status modeling. The same may be said of modeling of the sickness-disability-death processes. These methods have only begun to be introduced in forecasting efforts, but will no doubt come into wider usage.

(10) More specific to the older population, there is a need for assembling and reporting basic data on an age-cohort as well as an age-period basis. There clearly is greater need for more detailed data at the extreme ages. Many projections are truncated at age 75 or age 80, largely because of the absence of further detail or unreliability that prevents its use. Systematic efforts to encourage research on the oldest old by the program at the National Institute on Aging should stimulate greater data accumulation, which can then be incorporated into projection models.

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Data needs for policy analysis of long-term care[a]

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Introduction

Policy analysts and decisionmakers lament the lack of policy-relevant data to address key issues in long-term care (LTC) for the elderly. Although some data on LTC exist, major data needs of policy analysts often are unmet. The need for policy-relevant data about LTC is increasing as the population at greatest risk, those aged 65 and older, grows. What data are needed to address key policy issues in LTC over the next decade? This paper examines the Federal data system vis-a-vis data needs for policy analysis of LTC. It also recommends ways to fill the major data gaps.

LTC for the elderly is defined broadly in this assessment of data gaps. LTC includes health care, social services, and supportive housing for elderly who are functionally disabled. The functionally disabled are those with a chronic physical or mental condition that impairs them so that they require the help of another person in performing everyday activities (Doty, Liu, and Wiener, 1985; Federal Council on the Aging, 1981; Interagency Statistical Committee on Long-Term Care for the Elderly, 1980). Everyday activities fall into two general categories:

- Activities of daily living (ADL's)—These are personal care tasks of bathing, dressing, eating, toileting, and walking.
- Instrumental activities of daily living (IADL's)—These are tasks necessary for living independently in the community, such as shopping, preparing meals, doing household chores, managing money, using the telephone, and taking medicine.

Although this paper focuses on LTC for the elderly, it should be noted that the elderly are not the only LTC population. Other LTC populations include the mentally retarded, physically handicapped, and chronically mentally ill. Data needs for policy analysis of these LTC populations are beyond the scope of this paper.

Not all discussions of LTC cover such a broad array of services. In some cases, LTC is defined as solely nursing home care (Meiners, 1983). This paper addresses the entire service continuum from medical care to housing services. It does so to provide as broad a framework as possible for identifying data gaps in conducting policy analysis about the functionally disabled elderly. The purpose of this paper is to:

- Describe the LTC policy issues of major consequence for the next decade.
- Identify major gaps in data when addressing these issues.
- Recommend efficient ways to fill the gaps according to priority needs.

An assessment of data gaps in LTC for the elderly was conducted in 1980 (Interagency Statistical Committee on Long-Term Care for the Elderly, 1980). It focused on identifying data gaps through analysis of available national data. Some recommendations from this assessment, most notably those on analyzing existing data (Scanlon et al., 1983) and collecting data on informal supports, were implemented in the early 1980's. Much of the data resulting from these recommendations is "in the pipeline" today. In other words, data have been collected but are still being processed. Most of the data will be released publicly within the next 2 years. The LTC data collection efforts of the early 1980's represent a "spurt" in the Federal data pipeline, not a continuous flow. They were designed as single-time surveys. Although one survey has been repeated, none is on an established schedule. Hence, the need for periodic data to track trends in LTC remains largely unmet. This paper comes at an appropriate time to examine the contributions of this data "spurt" and to address the need for *periodic* data for LTC policy analysis.

The assessment of various surveys, inventories, and administrative records of the Federal data system was conducted by examining in detail the content of items, overall design, sample size, and collection procedures. The major policy issues are presented here as a framework for assessment of the available data. They were based on existing LTC policy analyses (Meltzer, Farrow, and Richman, 1981; Callahan and Wallack, 1981; Scanlon and Feder, 1984; Kemper et al., 1986; Office of the Assistant Secretary for Planning and Evaluation, 1981; Vladeck, 1980). To ensure that issues were relevant to future policy development, LTC policy analysts in the Federal Government, Congress, and private research organizations were interviewed. Each analyst was asked to reflect on key policy issues and on data needs for the next decade. The LTC policy issues identified by this process fall into four areas:

- Use of LTC services.
- Supply of LTC services.
- Role of informal support.
- Cost of LTC.

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[a] Contents are the opinions of the author and not those of the Department of Health and Human Services.

The remainder of this paper synthesizes the policy issues, assesses the relevant data systems and recommends ways to fill priority data gaps for each policy area. Recommendations build on existing data systems whenever possible so that available resources are used most efficiently.

Use of LTC

Introduction

The use of LTC—as determined by needs, attitudes toward seeking care, and availability of services and third-party payments—is a priority area for LTC policy analysis. Because functional disability increases with age, the elderly are at greatest risk of needing LTC and comprise the majority of the population using LTC services. The elderly LTC population included 2.6 million persons living in the community, according to 1979–80 data (Van Nostrand, 1985), as well as 1.1 million in nursing homes, according to 1977 data (National Center for Health Statistics, 1979). Of those in the community, 12 percent were disabled in ADL functioning only, 33 percent in IADL functioning only, and 55 percent in both. The majority of the elderly LTC population—75 percent—received LTC from informal supports only. A minority—only 10 percent—received LTC solely from formal sources (Van Nostrand, 1985). Because of the major growth projected for the elderly population, the future need for LTC and its cost are major concerns to policymakers.

There are diverse views on the future need for LTC. One view, based on demographic changes, forecasts major increases in the number of elderly who are functionally disabled and in their use of nursing home care (Rice and Feldman, 1983). Another view is that the need will decrease due to a compression of morbidity within a fixed lifespan (Fries, 1980). A third view is that projections of future need for LTC must also incorporate changes in qualitative variables such as living arrangements, economic status, and social networks (Manton and Soldo, 1985).

Policy issues

Policy issues concerning the use of LTC focus on four themes:

- *Need and use for LTC*—What is the need for LTC today and in the future? What is the degree to which today's needs are met? What is the use of LTC services in relation to need? What is the use by type of service? What is the lifetime use of nursing home care? What are the transitions in the use of LTC services as needs change? What is the use of acute care, especially hospital care, in relation to the use of LTC? What are the outcomes of various LTC services? How do outcomes vary by level of functional disability? What modes of care best meet the needs of subgroups of the LTC population? Do the need for LTC and its use change for different cohorts of the elderly?
- *Determinants of use*—How do type of disability and extent of its severity influence use of LTC? How does change in disability lead to change in use of LTC? How do qualitative aspects (such as living arrangements, marital status, social network, income/assets, and housing) impact on use of LTC? How do changes in these qualitative aspects lead to changes in use of LTC? What attitudes of the elderly lead to the decision to seek LTC services? Can the LTC population be classified into subgroups according to their service needs? What is the impact of technological innovations on the use of LTC? How do exogenous factors, such as cold climate and rural area, impact on the use of LTC? How does the supply of institutional and community-based LTC impact on use?
- *Functional disability*—What biological, psychological, and social factors increase the risk of functional disability? What impact do health promotion and disease prevention have on delaying the onset of disability or minimizing its severity? What are the effects of stress on functional disability? Is there a compression of morbidity occurring at older ages?
- *Impact of public policy*—How do recent changes in public policy for Medicare and Medicaid impact on the use of LTC? How do policies for retirement, housing, and taxation interact with those on Medicare and Medicaid to influence the use of LTC? Can case management control costs, satisfy unmet needs, and improve the well-being of the LTC population? What are the differential impacts of public policies on subgroups of the LTC population?

Existing Federal data

Brief descriptions of the major Federal systems which provide national data on the use of LTC are presented next. The descriptions begin with surveys covering elderly living in the community and end with surveys of those in institutions. Indepth descriptions are available elsewhere (U.S. Senate, 1986).

- 1982 and 1984 National LTC Surveys (NLTCS's), conducted by the Health Care Financing Administration and the Office of the Assistant Secretary for Health—The 1982 NLTCS collected data on persons 65 and older who were functionally disabled and lived in the community. The sample was identified by telephone screening of persons on the Medicare Health Insurance enrollment file. Those who were disabled in ADL or IADL functioning were eligible for the sample. Sample size was about 6,000 elderly persons. The NLTCS collected data on the degree of disability in ADL and IADL functioning, cognitive functioning, the informal support system, use of medical services, out-of-pocket costs for some LTC, insurance coverage, and income. The 1982 NLTCS collected indepth data about informal supports who provided assistance with ADL's. The 1984 survey was a followup of the 1982 sample; the questions asked were virtually identical except that the indepth survey of informal supports was excluded. It included persons who, when telephoned in 1982, were reported by their families as living in nursing homes. The NLTCS is a particularly rich source of information on functional disability, use of LTC services, characteristics of the informal support system, and days of help received. The potential exists for additional followup of the original sample to identify changes that have occurred. A public use tape is available.

- 1984 Supplement on Aging of the National Health Interview Survey (SOA/NHIS), conducted by the National Center for Health Statistics—The 1984 SOA/NHIS collected data on a sample of persons aged 55 and older who lived in the community. The core NHIS collected data on health status and hospital and physician care. The SOA/NHIS collected data on availability of informal support, retirement income, barriers in housing, home ownership, disability in ADL and IADL functioning, chronic conditions causing disability, and use of social services, nursing homes, and hospice care. Social security number was collected to link to the National Death Index. This linkage will provide cause-of-death data for those in the sample who die in later years. Also built into the survey was the potential to recontact the respondents to determine what changes have occurred. (An initial recontact effort—the Longitudinal Survey on Aging—is described next.) Sample size was 9,000 elderly; 3,500 of them were age 75 and older. The SOA/NHIS is a rich source of data on availability of informal support, functional disabilities, use of social services, and chronic conditions causing functional disability. A public use tape is available.
- Longitudinal Study of Aging (LSOA), conducted by the National Center for Health Statistics and the National Institute on Aging—The LSOA was conducted in 1986. It was a brief telephone interview of those persons 70 and over who were in the 1984 SOA/NHIS sample. The LSOA collected data on changes since the 1984 interview in functional disability and on the use of hospital, physician, and nursing home care in the interim. For those members of the 1984 sample who died, cause of death was determined by using the National Death Index. The LSOA is a particularly rich source of data for the oldest old on changes in functional disability, risk factors leading to institutionalization and death, and use of acute and LTC services. The potential exists for further followup; a 1988 LSOA is scheduled.
- National Health and Nutrition Examination Survey I Epidemiologic Followup Study (NHANES I EFS), conducted by the National Center for Health Statistics and the National Institutes of Health—This survey is a followup in 1982–84 of the sample of persons ages 1–74 who participated in the 1971–75 National Health and Nutrition Examination Survey (NHANES I). The NHANES I EFS collected data on family history, risk factors associated with morbidity and mortality, changes in ability to perform ADL's and IADL's, and use of hospital and nursing home care during the interim. The weight and blood pressure of each respondent were measured. Continued followup of the elderly was conducted in 1985. The size of the sample of elderly was 3,900. Because current data can be compared to data from the indepth physical examination conducted in NHANES I, the EFS is a rich source of data on change in health. It provides data on mortality and changes in morbidity, along with associated risk factors such as chronic conditions, diet, and alcohol consumption.
- The 1977 and 1985 National Nursing Home Surveys (NNHS's), conducted by the National Center for Health Statistics—The NNHS's collected data on the characteristics of the nursing home, its costs, staff, current residents, and discharges. Persons of all ages are included in the samples. Data on residents and discharges include functional disability, chronic conditions, services received, charges for care, and sources of payment. Data on discharges also include duration of stay and outcome. These data have been used to develop a synthetic admission cohort (Liu and Manton, 1983). The 1985 NNHS included items on use of hospital care before, during, and after stay in the nursing home. It also added a component on the next of kin of residents and discharges. This component collected data on lifetime use of nursing home care, changes in sources of payment over time, functional disability prior to admission, caregiver stress, and the family's view of the reason for institutionalization. Like the 1984 SOA/NHIS, the 1985 NNHS collected social security number for matching to the National Death Index. In both surveys, items on functional disability were structured to collect similar data to permit comparison between the LTC population in nursing homes and in the community. The sample size of the 1985 NNHS was about 12,000, equally divided between the resident and discharge samples. The NNHS is a rich source of data about use and cost of nursing home care, the functional disability of current and discharged residents, and charges and sources of payment for care. Because the NNHS's have been conducted periodically since the early 1960's, they provide trend data for assessing the impact of public policy on use of nursing home care. Public use tapes for the 1985 NNHS are available.

Assessment

Because most of the policy issues on use of LTC concern changes over time, the need for longitudinal data is paramount. Data are needed for extended time periods—5 to 10 years—on major changes in the characteristics of the LTC population, their need for and use of services, and their informal supports. Data are needed on *transitions:* what major changes occurred and when they occurred. Collection of data to identify transitions requires a contact, possibly by telephone, once or (preferably) twice a year. For example, take the situation where some elderly received social services that resulted in improvement in ADL functioning for a year. Then, when services were no longer received, they declined back to the original level of disability. A survey with a 2-year followup (like the NLTCS or the LSOA) would describe this subgroup incorrectly as having no change in functional disability. Furthermore, because the reference period for receipt of LTC is usually 3–6 months prior to the interview, such a survey would describe the group as having received no LTC services in the interim.

The availability of longitudinal data which identify major transitions in functioning and tie them to risk factors and service use is limited. Although the LSOA is collecting some data on changes which occurred since the 1984 SOA/NHIS via a brief telephone followup, it is limited in the amount of data collected and in the population covered (i.e., those 70 and older). It does not provide data on what transitions occurred during the 2-year period or on when they occurred. The situation is similar for the 1982 and 1984 NLTCS's. Although they provided data on the status at the first interview and at the second, they did not provide data on the transitions occurring in the interim. The NHANES I EFS has a similar limitation in describing transitions in morbidity because of the 10-year gap between the baseline and the followup survey. Although it is a rich source of data on use of hospitals and nursing homes, the EFS does not cover receipt of LTC social services. The NNHS covers only persons in nursing homes and excludes elderly in other long-term institutions, such as rehabilitation hospitals and facilities for the mentally ill and mentally retarded. Although the NNHS provides data on changes in functional disability and sources of payment between the date of admission and the date of discharge, it does not provide data on transitions occurring during the stay.

Recommendations

1. Collect longitudinal data about the LTC population and its use of services. The longitudinal data should be transitional in nature, providing data on each major change and on when it occurred. (Telephone interviews may be a cost-efficient method of collecting transitional data.) Appropriate models to examine for developing a longitudinal survey of LTC are the NLTCS, the SOA/NHIS, the LSOA for the elderly in the community, and the NNHS for the elderly in LTC institutions. Collect transitional data on:

    - Disability in ADL and IADL functioning and, for use in health promotion activities, the chronic diseases causing disability.
    - Mental health status, including not only cognitive functioning, but depression and behavior problems.
    - Qualitative factors such as living arrangements, marital status, housing, income, assets, and informal supports.[b]
    - Attitudes of the functionally disabled (and their families) that impact on the decision to seek, or not to seek, LTC.
    - Use of LTC and of acute care.
    - Use of nursing home care over the lifespan.
    - Costs and sources of payment for LTC.[b]
    - Availability of LTC services in the community.[b]

2. Expand the NNHS to collect longitudinal data from all types of LTC institutions and conduct it more frequently. Information on admission cohorts is one approach to provide longitudinal data for studying transitions in the use of services and outcome. Because of increases in the costs of nursing home care and frequent changes in policy, the NNHS should be conducted more often than every 6–8 years. Several policy analysts have indicated that a 3-year interval would be appropriate for addressing issues of changes in health of the elderly, outcomes of care, targeting/substitution, and policy impact. The expanded NNHS and the longitudinal survey of the LTC population in the community should have some questions which are similar in content. Such similarity will permit basic comparisons between the LTC population in institutions and in the community. The sample size of the expanded NNHS should be large enough to produce reliable data for the major types of LTC institutions and for important resident subgroups (e.g., the oldest old, minorities).
3. Include in the longitudinal survey of persons in the community both the elderly aged 65 and older and persons nearing retirement, i.e., those aged 55–64. Comparisons of the functionally disabled in these two age groups will address issues of entitlement versus need and the impact of different entitlement ages for Medicare, the Older Americans Act, and retirement benefits.
4. Include in the longitudinal survey of persons in the community those persons who are *not* functionally disabled. Comparison of the disabled and nondisabled will provide information on the differential use of acute care. Data on persons who become disabled during the course of the survey will provide information on risk factors and the early progression of functional disability.
5. Link the data from the longitudinal surveys of the elderly in the community and in institutions to the National Death Index and to Medicare and Medicaid tape files. These linkages require not only collection of the appropriate identification numbers and assurance of confidentiality, but also coordination and cooperation among various agencies responsible for the tape files. Such linkages will provide, at very low cost, detailed information for analyzing cause of death and use of publicly funded health care.

Supply of LTC services

Introduction

The supply of LTC services covers a broad continuum—health care, social services, and residential care. These services are provided in institutions, in community-based settings, or in the client's own home. The supply of LTC services by type includes:

- Health care—nursing homes, home health care, rehabilitation hospitals, rehabilitative adult day care, respite care, social health maintenance organizations, psychiatric hospitals, psychiatric treatment centers, and day-only or night-only psychiatric facilities.

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[b] Detailed recommendations on informal supports, costs and sources of payment for LTC, and availability of LTC services are presented in later sections of this paper.

- Social services—homemaker/chore services, social adult day care, income maintenance, congregate and home-delivered meals, transportation, counseling (legal, economic, housing), escort services, protective services, guardians/conservators.
- Housing with support services (i.e., residential care)—congregate housing, life-care communities, board and care homes, domiciliary homes, psychiatric halfway houses, psychiatric community residential facilities.

Although there is consensus that certain LTC services belong in a particular type (e.g., home health in health care and homemaker/chore in social services), the assignment of some services is debatable. For example, board and care homes and domiciliary care homes, though classified here as residential care, could possibly be health or social care. This depends on the type and level of services provided beyond the basic service of protective oversight. The lack of consensus illustrates the need for further efforts in clarifying the boundary line between residential care and institutions providing either health or social care.

Policy issues

Policy issues in the area of supply of LTC services fall under several themes:

- *Capacity*—What is the supply of each type of LTC service? What are the basic characteristics of each type? What is the capacity to provide care and how is it being used? What are the standard kinds of care provided (e.g., nursing services, rehabilitation therapy, protective oversight)?
- *Quality*—What is the quality of care provided? How can quality be maintained at an acceptable level? How are outcomes related to the kinds of care provided and type of functional disability? What are appropriate outcomes of LTC?
- *Targeting/substitution of services*—What is the appropriate service mix for different LTC subpopulations? What types of services are substitutions for others (e.g., home health and adult day care for nursing home care)? For which subpopulations are the substitutions most effective? For which subpopulations does housing with support services mitigate the need for health and social LTC services? Is case management a viable, cost-effective process for targeting of services? Are approaches such as social health maintenance organizations and vertical integration of hospital and LTC services viable, cost-effective services for certain LTC subpopulations?
- *Policy impact*—What changes are occurring in the supply of LTC providers based on changes in program benefits and in reimbursement and regulatory policy? What is the impact of policy which focuses on providing care in the least restrictive setting? What are the trends in nursing home bed supply in relation to reimbursement, targeting of care, and regulatory efforts at controlling growth?

Existing Federal data

Federal data systems about the supply of LTC exist for certain service types:

- Nursing homes—The National Master Facility Inventory (NMFI), maintained by the National Center for Health Statistics.
- Psychiatric facilities—The Inventory of Mental Health Organizations (IMHO), maintained by the National Institute of Mental Health.
- Medicare- and Medicaid-certified nursing homes, home health services, hospices—Master Providers of Service File, maintained by the Health Care Financing Administration.
- Drug abuse centers—National Alcohol and Drug Abuse Program Inventory, maintained by the National Institute on Drug Abuse.

Because information about these data systems has been available to the public for some time, they are not described here in any detail. Indepth descriptions are available (U.S. Senate, 1986).

The major Federal data system to address the issues of targeting and of substitution of services is the Channeling Demonstration (Kemper et al., 1986). It is a large-scale demonstration of case management in 10 sites. Though limited in geographic coverage, it provides detailed information to identify subgroups for targeting and for substitution of community services for institutional care.

Assessment

Most of these inventories provide basic data on service characteristics and use. Not all LTC services are covered by these inventories. Coverage is best for health care services, especially those certified for Medicare and Medicaid. It is poor for social services and for housing with support services. The inventories do not provide comparable data; even a basic item such as an "inpatient bed" has differing definitions. Comparisons of the same kind of care across service types cannot be made because there are no common definitions of the standard types (and units) of care. For example, although care from a physical therapist is provided in many LTC settings, data about such care are not measured or recorded in any uniform way. This lack of common definitions for care precludes analysis of the potential substitution of one LTC service for another. Although the quality of care is a major issue in LTC, the definition and measurement of high-quality care are not as well developed as for short-stay hospitals. Work in defining and measuring quality for LTC providers has been concentrated on nursing home care. The latest effort (Institute of Medicine, 1986) shifts the emphasis from characteristics of the facility to those of the residents. Outcome is also seen as an important factor in assessing quality. Most inventories are not structured to provide data to assess quality of care or to measure outcomes because they do not include data about *individual* clients. Although the impact of public policy on the supply and use of LTC services is an important issue, no ongoing data systems provide such information. The major gap is not as much with data on supply and use as it is with data on major policies. Data which summarize and quantify Federal and State policies on reimbursement, benefits, coverage, quality, etc. are not recorded on a consistent basis and are not linked to data on service supply and use.

Recommendations

1. Conduct inventories so that all health and social LTC services are covered. With the exception of nursing homes, psychiatric facilities, and Medicare- or Medicaid-certified providers, inventories are needed for the health care and social care services listed previously. The NMFI could be expanded to include these uncovered LTC services. Considerable work had been done in 1980–81 to develop specifications to include these services in the NMFI but was discontinued due to lack of resources.
2. Develop a sampling frame of the various types of residential care through the decennial census. This entails the development of definitions that distinguish (a) among the various types of housing with support services and (b) between housing and health care institutions as defined by the NMFI and the IMHO. It is essential that the Bureau of the Census develop this sampling frame through the 1990 census so that a nationwide list of residential LTC is available for conducting sample surveys. Such surveys can provide data on the living arrangements and the characteristics of the occupants. At present, some national data systems include persons in some types of residential care (e.g., the National Health Interview Survey and the Survey of Income and Program Participation), but the surveys are not able to identify them separately. Once a nationwide sampling frame is available, such surveys can produce data specifically for this subgroup of the LTC population.
3. Include the LTC Minimum Data Set (National Committee on Vital and Health Statistics, 1980) in all LTC administrative, survey, and research data collection activities. The LTC Minimum Data Set, developed by the National Committee on Vital and Health Statistics, is a basic set of data about persons receiving LTC services. It includes data items about the person, services, and reimbursement. The items have standard definitions and reporting categories. Use of the LTC Minimum Data Set will provide a core of data to make valid comparisons not only among different LTC services but also among different Federal data systems.
4. Implement a standard classification of kinds of care provided by LTC services. This classification should be included in the inventories of LTC services and in the sample surveys of the LTC population in nursing homes and the community. In addressing the issues of capacity and substitution of services, comparisons of kinds (and units) of care among providers are essential. The list of direct services in the LTC Minimum Data Set is an excellent starting point for definitions of major classes of care. It requires additions, particularly in the areas of assistance with IADL's and protective oversight. Because the National Committee on Vital and Health Statistics and an interagency task force currently are reviewing the LTC Minimum Data Set, they may be appropriate groups to be charged with expanding its list of direct services.
5. Develop criteria for defining and measuring quality of care in LTC services and include them in inventories and surveys of these providers. Special attention should be given to defining the criteria for community-based LTC services, especially where care is provided in the home. The work of the Institute of Medicine in defining quality for certified nursing homes should be the basis for the actual items to measure quality. These items should be included in the NNHS in order to assess the quality of *all* the Nation's nursing homes, not just those certified by Medicare or Medicaid. Longitudinal surveys should include items to determine both the immediate and long-range outcomes of LTC in order to assess quality. The data on quality from the 18-month Channeling Demonstration can be used to address the issue of maintaining quality at acceptable levels.
6. Identify items needed to address issues of targeting and substitution from the experience of the Channeling Demonstration. Once items are identified, incorporate them in the longitudinal surveys of persons in the community and in institutions.
7. Create a policy-impact data system for LTC services. Such a system can be developed by linking inventory data to policy data. For example, inventory data on growth and use of LTC services can be linked to data about Federal and State changes in legislation, regulations, reimbursements, benefit packages, quality assessment, and other policy. A possible model for this system is a project of the General Accounting Office, Nursing Home Data by State (U.S. Senate, 1986), which examined the impact of policy on changes in the nursing home bed supply during 1976–80.

Informal support

Introduction

Informal support is assistance in performing ADL's and IADL's provided by family, friends, and neighbors (Interagency Statistical Committee on Long-Term Care for the Elderly, 1980). Support is classified as informal as long as it is not provided by members of a formally organized group. For example, a lunch prepared and delivered by a neighbor is informal support unless the neighbor is a volunteer in an organized meals-on-wheels program.

Informal supports, especially from spouse and family, provide the greatest amount of assistance to the elderly LTC population (Shanas, 1982). Although informal support plays a dominant role in LTC, the contribution of formal care, especially for elderly without family, should not be overlooked. One systems model of social care emphasizes the ever-changing, interactive nature of the relationship between informal supports and formal care (Cantor and Little, 1985). Because of the dominant role of informal support in providing LTC and in preventing or delaying institutionalization, it is an important topic for policy analysis.

Policy issues

Policy issues about informal supports fall into five categories:

- *Availability and willingness*—Who is available to provide informal support to the functionally disabled elderly? Who is willing to provide informal support? How does willingness to provide care change as needs for care intensify? Does the provision of informal support differ by the characteristics of the recipient (e.g., level of impairment, type and frequency of assistance needed, relationship to caregiver, marital status, income)? Does the provision of informal support differ by the characteristics of the provider (e.g., employment, income, health status, ability to provide appropriate care, responsibilities to other members of the family)? What changes in informal support will occur for future cohorts of the elderly?
- *Impact of informal support*—What is the impact of informal support on the physical and mental well-being of the functionally disabled elderly? Does impact differ by the type and severity of need? Is the care provided of high quality? What types of informal support deter or delay admission to a nursing home?
- *Stress*—What is the capacity of the informal system to provide continued assistance? What are the factors that lead to the breakdown of the informal support system? How can this breakdown be prevented or minimized? How does providing informal support affect the caregiver physically, emotionally, and financially? What are the opportunity costs borne by the caregiver (i.e., the cost to the caregiver of opportunities foregone because time is spent on providing care)?
- *Substitution of formal care for informal support*—Does increased availability of formal care lead to its substitution for informal support? What factors about the care needed, formal services, and informal support are related to substitution? How rapidly does substitution occur?
- *Policy implications*—What financial incentives can encourage families to care for functionally disabled elders? What service incentives are needed to prevent breakdown of the informal support system and maintain its viability? How can high quality of informal support be assured? Can informal networks be "created" when family support is not available?

Existing Federal data

Data about informal support are from Federal systems that are "in the pipeline." In other words, data have been collected, but much of the data has not been released yet. The data are described briefly here. More detailed descriptions of the data systems were presented previously.

- Informal support for impairments in ADL's for the LTC population in the community—The 1982 NLTCS included a special component on caregivers who provided assistance with ADL's. It collected detailed data on the characteristics of the caregiver, including the assistance provided, associated stress, and opportunity costs (Stone, Cafferata, and Sangl, 1987).
- Informal support for impairments in *both* ADL's and IADL's for the LTC population in the community—The 1984 SOA/NHIS collected basic data on availability of persons who might serve as informal supports, their willingness to do so, and their kin relationship to the elderly recipient of care.
- Informal support received prior to admission to a nursing home—The 1985 NNHS collected data on availability and willingness of persons who might serve as informal supports, on assistance for impairments in ADL's, and on reason for "breakdown" of the informal support.
- Changes in the receipt of informal support over time—The Channeling Demonstration collected data for 10 sites at the initial assessment and at 6- and 12-month intervals. Data were collected on the amount and type of assistance provided, associated stress, and opportunity costs. This is the only source that provides data to address the issue of substitution of formal services for informal support (Kemper et al., 1986).

Assessment

The lack of data about informal support for the elderly who need LTC was identified in a 1980 assessment as a major data gap for LTC (Interagency Statistical Committee on Long-Term Care for the Elderly, 1980). Data were lacking on both the characteristics of the care provided and the characteristics of the caregiver. The Federal data systems described previously have made major efforts to fill this data gap. (The 1982 NLTCS, in particular, has collected some data about the care provided and the caregiver.) Their success in filling this data gap is difficult to assess until all the data are available for analysis by the research community. The cross-sectional data from the 1982 NLTCS and the 1984 SOA/NHIS have provided important information about informal support. Nevertheless, it is only longitudinal data that can address the bulk of the policy issues described earlier. This is because the concept of change underlies most issues. For example, issues of continued willingness to provide care and caregiver stress require data over time to address the dynamic nature of the situation. Lack of national data on the dynamics of informal support restricts analysis of interventions to strengthen the informal support system. It also restricts the ability to model changes in informal support for future cohorts of the elderly.

Recommendations

1. Collect longitudinal data about informal supports by using, if possible, the longitudinal surveys on use of LTC recom-

mended previously. If the same longitudinal survey collects data on use of LTC and on informal support, it will provide a rich data base for analysis of dynamics of the relationship between formal and informal care. It is important that longitudinal data be collected for a sample of *all* elderly, rather than only those disabled in ADL's or IADL's. Information on elderly who may become disabled is crucial to understanding what factors influence the willingness of persons to provide informal support. Relevant questions from the Federal data systems described previously provide a starting point for development of items for the longitudinal survey.

2. Include in the longitudinal survey the following data:
    - Availability of a *potential* network of persons who might serve as informal supports. (The questions from the 1984 SOA/NHIS are a useful model.)
    - Factors that determine the willingness of available persons to provide informal supports when the need arises.
    - Changes in the assistance provided by the informal support system as type and severity of disability change.
    - Changes in stress and the identification of events precipitating the breakdown of informal support. (Questions from the 1982 NLTCS on the caregiver's health, emotions, finances, and ability to work are a useful model.)
    - Use of formal care (i.e., nursing home care, community-based LTC, and hospital care) in relation to changes in disability and in informal support provided. Include in the survey questions about factors that impact on substitution of formal care for informal support. (Analysis of data from the Channeling Demonstration should identify some factors.)
    - Quality of informal care from an assessment of changes in the care recipient's physical, mental, and emotional functioning.
3. Conduct research and, when necessary, demonstrations to determine:
    - What financial and service interventions could prevent the breakdown of informal supports. Research should build on the existing work done on incentives for family caregivers (Shanas and Sussman, 1981). Data from the Channeling Demonstration and the 1982 NLTCS also may be useful.
    - How to "create" informal supports when family are not available through mechanisms such as church groups, volunteer organizations, and block associations.
4. Develop models for forecasting the informal support networks of future cohorts of the elderly. An approach to such modeling has been proposed (Manton and Soldo, 1985) which addresses not only demographic variables (e.g., marriages, births, divorces, labor force participation, income) but also health status and disability data from the cross-sectional surveys described earlier.

Cost of LTC

Introduction

A major concern of policymakers is the growth in costs of LTC and the substantial proportion paid by the public sector. The cost of nursing home care, for example, has increased fourfold from $7.2 to $28.8 billion over the period 1973–83 (Gibson et al., 1984). Economists identify nursing home care as the most rapidly growing sector of the health care delivery system. In 1983, public funds accounted for nearly one-half of nursing home costs. Costs for LTC are projected to increase in the future (Freeland and Schendler, 1983). This is because of the great increases projected for the group that is the major user of LTC—the oldest old. Increasing attention is being given to various approaches for controlling the cost of LTC. These run the gamut from Federal LTC insurance to incremental changes in existing programs to private sector initiatives such as LTC insurance packages and life-care communities (Doty, Liu, and Wiener, 1985). It is the costs of LTC for both the aggregate and the individual that are addressed in this section.

Policy issues

Policy issues in the area of costs of LTC fall into the following categories:

- *Expenditures for LTC*—What are the national expenditures for LTC by type of service and source of payment? What are the historical trends in national expenditures and what key factors (e.g., inflation, service intensity, population growth) account for these trends? What are the costs and payment sources for particular LTC subpopulations as defined by disability, income, amount of informal support, and program eligibility? How do costs and payment sources vary for different LTC services? How do costs of LTC services vary based on the types of care provided (e.g., nursing care, physical therapy, protective oversight)?
- *Financing and reimbursement issues*—What would be the design of a comprehensive package of Federal LTC insurance? How viable are private sector initiatives (such as social health maintenance organizations, life-care communities, and home equity conversions) in meeting needs for LTC? How can the role of the private sector in financing LTC be expanded? What is the extent of asset transfer and "spend down" in meeting Medicaid eligibility requirements? What are the costs of LTC over the lifetime of a cohort or for a specific LTC subgroup? How can prospective payment successfully be applied to various types of LTC services? What are the incentives and disincentives of prospective payment for institutional and community-based care? How do the disabled finance LTC over time in relation to their income and assets?
- *Cost control*—Are community-based services less costly than institutional care? Is channeling (i.e., case manage-

ment) a viable mechanism for controlling costs of LTC? What impact would coinsurance or deductibles have on the use of LTC services? How can the catastrophic nature of nursing home costs be minimized?

Existing Federal data

Existing Federal systems which provide data on costs of LTC are described briefly below. Information on macro-level systems is provided first, followed by information on the micro, or individual, level.

- National Health Accounts (NHA), prepared by the Health Care Financing Administration—The NHA provide macro-level data on aggregate health care expenditures (Gibson et al., 1984). The only LTC service for which costs are presented separately is nursing home care. Home health care, though included, is subsumed in the category "other professional services." Costs for social services funded by the Social Services Block Grant and the Older Americans Act are excluded from the NHA.
- The 1982 and 1984 NLTCS's—They collected cross-sectional data on out-of-pocket costs and third-party payments for *some* LTC services. These services include care from visiting nurses, therapists, and mental health professionals, as well as assistance with IADL's. Data were also collected on the out-of-pocket expenditures paid by caregivers to cover services, medicine, and special equipment for the disabled elderly.
- The 1980 National Medical Care Utilization and Expenditure Survey (NMCUES)—It collected cost and source-of-payment data over a 15-month period for home health care. The 1980 NMCUES also provided data on LTC services funded by Medicare and Medicaid by linking to provider and claims files.
- The 1987 National Medical Expenditure Survey (NMES)—This survey is being developed by the National Center for Health Services Research. In concept, the planned 1987 NMES will collect data on medical expenditures for persons in households, nursing homes, and facilities for the mentally retarded. The design of the survey, its questionnaire content, and procedures will be determined in the fall of 1986 based on pretest experience gained earlier in the year. Because this survey is in the developmental phase as of this writing, assessment of its utility is premature. If implemented as originally designed, it has the potential to make an important contribution in addressing issues on the cost of LTC.
- The 1985 NNHS—Data were collected for nursing home residents and discharges on costs, sources of payment, changes in sources of payment since admission, and the sequence of payment for previous nursing home stays (i.e., the Medicaid spend-down phenomenon).

Assessment

Available data on aggregate costs for LTC services are fragmented. Although the NHA cover nursing homes and home health care, costs for social services funded by the Social Services Block Grant and the Older Americans Act are excluded. It is left to the analyst to compile LTC costs by tracking down the various data sources and reviewing their descriptions in the hope of aggregating comparable information.

Data on expenditures at the micro level are also limited. Neither the NLTCS nor the NMCUES provided cost and source of payment data on the complete spectrum of LTC services received by functionally disabled elders living in the community. Although the NNHS covers costs and sources of payment for nursing home care, comparable data are not available for other LTC health institutions (e.g., rehabilitation hospitals; inpatient hospice service; facilities for the mentally ill, for the mentally retarded, and for the physically handicapped) or for housing with support services. It is also important for cost surveys of institutions to collect cost data on services provided to residents outside the walls of the institution and not included in their bill (e.g., hospital care, community-based care). Inclusion of such data will provide a more complete picture of the cost of an episode of institutional care.

It should be noted that the NLTCS and the NNHS (and to a lesser extent the NMCUES) are rich data systems for information on functional disabilities, demographic variables, and caregiver characteristics. This richness is important to cost analysis because it permits examination of cost data in relation to health and demographic characteristics of specific LTC subpopulations.

Several of the policy issues deal with changes in cost over time (e.g., issues about Medicaid spend down, cost of LTC insurance, and the economic viability of social health maintenance organizations). Data to address these issues range from severely limited to nonexistent. The NMCUES covered only home health costs for a 15-month period. The NNHS covered costs from the most recent admission. Neither of these time periods is long enough to provide data to address these policy issues. A period of 3–4 years would be more appropriate.

Recommendations

1. Prepare aggregate national LTC expenditures for health and social services. The NHA should be used as a model. The expenditure data should be presented by type of service and source of payment, as was done in the Urban Institute analysis of LTC data (Scanlon et al., 1983). The national LTC expenditures should include data about historical trends and an analysis of key factors accounting for cost increases (e.g., inflation, service intensity, and population growth).
2. Conduct periodic surveys on the costs and sources of payment for *all* LTC services received by elders disabled in ADL and IADL functioning who live in the community. It is essential (a) that total costs, as well as out-of-pocket expenditures, be collected and (b) that expenditures for each sampled person be collected for each and every type of LTC service. Such a survey will provide comprehensive cost information on the entire spectrum of

LTC services. The survey should also include data on demographics, disability, income, and receipt of informal support so that analyses can be done for special LTC subpopulations. The NLTCS, the NMCUES, and the NMES can be used as the basic model. Once a sampling frame of housing with support services is developed (see previous section on supply of LTC services), elderly in these living arrangements can be specifically sampled for this cost survey and analyzed as a special population.

3. Conduct periodic surveys on the costs of care and sources of payment for persons in *all* types of LTC institutions. Cost data on care received outside the walls of the institution (e.g., from acute care hospitals or community-based services) should be included. The NNHS and the NMES could serve as the basis for developing a periodic survey covering all LTC institutions.
4. Add a longitudinal component to the periodic LTC cost surveys of the community and institutions recommended previously. This component, perhaps only a subsample of the total survey sample, would be followed for 3–4 years (possibly by telephone) to provide data on changes in costs, in sources of payment, and in use of LTC. Such longitudinal data are essential to estimating the costs of program benefits, LTC insurance packages, life-care communities, and care for specific subgroups of the LTC population.

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Data requirements for long-term care insurance[a]

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Introduction

The potential of insurance for long-term care (LTC) is beginning to receive widespread attention. However, this kind of coverage is currently available on only a limited basis. Only recently have insurers begun to seriously explore the market. One of the primary barriers to their efforts has been the lack of reliable data on virtually all the key elements necessary for product development and marketing. Nonetheless, the state of knowledge has progressed rapidly in recent years and a variety of insurers are committed to exploring the market. To a large extent, these efforts reflect the belief that the market for LTC insurance is viable, growing, and profitable. Progress in testing this belief, however, will be slower and more conservative than is desirable until insurers are comfortable with the data available for actuarial pricing of such products. The purpose of this paper is to examine data needed for LTC insurance as a basis for stimulating further data base development.

In thinking about the kinds of data that will be required to evaluate and further develop the market for LTC insurance, it is quite easy to feel overwhelmed by the wide array of information to consider. A broad range of covered services is theoretically possible. The care can range from intensive skilled services to custodial care and can be provided in a variety of settings including hospitals, nursing homes, board and care homes, in a person's own home, as well as in the community.

The delineation of covered services is a crucial step in the design of such coverage and will dictate the data that are needed to fulfill that design. Ideally, service coverage will be precisely defined in terms of what services are covered, who may provide the service, and under what conditions the services may be provided. Precise definitions are important for the prediction of utilization, as well as for administering the claims payment process.

Background[1]

To understand how data requirements are driven by policy specifications, consider the seemingly straightforward goal of insuring long-term nursing home and home health needs. The first step is to recognize that, to accomplish this goal, the policy must cover more than what is currently covered by Medicare. Medicare was not designed to address the need for long-term care. Nursing home care is covered up to 100 days, with the first 20 days completely covered and a daily copayment equal to one-eighth of the hospital deductible for the remaining 80 days. In order to qualify for this coverage, a person must have been hospitalized for at least 3 days for the same sickness or injury; the patient must be transferred to a skilled nursing facility (SNF) within 30 days after discharge from the hospital and the transfer certified by a doctor; the SNF must be certified by Medicare; and the patient must need and receive daily skilled nursing care or daily skilled rehabilitation therapy to improve his or her condition.

In practice, users of Medicare nursing home benefits receive only about 27 days of covered care per year (Muse and Sawyer, 1982). Medicare claims criteria are often complex and restrictive; also, they are subject to the individual judgments of claims reviewers, which can vary substantially (Smits, Feder, and Scanlon, 1982).

Also, only a portion of all nursing home beds are certified for Medicare, limiting access to covered care. Medicare certification has lost its appeal for nursing home operators for a number of reasons. Some of these are the fear of retroactive denials of claims, strict Federal requirements for Medicare SNF certification, and the paperwork burden of a reimbursement system that encourages rapid turnover and is different from the system used for private-pay and Medicaid patients (Feder and Scanlon, 1982).

Home health care is covered under both the hospital insurance (Part A) and supplementary medical insurance (Part B) portions of Medicare. Benefits are payable if a beneficiary needs part-time skilled nursing, physical therapy, or speech therapy. Although the number of visits is unlimited under Medicare Parts A and B, the program requires that the needed services be documented by a physician as primarily skilled care and that the patient be "homebound." These requirements effectively limit use. The average user has only about 23 visits per year (Muse and Sawyer, 1982). Personal care services provided by home health aides on a part-time or an intermittent basis are covered if the patient is receiving one of the qualifying

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[a] Contents are the opinions of the author and not those of the Department of Health and Human Services.

[1] Portions of this section appeared earlier (Meiners, 1984).

skilled services. Homemaker services can be provided if they are incidental to personal care and do not substantially increase the time spent by the home health aide.

To be meaningful for long-term care, nursing home and home care benefits must cover a broader range of services than is covered by Medicare. In nursing homes, coverages below the skilled level are typically referred to as intermediate and custodial care. The concept of intermediate care, which comes from the Medicaid program, addresses coverage of what amounts to personal care with skilled nursing services, but on a less frequent basis than would be the case with skilled care. In practice, the intermediate care definition varies greatly by State, with many viewing it simply as a cheaper version of skilled care. The definition of custodial care also varies, ranging from personal care with some nursing, to only personal care, to simply sheltered living with no specific provision for personal assistance. People with chronic illness requiring long-term care need coverage for personal care along with nursing care and will benefit most if coverage continues even when personal care is the predominant service they receive.

For home health care, further liberalization of Medicare means removing the homebound requirement and/or increasing the coverage to include personal care and homemaker services without the strict ties to skilled care. Removing the homebound requirement involves expanding into community care benefits that are considered important services in the LTC continuum. A broad array of services such as day care, transportation, nutrition services, respite services, and chore services can be imagined.

The problem insurers have with expanding the insurance package beyond Medicare's nursing home and home health benefits is that long-term care needs are complex and definitions are not uniform. Services tend to overlap in their purpose and there is little consensus as to how services should or could be packaged, staffed, and provided. In addition, the best approach to providing care often depends on the living circumstances of the individual, including the availability of family care and other informal support.

Many of the services are nonmedical and are required to assist with health status deficiencies associated with the normal aging process. Insurers seriously question whether such services are insurable. They are concerned about having to pay for the care of a person who no longer wants to live independently and are inclined to rely on medical needs to define insurable events.

Traditionally, services are considered insurable if they would not be affordable without significant financial difficulty, if the probability of needing them is low enough to allow the risk to be spread, and if the need is random enough that users cannot be identified in advance. Many LTC services do not satisfy these criteria without further clarification. For example, nursing home care is often a catastrophic expense because it is needed for an extended spell of illness rather than because it requires intensive services. Many home and community services meet the criteria only indirectly. The services are considered insurable only because they are believed to be lower cost substitutes for insurable services.

Ideal data base

It should be clear from this discussion that insuring long-term care is not straightforward. Ideally we would like to have a longitudinal data set that tracks the utilization patterns of a large representative population insured under provisions similar to those being considered in the product design. It would contain the date the policy was issued; basic demographic information on the insured; and dates of admission and discharge for all hospital, nursing home, home, and community care utilization by skill level required. It would also include the date and location of death.

Such a data set is ideal in several respects. Because the utilization patterns would have been established under a known insurance plan, the effect of insurance on the demand for care would be taken into account. Also, the comprehensiveness of the data base would allow consideration of the effect of service availability on utilization patterns. Furthermore, the longitudinal aspect of the data would provide information on how those patterns change as the cohort of insured persons ages.

In its broadest sense, the ideal data base for developing long-term care insurance is essentially similar to what policymakers and planners would like to have to guide their decisionmaking for long-term care. The data are not easily obtained for several reasons. In a recent overview of international perspectives on LTC, Laura Reif noted three important problems with obtaining the ideal data set: "(1) most nations have no systematic and universal scheme for data-reporting that would make it possible to obtain information about care-recipients and service use in different service sectors, and across government programs and jurisdictions (local, regional, national); (2) implementing such a scheme is very problematic because it is difficult to track the movement of care-recipients among assistance programs, and from one service setting to another; and (3) even if an accurate picture of current care-recipients, service use, and costs could be obtained, planners would still lack adequate information about the extent of unmet need, and what service utilization and expenditures would look like if services were matched to need, rather than being constrained by inadequate funding and limited availability of services" (Reif, 1985). It is clear that the United States shares these problems with other countries.

In reality, insurers would be satisfied with much less than the ideal data set. To understand just how much less, the next section will review the approach and data used to develop workable LTC insurance in the face of these difficulties. The discussion is suggestive of areas where marginal improvements in data can be especially helpful.

Stepping back from the ideal

In spite of having much less than ideal data, insurers can begin to provide useful LTC benefits, minimizing many technical concerns through careful policy design. To demonstrate this, the National Center for Health Services Research

(NCHSR) undertook the specification and pricing of a prototype LTC policy (Meiners, 1983; Meiners and Trapnell, 1984). The prototye was designed to avoid policy features which required data that were unlikely to be available. At the same time, an effort was made to address considerations important to buyers and sellers of such coverage.

The policy focuses on nursing home care. However, in recognition of data weaknesses, no effort is made to distinguish length of coverage or amount paid on the basis of the level of care provided. Nursing home coverage is emphasized over home care because such payments are the largest single out-of-pocket health care expense faced by the elderly (Fisher, 1980) and there is a need for improved insurance coverage for this risk. Private insurers are more likely to be willing to provide extended coverage for care at both the skilled and personal care levels in nursing homes than in the home. They know that the elderly have a strong preference for home health care and fear that such insurance would encourage increased utilization due to lower out-of-pocket expenses. In addition, the data necessary for setting insurance rates for home health care are more limited than those for nursing home care. Home and community care benefits are available in exchange for nursing home benefits once nursing home use has been established. This benefit is included to help relieve the bias toward remaining institutionalized by providing the beneficiary the option of being discharged to home or community care.

Benefit payments are limited to a fixed amount for each day of covered service to encourage patients and their families to search for efficient providers who can supply the necessary care within the budget. It is also a simple way to limit the insurer's liability and reduce the risk of providing insurance. Policies paying the "reasonable and customary" charge for specific services are much more open ended and have been criticized as one of the reasons for the rapid inflation of health care costs because there is little incentive for patients or providers to hold down costs.

To minimize insurers' concerns about an open-ended liability, the prototype recognizes the need for time limits on eligibility. A 90-day elimination period is required before benefits begin. The 90-day elimination period was chosen to provide protection from catastrophic long-term care expenses. A period of about 3 months in a nursing home tends to be the critical break between whether the patient is going to be a long stayer or a short stayer (Meiners, 1983). It also represents a significant deductible which should help limit insurance-induced demand. A 3-year limit on coverage was chosen to encompass a reasonably large portion (about 85 percent) of all nursing home stays. For those few beneficiaries whose stay exceeded the benefit period, Medicaid would serve as the payer of last resort after private resources are exhausted.

The prototype policy is a hybrid of features modeled after other types of insurance. Included are elements of whole life insurance (level payments based on expected lifetime risk), term insurance (annual premium payments in return for guaranteed continued protection), and disability/health insurance (payment of benefits on the basis of the onset of a covered event). The key data elements for estimating premiums are the frequency of establishing a benefit period (the admission rate) and the utilization per benefit period (the length of stay) of potential purchasers. Other necessary data are actuarial data related to mortality. The estimates also required experience data on withdrawal rates of policyholders, financial data (interest and inflation rates) for estimating investment returns on reserves, and operating expense factors (commissions, profit and risk allowances) reflecting the insurer's mode of operation. It is the utilization data, however, that distinguish a long-term care premium calculation from other insurance products. The following discussion focuses on those contingencies to illustrate how available data were used to estimate utilization and to highlight those areas where better data are needed.

Utilization data and assumption[2]

The National Nursing Home Discharge Survey of 1976 was used for calculating both frequency of benefit periods and the average number of covered days per period. The data were analyzed according to a number of characteristics that it was believed might disclose significant variations in the shape of the distribution of people across differing lengths of stay, including age, sex, and marital status. In the final analysis, utilization patterns were distinguished only by age. Frequencies were determined for three age groups (65–74, 75–84, and 85 years and over) and the intermediate frequencies were determined by interpolation.

Although marital status appeared to have a major impact on the average length of stay, marital status was not used in classifying the data since the status reported relates to the time of a claim rather than to the time at which a policy is issued. Thus, an insurer could not use this information in setting separate rates for married and nonmarried persons.

Sex was also not used as a basic classification variable. The patterns of length of stay did not appear to be sufficiently different to require use of separate tables by sex. In reality we know, however, that women, in general, live longer than men. Increasing age and loss of spouse are thought to be associated with increased need for LTC. One of the practical difficulties in using these data to understand utilization patterns among different population groups is the sample sizes. The more detailed the analysis, the thinner the data and the more suspect the conclusions.

Though the Discharge Survey data were the best available for the necessary utilization estimates, adjustments were needed to overcome several problems. The Discharge Survey was not designed to track patients through the various transitions that may occur during a covered stay. For example, a transfer between nursing homes will continue a covered stay for application of the elimination and benefit periods of the policy, but may result in the duplication of cases according to the Discharge Survey. Similarly, brief transfers home or to a general hospital and then back to a nursing home would be part of one covered stay, but may be recorded

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[2] This section draws on material that appeared earlier (Meiners and Trapnell, 1984; Trapnell et al.).

as multiple discharges. In addition, adjustments were necessary due to classification problems that occured because some of the survey responses did not provide the information that allowed for classification. For example, it was not always known whether a patient died after being discharged to a hospital.

The discharge data needed to be classified into one of the following three categories of nursing home discharges:

- Death causing an end to the benefit period, either as the reason for the discharge from the nursing home or following a hospital or other institutional stay without readmission to a nursing home.
- Discharge home or to another setting in which home care benefits would be paid.
- Transfer to another nursing home, or transfer to a hospital or other noncovered institution followed by readmission to a nursing home.

Each category has a different effect on the benefit period. Policyholders in the first category are not eligible for further nursing home or health benefits. Those discharged home are eligible for home care benefits. The last group represents stays that are continued. In the final tally, only the discharges classified as recoveries or death counted in the admission rates.

The transfers were estimated to be about 23 percent of all discharges. To evaluate the reasonableness of this estimate, longitudinial data from a study of admissions to proprietary skilled nursing homes in San Diego were examined (National Center for Health Services Research, 1983). About 28 percent of the admissions were transfers. The shorter timeframe of the San Diego data and more limited coverage of facility types relative to the national data limit the applicability of this check. However, it is clear that multiple admissions occur to a significant extent and estimates of lifetime admission rates need to be adjusted for this phenomenon.

The transfers, although dropped from the frequency count, had their days added to the days of the discharge groups. Since only limited information was available for matching transfers to the continuation stays, each nontransfer stay was assumed to be equally likely to represent a continuation. The transfers were in effect randomly assigned to nontransfer discharges in the same age group. Data on the length-of-stay patterns of patients with multiple admissions are needed to examine this approach.

The adjustments significantly shifted distributions toward longer stays. In the 75–84 age group, for example, the preconvolution distribution shows only 10.5 percent remaining after 3 years compared to 15.8 percent remaining in the convoluted distribution. At the lower end of the distribution, the preconvolution distribution shows 52.4 percent discharged within 90 days compared to 43.4 percent for the convoluted distribution. Nearly all of this difference occurs within the 30-day interval.

Finally, life table techniques were used to convert the discharge data to an admission cohort. Because discharges in 1976 were used to estimate admissions in 1976, when the admissions in reality occurred prior to 1976, adjustments to the distribution of admissions were necessary. The discharges for stays longer than 6 months originated, on the average, in years before 1976, when the population from whom these admissions arose was somewhat smaller. This biases downward the proportion of discharges for longer stays.

If there were no restraints on utilization (e.g., an unlimited supply of beds) and if the admission rates for each age-sex group did not change, the relevant growth rate would be that of the corresponding population group. But since the bed supply constrains utilization, the bias will be proportional to the number of beds (Scanlon, 1980). The problem may then be restated by saying that the number of discharges admitted in some past period must be increased to reflect the number that would have been admitted if the bed supply had always been as large as it was in 1976.

According to the National Master Facility Inventory, the bed supply was growing at approximately 2.24 percent annually from 1973 to 1976, a period which includes the admission dates for most of the discharge sample (National Center for Health Statistics, 1979). Thus, the bias can be approximately offset by increasing the stays by 0.18 percent per month. The number of people in each interval was then weighted by the average length of stay for the interval to derive the necessary utilization estimates.

In the absence of data concerning the average number of post-nursing-home-confinement home or community care visits that would be reimbursed by the policy, utilization was proxied by assuming that all persons discharged home used all the visits per week allowable under the policy as long as they were alive and not reinstitutionalized. The mortality and reinstitutionalization rates were set higher (250 percent) than those for the general population to reflect their higher health risk. The maximum for home health benefits is the number of weeks remaining in the lifetime benefit period after the discharge from the nursing home. The estimates implicitly assume that formal home or community care will be substituted for family care.

Areas for improvement

It is clear that the utilization estimates involved numerous assumptions and adjustments to compensate for weaknesses in the data. In particular, data are needed that do a better job of tracking transitions over an extended period so that estimates of admission rates and length of stay accurately reflect the fact that a spell of illness can involve multiple admissions. The data are particularly weak for estimating the projection of those who die after discharge to another institution, also for understanding the frequency of discharge from a nursing home to home or community care as well as the circumstances that make this transition feasible. Clarification of any of these transitions from virtually any data source would be useful at this early stage of data development.

Another weakness of the data is that they reflect general population utilization patterns that are influenced in an unknown way by numerous factors, most notably the supply of nursing home beds and the availability of other LTC services that might serve as alternatives to using those beds. To some extent, this is as much an analytic problem as a data problem. Further analysis of available data sources is needed to help clarify the determinants of LTC utilization patterns.

Faced with uncertainty about the determinants of utilization, insurers apply a range of risk-management techniques to help them select among applicants. Typical risk-management techniques to avoid adverse selection include screening applicants for health status and requiring waiting periods before preexisting conditions are qualified for coverage. Data and analysis are needed to help assess the importance of these practices. For example, how many prospective insurance purchasers are likely to be screened out and whether screens are justified are important issues for determining product design as well as whether the market can be widespread.

Insurers are also faced with the unknown effect of insurance-induced demand ("moral hazard"). Besides drawing inferences on this problem from other insured products, there is little information to guide adjustments for this problem. Typical risk-management techniques used by insurers to limit insurance-induced demand include specific definitions of qualifying facilities and care, prior hospitalization requirements, physician recommendation and review of care, and the use of copayments and deductibles. Data and analysis are also needed to understand the feasibility and implications of applying these techniques. As noted earlier, distinguishing benefits on the basis of definitions of facilities and care is likely to be controversial and difficult to administer. How important is it to require a 3-day hospital stay before benefits begin? Does the answer change if there is an elimination period deductible of 30–90 days? How frequently, if at all, does utilization review need to be done given changes in the health status of chronic care patients? Better answers to these questions will further the development of LTC insurance that provides consumers with meaningful coverage and keeps insurers solvent.

Utilization estimates from general population data are not likely to reflect the patterns faced by a particular insurer. However, they provide a convenient benchmark that insurers can use as a basis for their own estimates. An insurer's own risk-selection factors will dictate the necessary adjustments. If an insurer carefully "underwrites" a policy (i.e., selects applicants in good health or with characteristics that make utilization less likely), the average admission rates may be expected to be lower than in the general population. In underwriting policies, insurers are essentially trying to eliminate those persons for whom the risk is predictably higher than what they had estimated in their premium calculations. Further data and analysis are needed to help establish conclusively how long-term care benefits can be structured to meet criteria of insurability for broad segments of the population.

Premium calculations also require mortality rate estimates for all insured persons whether or not they are institutionalized. One of the interesting facets of the need for nursing home care is that most people die without ever having been admitted to a nursing home and a significant number of those admitted die after only a short stay, usually following an acute care episode of illness. These people use little or no nursing home care. At the same time, we know that utilization of health care in general is disproportionately higher in the last year of life. The implications of this for long-term care insurance are unclear. Further data and analysis on the interrelationship of mortality and morbidity are needed to help clarify the potential role of LTC benefits (e.g., hospice) as lower cost substitutes for acute care services.

Other models of LTC insurance

The freestanding type of coverage which has been the focus of the discussion is one of three basic LTC insurance models which have been emerging. The others are the social health maintenance organization (S/HMO) and continuing care retirement communities (CCRC). Each approach has different degrees of benefit comprehensiveness which determine the data that are needed to insure the LTC risk. Each approach is similar, however, in the sense that they all require essentially the same types of data described earlier, with the specific requirements determined by the detail of the health care guarantee and the administration of the risk.

Continuing care retirement communities are perhaps the oldest example of LTC insurance. They are organized communities for the elderly which provide permanent apartments along with health care guarantees in exchange for entry fees, most typically in the range of $13,000 to $65,000, plus monthly fees, most typically ranging from $300 to $900.[3] LTC in a nursing care unit is available on either a temporary or a permanent basis when residents can no longer live in their apartments. Different health care guarantees exist. Some communities have no extra charges beyond the monthly fee, while others make only partial health care guarantees. Though there are a variety of types, in their most comprehensive form these communities offer the full range of LTC services, including sheltered living arrangements, meals, care in their own apartments, and nursing home care, all paid for on the basis of pooling the risk and cost among community residents.

This form of LTC insurance is the most comprehensive because it explicitly considers the resident's home in the community as one of the factors in estimating the costs of the benefit package. As Winklevoss and Powell (1981) point out, "community sponsors must determine the associated (health care) liability and develop their pricing structure accordingly to insure the long-term financial viability of the community" (p. 10). The estimates must balance the fact that, while permanent transfers from the community to the nursing home will result in increased health care costs, the resale of the permanently vacated apartment will also generate increased revenue.

The components of the Winklevoss and Powell model of health care utilization in CCRC's include both permanent and temporary transfers from the community to the health care center, as well as death rates for persons residing in

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[3] The most comprehensive work to date on CCRC's is by Winklevoss and Powell (1984).

each of those settings during a particular year and in subsequent years. To operationalize this model, a separate schedule of mortality rates for community residents and nursing home residents is needed, along with a schedule of mortality rates applicable to permanent transfers and a schedule of morbidity rates applicable to temporary use of the nursing home. Winklevoss and Powell (1981) elaborate further:

> Because mortality and morbidity rates vary by age, a schedule of rates is needed instead of simply one rate for each assumption. Since mortality rates tend to improve over time, a mortality improvement scale also is desirable, producing lighter rates for each future calendar year. In addition, such rates vary by sex, requiring eight schedules, four for women and four for men. Finally, the mortality and morbidity schedules are generally dependent on each person's length of stay in the community. In other words, the death rate applicable to a female age 80 who entered the community at age 75 is generally higher than the rate applicable to a female age 80 who just entered the community. Consequently, eight schedules (along with a mortality improvement scale and select factor) should be established for each age at which individuals enter the community (pp. 10–11).

The data requirements for insuring the LTC risk in CCRC's are essentially the same as described for freestanding LTC insurance. In fact, some CCRC's are exploring the possibility of purchasing such insurance as a way to cover their nursing home liability. Such contracts need to reflect the fact that people who join such communities tend to be older than the average elderly population and live longer than the average for people their age. The contracts also may need to be structured in a way that shares the risk among the community, the insurer, and the resident so that the utilization incentives are balanced among the key participants in the insurance contract.

Sharing the risk among providers, insurers, and consumers is the cornerstone of the S/HMO model, an innovative attempt to extend the health maintenance organization acute care model of case management and prepaid capitation to include LTC benefits. Four essential features of the S/HMO model are described by Greenberg and Leutz (1984):

> First, a sponsoring agency (or agencies) takes responsibility for bringing the full range of acute and chronic care services into a single system. Second, this new S/HMO entity serves a membership that is representative of the community. Most importantly, it enrolls both disabled and able-bodied elders. Third, the S/HMO is paid on a premium or "prepaid capitation" basis—by both individual members and third parties (Medicare and Medicaid). The S/HMO pools these premiums to pay for member services. Fourth, the S/HMO is "at risk" for service costs. That is, the organization takes responsibility for meeting its own budget, and it stands to experience some level of profit or loss for its efforts (p. 58).[4]

The goal of the S/HMO model is to provide comprehensive health benefits including LTC. Conceptually the model is between freestanding LTC insurance and the CCRC approach in terms of comprehensiveness. It attempts to integrate the entire continuum of health care services into its benefit package rather than just focusing on LTC but does not include the use of the insured's home in the calculation of benefit costs.

In practice the experimental nature of the S/HMO and market pricing considerations have required a more conservative approach. For LTC the emphasis is on comprehensive home care for chronic or disabling conditions which require rehabilitation, support, and maintenance care that may not meet Medicare criteria. This home care includes medical transportation, home-delivered meals, adult care, and homemaker services, as well as nurse, therapy, and home health aide services. Utilization of these benefits will be controlled by case management, copayments, and benefits ceilings set at the discretion of each participating site.

The value of the "chronic care benefit" ranges from $6,500 to $12,000 per member per year and the copayment rates vary from 10 percent to 20 percent, depending on the site (Greenberg and Leutz, p. 61). The chronic care benefits are renewable annually at all sites for the community and home-based benefits, but are not necessarily renewable for institutional care. The S/HMO benefit package is likely to cover only part of the costs for the most impaired, especially those needing nursing home care (Greenberg and Leutz, p. 61).

Although the basic data requirements for estimating the LTC risk in the S/HMO are similar to the data needed by the other LTC models, the comprehensiveness of the capitation approach introduces some additional complexity. The pooling of Medicare, Medicaid, and private insurance dollars requires estimates of the average acute and LTC liability of all three payers rather than just the risk of LTC expenses for the insurer. The Greenberg and Leutz discussion of data required for the S/HMO estimates strikes some familiar themes.

> Data on long-term care utilization and costs are skimpy, and even the best had to be interpreted in light of differences in such areas as program, benefits, population served, and reporting format. HMO data on acute-care costs had to be interpreted to account for both the S/HMO's older, poorer, and more disabled population and for the lack of HMO experience at some sites. Furthermore, existing data and methodologies gave little guidance on two key issues: (1) how full consolidation would affect acute-care utilization and (2) what proportion of the membership would use chronic-care service (p. 72).

They go on to point out that in the face of these data gaps most of the sites made relatively conservative assumptions in estimating their risks.

The S/HMO has recently begun at four sites: The Metropolitan Jewish Geriatric Center in Brooklyn, New York; Kaiser Permanente in Portland, Oregon; the Ebenezer Society in Minneapolis, Minnesota; and the Senior Care Action Network in Long Beach, California. The demonstration is scheduled to run for 3 years with an outside evaluation, funded by

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[4] The most comprehensive work to date on the S/HMO is by Leutz et al. (1985).

the Health Care Financing Administration (HCFA), that will focus on issues such as cost-saving potential, health outcomes, and selection bias in enrollment. In addition, Brandeis University, in cooperation with the four sites, is currently seeking private funding to conduct its own evaluation of the S/HMO, focusing more on the internal dynamics. The intent of the Brandeis effort is to "become part of the intervention itself by using research to detect problems, make timely mid-course corrections, and improve the model" (Research Consortium of Social Health Maintenance Organizations, 1985). To accomplish its goals, the Brandeis consortium has identified the following key elements of a core data set to be standardized across the four sites:

- Social/demographic.
- Health status.
- Functional status.
- Mental status.
- Personal adjustment.
- Informal support system.
- Care plan elements.
- Hospitalization/SNF utilization.
- Ambulatory visits.
- Care in an intermediate care facility.
- Home care services.
- Enrollment/case mix/targeting data.
- Medicaid status/spend-down experience.
- Marketing data.

The S/HMO experiment and evaluations will provide valuable information about costs and utilization of LTC services in the context of a prepaid capitated environment where the providers have incentives to be cost conscious in the management of the clients' care. The significant role of public funding and support for the S/HMO experiment should provide a rare opportunity for disseminating these valuable data to wider audiences than is normally the case when individual entrepreneurs accept the risks and rewards of such innovative efforts on their own.

Other areas for data development

The last two items listed in the proposed S/HMO care data set (Medicaid status and marketing) deserve some additional attention. So far the discussion has focused on the data needed to define the risks associated with the need for LTC as a basis for specifying and pricing meaningful insurance protection. The supply side of the issue tends to dominate the discussion because until recently LTC was generally not perceived to be insurable, and without a product to sell there is little basis for discussing the demand and impact aspects of the market. With LTC insurance beginning to emerge as a viable product, consumer demand and the potential impact of such coverage on public as well as private budgets become essential topics for further analysis.

That a market cannot exist without consumer demand is obvious. However, the details of consumer demand for LTC insurance are only beginning to be understood. Questions of consumer knowledge, preferences, ability to pay, and willingness to pay are all part of what insurers need to know as they go forward in their product development. It is becoming recognized that consumers generally do not have a good understanding of Medicare and their private supplemental insurance. Their knowledge of the risks of LTC and how such care is financed is inadequate for wider market development. They have a strong preference for the more difficult to insure home and community benefits and have an aversion to nursing home care, for which LTC insurance is more feasible. Even when there is interest, there remain questions about affordability. For the market to be widespread, insurers will have to carefully examine their product design and actuarial assumptions to bring prices down from current levels. It is a process that requires better data on the demand side as well as the supply side of the market. In particular, better data are needed on income and assets along with analysis of lifetime savings and consumption patterns and how those might be changed to help finance LTC for an aging population.

Market development is also influenced by the significant role currently played by Medicaid in financing LTC. It has been suggested that the availability of Medicaid is a major barrier to private market development because it is viewed by consumers as acceptable protection against LTC risks. Whether this is true is open to question. We need a clearer understanding of the process by which people become eligible for Medicaid, particularly for people who end up on Medicaid because of their need for LTC (the "spread-down" process). The relationship of private and public payment for LTC is also important because there is a potential for public savings if LTC insurance is widely marketed. The significance of this potential needs to be examined to determine whether public intervention or subsidies (such as tax incentives) should be used to stimulate the market and, if so, which approaches are likely to produce the best results.

Summary and discussion

The development of insurance coverage for long-term care is currently receiving considerable attention. There is widespread interest among consumers, insurers, government, and providers of services in such coverage. A number of insurers are now selling such policies, but questions remain relating to the scope and type of benefits as well as the premium costs. Part of the problem in designing long-term care insurance is the availability of an adequate data base for actuarial pricing. This paper addresses a number of important data issues relating to the design, pricing, and marketing of long-term care insurance.

It is clear that the development of LTC insurance is in its infancy and there is a need for improved data on virtually all aspects of that development, including information on utilization, costs, risk management, marketing, and the impact of such coverage. Policy design and service definitions play an important role in determining specific data needs. The most important data are utilization data on covered services. Ideally, insurers would like to base their planning and development on a data set containing longitudinal utilization patterns for a large number of persons insured under provisions similar to those being contemplated.

In reality, insurers can begin to make the necessary estimates with much less than the ideal data set. As an example, the features of a beginning LTC insurance prototype and the data used to estimate the necessary utilization patterns are described. The example is illustrative of the kinds of policy features, data assumptions, and analytical techniques that can help insurers to begin with available information. The prototype features and estimates are also indicative of the compromises insurers must make without better data.

Freestanding LTC insurance is only one of the models that are emerging. Insurance for LTC is also an important part of continuing care retirement communities and social health maintenance organizations. The basic data requirements of these alternative models are also examined. Each model represents different levels of comprehensiveness: the S/HMO merging LTC benefits for chronic care with the more standard acute care coverage; the CCRC's (in their most comprehensive form) considering virtually all aspects of daily living for an elderly person, including a sheltered living environment, in their benefit package calculations. For each model, however, the basic data needs for insuring LTC risk are similar, with the specifics determined by the benefit design and administration of risk.

The review of alternative models suggests that we know enough to begin insuring LTC but that there is ample room for improvement. In particular, we need to do a better job of tracking health care utilization patterns over time. Fortunately there is a growing recognition of the importance of understanding the dynamics of long-term care utilization patterns. The 1985 National Nursing Home Survey not only includes a much needed update of the 1976 National Discharge Survey but makes a concerted effort to gather data on a complete history of nursing home utilization of both residents and discharges by doing followup with the patient, a relative, or other knowledgeable person. The survey is also designed to capture data on where patients were admitted from (including length of stay in a hospital) and their discharged destination. Also included is information on whether there were short-term hospital stays that did not require a formal discharge from the nursing home. The survey will again try to determine if death occurred following a discharge to another facility. These data will be extremely useful for reexamining the nursing home utilization estimates made with the 1976 National Discharge Survey and for understanding how those patterns may be changing as the population ages and the impact of changes in public policy interventions such as hospital diagnosis-related groups.

Other valuable data gathering efforts that are in the planning stages are the HCFA and Brandeis evaluations of the S/HMO (described earlier) and the 1987 National Medical Expenditure Survey of the National Center for Health Services Research. This survey is an update of the 1977 National Medical Care Expenditure Survey. It will give special attention this time to LTC data collection. A detailed set of questions is planned regarding home health care events, including the content of the care given (i.e., skilled rehabilitation, assistance in activities of daily living), the relationship of the home health event to medical provider events, charges and sources of payment, and the frequency of events over the year. The survey will also include an institutional component to collect data on current residents and admissions of nursing homes, personal care homes, facilities for mentally retarded, and psychiatric hospitals. This survey will provide valuable longitudinal data needed for LTC insurance by tracking the utilization patterns for noninstitutionalized as well as institutionalized persons.

These data bases hold much promise for better data for LTC insurance esimates in the future and deserve support. In the short term, however, we will need to rely on existing data, which may be useful only for understanding smaller pieces of the big picture. Data from the channeling demonstration and the 1982 and 1984 Long-Term Care Surveys of disabled persons in the community are examples of forthcoming data sets that hold promise for further insights concerning the development and pricing of LTC insurance. Other possibly useful data sources that need further exploration may be available from the States. Perhaps insurance companies and CCRC's can be encouraged to pool their data through independent private organizations such as the National Association of Insurance Commissioners or the Society of Actuaries or through a government agency such as the National Center for Health Services Research so that all can share in an improved state of knowledge and key data elements regarding the insurance of LTC risks. LTC insurance is potentially an important piece of the LTC financing puzzle. How such coverage emerges will be greatly influenced by the availability of reliable data on which to base further development.

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Coordination of Federal statistics related to the elderly[a,b]

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Introduction

The U.S. Federal statistical system, by design and in practice, is decentralized; responsibility for the collection, processing, analysis, and dissemination of statistics which relate to the economic, physical, and social well-being of various groups in the population is spread among many agencies and departments of the Federal Government. More than 60 years ago, a report prepared for the Congress by the Bureau of Efficiency noted:

> Practically every bureau in Washington collects or disseminates statistics of one kind or another; and there is much confusion in the public mind concerning the work done by the various offices.
>
> The statistics collected by the Government relate to nearly every aspect of our economic and social life. Statistics of agriculture begin with the seed and follow through to the marketing of the ripened product. Statistics of manufacturers extend from the mining of crude ore to the production of the manufactured article; those of commerce, from the lighting of rivers and harbors to the consumption of imported commodities; and those of social relationships from a mere enumeration of population to elaborate data regarding the incidence of disease (U.S. Bureau of Efficiency, 1922, p. 1).

The trend described in 1922 continues. In 1985, the Office of Management and Budget provided budget and program information on more than 70 agencies which reported outlays of at least $500,000 for statistical activities in any of fiscal years 1984–86 (Office of Management and Budget, 1985).

Debates over the relative merits of centralized versus decentralized organizational structures for the production of Federal statistics have occurred with regularity during the 20th century. (See, for example, Duncan and Shelton, 1978, and Bonnen et al., 1980.) However, the United States has continued to follow a decentralized model. Proponents of the decentralized organizational structure have argued that certain benefits derive from such an arrangement for gathering and distributing Federal statistical information. In particular, they have suggested that the statistical programs are, as a consequence, more relevant to policy and program concerns. At the same time, both proponents of decentralization and those who favor a more centralized system have recognized that there are costs attributable to such an organizational structure. For example, difficulties in ensuring the availability of a comprehensive and consistent body of data to explore the condition and problems of particular populations may arise when no single agency has lead responsibility for meeting information needs related to that population group.

Attendant to the decentralized structure of U.S. statistical activities have been initiatives, particularly within the past 50 years, to provide mechanisms for coordination of the Government's statistical programs. Sustained efforts to coordinate Federal statistics began in 1933 with the formation of the Central Statistical Board, which was later merged, in 1939, with the Bureau of the Budget (BOB). By 1947, the Division of Statistical Standards in BOB had become a 69-person unit managing statistical policy coordination and forms clearance under the authorities of the Budget and Accounting Procedures Act of 1921[1] and the Federal Reports Act of 1942. Essentially, these acts gave the Statistical Policy Division authority to:

- Develop programs and issue regulations and orders for the improved gathering, compiling, analyzing, publishing, and disseminating of statistical information for any purpose by the various agencies in the executive branch of the Government.
- Prevent use of unapproved forms; designate a single agency to perform the collection when more than one agency required specified information; prevent agencies from collecting unnecessary information; and require agencies to disclose information they had gathered to other agencies (under prescribed conditions for maintaining confidentiality).

Through a variety of mechanisms, including the review of fiscal budget requests, the clearance of proposed requests for information, and the formation and leadership of interagency committees and working groups, the statistical policy staff served to coordinate activities among various involved and affected agencies.

During the ensuing years, while Government statistical programs expanded, the size of the staff for statistical policy and coordination functions decreased. By 1977, the staff of

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[a] Contents are the opinions of the author and not those of the Department of Health and Human Services or the organization she works for.

[b] © 1985 National Academy of Sciences.

[1] Relevant provisions were later incorporated in Section 103 of the Budget and Accounting Procedures Act of 1950.

the Statistical Policy Division in the Office of Management and Budget (OMB) numbered 29. Nonetheless, that staff (and its successor, the Office of Federal Statistical Policy and Standards, located from 1977 to 1981 in the Department of Commerce) carried on efforts to coordinate statistical programs in order to prevent unwarranted burden on respondents, to prevent duplication, and to assure adequate coverage of important issues.[2]

In the view of the President's Commission on Federal Statistics, the central statistical office served the decentralized Federal system well by:

> Designating one agency to obtain and process data of interest to several agencies;
>
> Encouraging agencies to use—or make available for the use of others—administrative data that can substitute for survey data;
>
> Clarifying the wording of questions and eliminating unnecessary questions on both survey and administrative forms;
>
> Encouraging the use of probability sampling in place of judgment sampling or complete coverage;
>
> Increasing comparability of data from different sources by requiring the use of standard definitions and classifications, standard reporting periods, and standard reporting populations;
>
> Improving the quality of analysis of problems by calling attention to ways in which data obtained from different sources could fruitfully be used to modify both survey questions and administrative records so that they can be used in complementary fashion to provide information on a common problem; and
>
> Sparking considerable reexamination of individual surveys by the smaller producer agencies with the result that some of those series have been eliminated (President's Commission on Federal Statistics, 1971, pp. 139–140).

Whether or not the statistical coordination functions performed during the period from 1933 through 1980 constitute a complete, or necessarily proper, set of activities, an understanding of the types of initiatives undertaken historically is important both to appreciating the views of statistics producers and users with respect to the current environment and to formulating possible recommendations for the future. This background paper explores current mechanisms for oversight and coordination[3] of Federal statistics relevant to the elderly population, provides an assessment of those existing activities, and presents possible recommendations for future efforts.

Responsible departments and agencies

Responsibility at the Federal level for the collection, processing, analysis, and dissemination of statistics of interest to those involved in research, policy-setting, and programmatic decisions affecting the aging population is dispersed among almost two dozen executive branch agencies. Among the data of greatest interest to users of information on the elderly—located not only in the statistics-producing agencies but in other Federal and non-Federal organizations as well—are general population statistics and statistics on income and wealth, health and nutrition, labor force participation and retirement, and housing and living arrangements.

At the present time, the Federal executive branch agencies with complete or partial responsibility for production of statistics related to these areas include the following:

- Department of Agriculture
  - Economic Research Service
  - Food and Nutrition Service
- Department of Commerce
  - Bureau of the Census
- Department of Health and Human Services
  - Administration on Aging
  - Alcohol, Drug Abuse, and Mental Health Administration
  - Assistant Secretary for Planning and Evaluation
  - Centers for Disease Control
  - Health Care Financing Administration
  - National Center for Health Services Research
  - National Center for Health Statistics
  - National Institute on Aging
  - Office of Human Development Services
  - Social Security Administration
- Department of Housing and Urban Development
  - Office of Planning, Development, and Research
- Department of Labor
  - Bureau of Labor Statistics
  - Employment and Training Administration
  - Office of Pension and Welfare Benefit Programs
- Department of the Treasury
  - Statistics of Income Division, Internal Revenue Service
- Veterans' Administration

To gain a fuller understanding of current authorities, policies, and activities related to oversight and coordination of

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[2] For example, in 1979 the Office of Federal Statistical Policy and Standards formed the Interagency Statistical Committee on Long-Term Care for the Elderly. This committee, which included representatives from every department concerned with the elderly population, prepared a series of recommendations on needed improvements to data in areas such as board and care and informal supports. When the responsibility for statistical policy was returned to OMB under the Paperwork Reduction Act of 1980, however, the Committee ceased to function.

[3] Within this paper, "coordination" generally refers to interagency activities intended to increase the quality and utility of statistical information for multiple users, while minimizing the cost and the burden of data collection on the public. Such activities include, for example, those related to the determination of which agency will collect the required information; the design of particular statistical programs (e.g., decisions on content and coverage); the establishment of standard concepts and definitions; and the development of requirements for data analysis, presentation, and dissemination.

statistics on the elderly population, and views on the effectiveness of these mechanisms, interviews were conducted with representatives of each of the agencies currently involved in the production of information in major areas of interest. In addition, interviews were conducted with representatives of two units with assigned responsibility for oversight of the statistical programs of concern—the Office of Management and Budget (Office of Information and Regulatory Affairs and the Special Studies Division) and the Office of Health Planning and Evaluation in the Public Health Service. To complement the views provided by those involved substantially in the production of statistics, representatives of Federal legislative branch organizations—the Congressional Budget Office, the General Accounting Office, the Office of Technology Assessment, and the Senate Special Committee on Aging—and of selected non-Federal organizations—the American Association of Retired Persons, the Employee Benefit Research Institute, and The Gerontological Society of America—were asked to provide a "user's" perspective. (A listing of the individuals interviewed is provided as appendix A.)

Questions posed to obtain background information on current activities and suggestions for the future were as follows:

> What formal or informal authorities does your agency have, if any, for inter- or intra-agency oversight and coordination of Federal statistics related to the elderly?
>
> What general policies (formal or informal) does your agency follow in matters related to oversight and/or coordination of statistics on the elderly?
>
> What formal or informal activities does your agency undertake to encourage or execute inter- or intra-agency oversight or coordination of statistics related to the elderly?
>
> What formal or informal policies or practices do you believe enhance or inhibit fruitful oversight and/or coordination of statistics on the elderly?
>
> What mechanisms and practices have produced improvements to the coverage, quality, relevance, and timeliness of statistics related to the conditions and problems of the elderly?
>
> Where has the lack of inter- or intra-agency oversight or coordination resulted in failure to produce needed information, or in less than optimal products to inform decisions related to the elderly?
>
> What alternatives might be considered for improving the oversight and coordination of statistics on the elderly? What would be involved in making such changes? What factors might inhibit the success of such initiatives?[4]

The responses provided by those interviewed are summarized in the following sections of this paper and form the basis for the evaluation of current mechanisms and suggestions for the future.

Current mechanisms for oversight and coordination

At the present time, legislative authority to coordinate Federal statistics of interest to those involved in research, policy-setting, and programmatic decisions affecting the aging population is embodied in two statutes. The first of these, the Paperwork Reduction Act of 1980, provides to the Office of Management and Budget broad responsibility to:

- Develop long-range plans for the improved performance of Federal statistical activities and programs;
- Coordinate the functions of the Federal Government with respect to gathering, interpreting, and disseminating statistics; and
- Develop and implement government-wide policies, principles, standards, and guidelines concerning statistical collection procedures and methods, statistical data classifications, and statistical information presentation and dissemination.

The Paperwork Act also assigns to OMB responsibility for clearance of information collection requests, i.e., the authority to review and approve information collections proposed by agencies, and to determine whether the collection of information by an agency is necessary for the proper performance of the functions of the agency. Both the statistical policy and reports clearance functions are delegated, by the act, to OMB's Office of Information and Regulatory Affairs.

The second legislatively prescribed authority to coordinate Federal statistics related to the elderly population is far more specific. Under the Older Americans Act of 1965, as amended, the Administration on Aging is assigned the duty and function to "gather statistics in the field of aging which other Federal agencies are not collecting, and take whatever action is necessary to achieve coordination of activities carried out or assisted by all departments, agencies, and instrumentalities of the Federal Government with respect to the collection, preparation, and dissemination of information relevant to older individuals." Further, the Act assigns to the Commissioner of the Administration on Aging the responsibility to advise, consult, and cooperate with the head of each Federal agency or department proposing or administering programs or services substantially related to the purposes of the Older Americans Act, and requires the head of each Federal agency, in turn, to consult and cooperate with the Commissioner. Among the programs cited in this context are the demographic statistics and analysis programs conducted by the Bureau of the Census.

Despite the existence of these legislative authorities to oversee and coordinate statistics related to the elderly population, neither the Office of Management and Budget nor the Administration on Aging is aggressively pursuing such activities. The Statistical Policy Office in OMB's Office of Information and Regulatory Affairs (OIRA)—which currently has a staff complement of six professionals—is not focusing

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[4] Note: Interviews with individuals in organizations not responsible for the production of statistics focused on the last four questions.

attention on statistics related to the elderly. OIRA desk officers responsible for clearance of information requests may, in the interest of minimizing respondent burden, question the need for proposed collections of information or suggest the use of alternative data collection sources. But active efforts to coordinate or improve the scope and quality of information on the elderly population are not being undertaken by OMB's Office of Information and Regulatory Affairs.

Likewise, while the Administration on Aging currently is reviewing plans for the statistical programs and publications of a few agencies (e.g., the aging supplement to the Health Interview Survey, the National Mortality Followback, and the Standard Death Certificate programs of the National Center for Health Statistics, and the Decennial Census and the Survey of Income and Program Participation conducted by the Bureau of the Census), such reviews are conducted largely in response to requests from the data collecting agencies rather than at the initiative of the Administration on Aging. Although some leadership to coordinate statistics related to the aging was taken by the Administration on Aging during the mid-1970's (i.e., an interagency group on statistics related to the elderly was established, and an inventory of existing statistical programs was compiled and published in 1979), such efforts have not been pursued in more recent years, primarily because of a lack of staff resources.[5] In sum, while present efforts by the Office of Management and Budget and the Administration on Aging may serve to eliminate duplication or to improve a particular survey, the current coordination activities of these agencies are not directed to identifying gaps in data on the elderly, or to ensuring that such gaps are filled.

While the two Federal agencies with specific legislative authority to oversee and coordinate statistical programs related to the elderly population are not currently undertaking efforts to meet these mandates, two other Federal agencies, within the past year, have initiated interagency activities to improve the coordination of such information. Noted most often by those interviewed was the "Forum for Statistics on Aging," an informal group instituted at the initiative of the Census Bureau. Composed of statisticians from various Federal agencies that develop statistics on the elderly population, the Forum for Statistics on Aging was established as a means to:

- Exchange information;
- Coordinate the approach to the collection and tabulation of data on the elderly population;
- Keep the Federal agencies informed about needs for data; and
- Identify data gaps in the Federal statistical system relevant to the elderly.

The second mechanism established during the past year to enhance interagency coordination of statistics on the elderly population is a Subcommittee on Data Sources under the aegis of the Interagency Committee on Research on Aging, led by the National Institute on Aging (NIA). The overall Committee, created some 10 years ago, includes as members representatives of approximately 30 Federal agencies within and outside the Department of Health and Human Services. Various subcommittees address topics such as research priorities, technology and aging, and noninstitutional care. The recently formed Subcommittee on Data Sources, established primarily to promote the exchange of information on existing data sources and to assess how such sources have been influenced as research priorities have changed, reviewed potential changes for the 1990 decennial census and provided feedback on concerns and priorities. The subcommittee also has had some preliminary discussion on developing an inventory of research on aging, including statistics, and may in the future look at data gaps. In general, the NIA-sponsored Subcommittee focuses on data sources as they relate to research issues, whereas the Census-sponsored Forum is concerned with data for a broad spectrum of policy and programmatic uses.

Beyond these two "government-wide" efforts, agencies responsible for statistics related to the elderly population indicated that current activities to coordinate with other Federal units were largely limited to one-to-one efforts. For example, the National Center for Health Services Research has shared research plans for the proposed 1987 National Medical Expenditure Studies with agencies providing financial support for the program, and the National Center for Health Statistics (NCHS) coordinates with specific agencies on plans for particular data collection activities. The Food and Nutrition Service at the Department of Agriculture will provide drafts of its plans for nutritional monitoring to interested agencies for comment, and the Health Care Financing Administration now has about 30 cooperative agreements to meet information requests from other organizations such as NCHS, the National Cancer Institute, the Census Bureau, and the Centers for Disease Control.

Within Health and Human Services, the Federal department housing the largest number of agencies responsible for research and service programs affecting the elderly population, efforts to coordinate statistical activities are fragmented. For example, both the National Institute on Aging and the Administration on Aging have reviewed plans for certain NCHS programs (e.g., the aging supplement to the Health Interview Survey, the Standard Death Certificate, and the National Mortality Followback). The National Center for Health Services Research has undertaken activities to coordinate with the Health Care Financing Administration and with NCHS, but has not worked in cooperation with the Administration on Aging or the Office of Human Development Services. Two offices which have specific coordination responsibilities review the plans of some, but not all, of the departmental units which provide data on the elderly population. The Office of Health Planning and Evaluation (Public Health Service), largely in the context of reports clearance activities, provides some coordination of programs sponsored by the National Institute on Aging, the National Center for Health Statistics, the Alcohol, Drug Abuse, and Mental Health Administration, and the Health Care Financing Administration, while the Office of the Assistant Secretary for Planning and Evaluation reviews

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[5] At the present time, only one individual in the Administration on Aging is assigned to work on statistical analysis.

planned activities of the Health Care Financing Administration, the National Center for Health Services Research, and the Office of Human Development Services.

Effectiveness of current mechanisms

As a means to achieve interagency coordination on issues and problems and to improve the statistics available on the elderly, the Census-sponsored Forum received high marks from those who are participating. While the relative newness of this initiative precluded an assessment of its ultimate effectiveness, the sense of the agencies was that the Forum for Statistics on Aging has great potential for increasing awareness of available statistics, for sharing information on gaps, and for suggesting solutions to meet such needs. As a case in point, the signatories to the Forum's memorandum on proposed changes in the 1990 census hope that, by presenting a modest, unified proposal on suggested modifications, their recommendations will carry greater weight with the Bureau of the Census and the Federal Agency Council, and will meet with more success in the clearance process at the Office of Management and Budget.

Also cited as examples of "good practice" were selected one-to-one efforts that have been undertaken by some of the data-producing agencies. In particular, close coordination with other agencies by the National Center for Health Statistics on the Mortality Followback, and by the Health Care Financing Administration and the Bureau of the Census in preparing special tabulations from existing data sources, were viewed as having positive outcomes.

A number of individuals interviewed noted that recent budget stringencies, which have necessitated more frequent joint funding of data collection programs, have led to greater interagency coordination. The Survey of Income and Program Participation and the National Nursing Home Survey were key examples mentioned in this context.

Although some cases of positive outcomes from coordination were cited by agency and other respondents, examples of losses occasioned by the failure to coordinate were more frequent.[6] Virtually every individual interviewed noted at least one instance of a data collection program or analytic activity that might have been improved through greater interagency coordination. In some cases, these "lost opportunities" resulted in failure to meet a particular need, or "data gaps," while in other cases, the consequence was a lack of comparable information from sources in various agencies.

Among the data gaps noted by producers and/or by users of data on the elderly population were the following:

Information on the "old old," i.e., those 85 and over.

Information on age segments of the elderly population by, for example, 5-year breaks of the population 65 and over.

Information on subgroups of the elderly population—those with serious health problems, women living alone, and minorities.

Longitudinal information on utilization and financing of health care facilities and services.

Information on "out-of-pocket" expenses, e.g., for over-the-counter drugs, by income group and by race.

Information on housing and alternative living arrangements for the elderly.

Information on family support systems.

Information on the types of long-term care that are available and on needs for long-term care which are not being met under present arrangements.

Information on the nursing home population, including, among other things, diagnostic data.

Information on functional abilities and chronic diseases of the elderly.

In addition to data gaps which result from the lack of efforts to coordinate between and among agencies responsible for collecting and using information related to the elderly population, those interviewed suggested a number of instances where the absence of coordination by the data-producing agencies—in particular, failures to integrate appropriate content and to use comparable concepts and definitions in designing data collection programs—has led to noncomparable or inconsistent information from Federal data sources.[7] For example, several respondents noted the difficulty in obtaining useful data relating income level to the use of and methods of payment for health care services. The Current Population Survey, which has good data on income, lacks information on use of health services and methods of payment, while health data sources, e.g., the Health Interview Survey, generally lack good information on income. Other examples of cases where insufficient interagency coordination has led to noncomparable or less than optimal products included inconsistencies between questions in Census Bureau surveys and the Health Interview Survey, differences between Census and Social Security projections of birth and mortality rates, and the failure to match Social Security Retirement Histories with Medicare files.

Beyond the citation of particular data gaps or instances of failure to produce comparable or integrated information, several cases of inattention to the appropriateness for the elderly population of survey coverage or of specific questions asked in general surveys were noted. For example, the Current Population Survey (CPS) queries the noninstitutionalized civilian population; as a consequence, other surveys tied to the CPS frame suffer by failing to include the institutionalized population (e.g., those in nursing homes, who are likely to have the highest health care costs) in examining questions such as total costs of medical care. In the case of the 1980 decennial census, it was noted that the "disability" items, which were related to the ability to work and the ability to use public transportation, were of little relevance for major

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[6] The failure to coordinate may, of course, be only partially responsible for such data gaps. Fiscal and burden budget constraints may be contributing factors in some cases.

[7] This is not to suggest, of course, that every survey should include all potentially useful content areas; integrated planning with respect to key areas, however, could substantially enhance ongoing and proposed programs.

segments of the elderly population. A third example in this general category was the weakness of reporting in the CPS with respect to rents, dividends, and interest, an increasingly important source of income for some sectors of the older population.

At a more general level, the individuals interviewed suggested a number of reasons why coordination and cooperation among agencies have not always been successful. Among the problems cited were:

> Lack of a "structure" that leads to coordination—incentives currently favor agencies acting independently, in their own perceived best interests.
>
> Lack of a clear, formalized decision process within various agencies for developing particular data collection programs, making it difficult for other data producers and users to interact with the collecting agency.
>
> Absence of information which would enable data producers and users to know what other agencies are doing.
>
> Lack of information from data users inside and outside the statistics-producing agencies about information requirements, and about how the information is or could be used.
>
> Failure to reach out to see what others are doing (i.e., to examine existing data sources) or to obtain the views of counterparts when initiating or modifying data collection programs.
>
> Lack of exchange of information early enough in the process to influence design of data collection or tabulation programs. (For example, coordination on the National Nursing Home Survey did not take place until the time of OMB clearance.)
>
> Failure to take advantage of special expertise of kindred agency personnel in designing survey programs.

Underlying these factors which inhibit the coordination of Federal statistical programs of interest to those involved with research, policy formulation, and programmatic decisions affecting the aging population are several fundamental causes: the historic lack of mechanisms, formal or informal, to foster coordination; current fiscal budget stringencies; present-day philosophy and regulations governing Federal information collection, which require adherence to the "burden budget" and demonstration that data have "practical utility" for the agency sponsoring the information collection request; the tendency for data collection activities to mirror program structures (e.g., how the elderly are housed is the responsibility of the Department of Housing and Urban Development, whereas determining what kinds of services the elderly receive is largely the responsibility of the Department of Health and Human Services—in turn, the agencies collect information in their respective domains);[8] reluctance to open information collection programs to the broader community, with the concomitant potential for "loss of control" of the survey; and the fact that cooperation generally benefits the "user" agency far more than the "producer" agency.

Suggestions for the future

In spite of the frequent citation of specific examples where coordination among the statistics-producing agencies might lead to more useful or usable information products, the individuals interviewed expressed little support for any substantial, formal mechanism to engender cooperation.[9] As one respondent noted, there is no need for a "grand guru of aging data." Reasons given by the many who shared this opinion included:

> The current policy of "less data," which could lead to a situation where coordination would be used as a means to further cut back on Federal information collection activities.
>
> The delays in implementing data collection programs which result from undertaking coordination activities.
>
> The lack of human resources to lead or to participate in coordination activities.
>
> The fact that there are too many groups of special interest to establish formal mechanisms to coordinate data on each.
>
> The view that the interest and desire of technical personnel to cooperate, rather than formal mechanisms, prove most effective in achieving coordintaion.

While little enthusiasm was expressed for the establishment of a formal mechanism to coordinate statistical activities related to the elderly population, there remain nonetheless various problems which must be resolved through cooperative efforts among Federal agencies. Based on the interviews conducted with agency representatives, a list of improvements to be gained through further cooperative efforts among agencies would include the following:

> The establishment of mechanisms to educate users and producers of statistics on the elderly, both within and outside government, about existing sources of information.
>
> The establishment of mechanisms to improve the flow of information about data needs and problems with current data sources between users of information and those responsible for the collection, tabulation, and dissemination of Federal statistics.
>
> The establishment of a means to provide early information on plans for new data collection programs or for modifying existing systems.

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[8] Indeed, even within an area, such as health care, the delivery system is fragmented, and the Federal data sources mirror that fragmentation.

[9] It is interesting to note, however, that several inquiries have been made by individuals wishing to coordinate proposed activities through the defunct Interagency Statistical Committee on Long-Term Care for the Elderly.

The establishment of efforts to merge existing data files (from both statistical survey and administrative record sources).

The establishment of mechanisms to develop and exchange methodological knowledge on techniques for obtaining information from the elderly population, and to examine the appropriateness of survey questions for older respondents.

In an environment characterized by staff resource and response burden constraints, the incentive to coordinate, and the success of such efforts, will depend in large measure on the assurances provided to the Federal agencies that the products of such efforts will have status and acceptance throughout funding and clearance processes. Lacking evidence of such "clout," initiatives such as those related to the 1990 decennial census, and others currently envisioned by the Forum on Statistics for the Aging, will have little chance of achieving ongoing support from either working-level personnel or agency leaders.

Although it might seem appropriate, in the context of the mission of the Panel on Statistics for an Aging Population, to strive for solutions unhampered by current policies, trends, and constraints, more modest proposals, taking into account current and foreseeable realities, are offered in the balance of this paper. These proposals recognize

Current formal and informal coordination authorities and activities.

The decentralized character of Federal assistance and statistical programs.

Federal domestic spending limitations.

Present philosophy and practice with respect to the approval of Federal information collection and dissemination activities.

Given the breadth of Federal agencies involved in the production of statistics related to the elderly population, it would seem perhaps self-evident that the logical focal point for coordination of the statistical programs of interest would be the Office of Management and Budget. OMB clearly possesses the strongest set of authorities over the many agencies and departments involved; it has responsibility not only for executive branch decisions on fiscal budget matters, but also, by law, for statistical policy and information clearance decisions. Nevertheless, at least two factors argue against the feasibility of substantially improved efforts by OMB, in the currently constituted Office of Information and Regulatory Affairs, to coordinate Federal statistics on the elderly population: the extremely limited staff available for statistical policy and coordination activities, and the current organizational arrangement for information clearance activities, which are conducted by desk officers essentially on an agency-by-agency basis.

In spite of the fact that OMB is unlikely either to accept or to be able to exercise a broad mandate to coordinate statistics on the elderly, there are at least two steps that might be taken by the Office of Information and Regulatory Affairs.

1. At the present time, the Office of Information and Regulatory Affairs requires of each department an Information Collection Budget, which details all planned activities for the current year. To address the need cited by many producers and users of Federal statistics on the aging for more advance notice of plans to institute new data collection programs or to modify existing activities, OIRA could include in the Information Collection Budget request to Federal departments and agencies a requirement for information on planned activities during the coming 3 to 5 years. While those wishing to make use of this resource would still be required to look at the plans of several agencies, the information base to do so would exist. Further, a group such as the Subcommittee on Data Sources of the NIA-sponsored Committee on Research on Aging could accept responsibility for collating a cross-agency synthesis of planned data collections related to the elderly.
2. The Federal Committee on Statistical Methodology, under the sponsorship of the Office of Information and Regulatory Affairs, has served in the past to focus attention and conduct research on crosscutting methodological problems in Federal statistics. For example, the Committee has been responsible for two studies related to statistical uses of administrative records. In view of the fact that the Committee's agenda is driven primarily by issues suggested by the participating agency representatives, it would be appropriate to ask the Committee to address the need for the development and exchange of methodological knowledge on techniques for obtaining information on the elderly population, and for an examination of the appropriateness of survey questions for older respondents.

Under the assumption that OMB is unlikely to shift either the orientation (to reduce data burden) or the organization (by agency) of its current information collection oversight activities—or to experience a substantial increase in staff resources for statistical policy activities—it is necessary to look elsewhere for a mechanism to improve coordination of Federal statistics related to the elderly population.

The second agency with existing, but currently unused, legislative authority to coordinate statistical programs related to the elderly population is the Administration on Aging (AOA). As noted in earlier sections of this paper, AOA has declined to exercise this authority in recent years, reportedly because of a lack of staff resources. Nonetheless, it may be appropriate, in looking toward the future, to suggest one or more specific roles that could be played by the Administration on Aging. For example, OMB could be asked to delegate to the Administration on Aging certain responsibilities for reviewing agency budget proposals calling for modifications to existing data collection activities, or for the implementation of new statistical programs, and request that an assessment of such proposals be provided to OMB. Such a review process would provide an early opportunity to identify whether priority data gaps were being addressed in agency budget proposals. Similarly, if the Information Collection Budget process were modified to include plans for a 3- to 5-year period in the future, the information collection plans could be reviewed by AOA. This procedure would provide a considerably more timely opportunity for ensuring that appropriate interagency linkages were developed as an integral part of the design of new or revised statistical programs.

While proposals for strengthening the coordination efforts of OMB and/or the Administration on Aging have the advantage of resting on an established legislative authority, they suffer from not insubstantial problems: the time it will take to put such activities in place, the resources necessary to make them more than "paper exercises," and the largely negative view currently held toward formal coordination mechanisms. These factors (and others, no doubt) must be weighed against the inherent appeal of legislatively founded, formal coordination mechanisms.

In the interim, past experience coupled with current attitudes seem to suggest that the type of mechanism most likely to succeed in the near term is one constituted by concerned agency representatives willing to devote the time and energy to share information and problems, and to work cooperatively toward solutions. Although still in its infancy, the Forum for Statistics on Aging, initiated by the Bureau of the Census, appears to hold great promise for operating under these requirements. Both the goals of that entity and specific topics suggested for its agenda, as outlined in a March 1985 memorandum to the members (appendix B), point toward the Forum's potential for addressing needs to educate producers and users about existing data sources, to provide a means for improving the flow of information about data gaps, and to merge existing and planned data sources in more useful ways.

At the same time, it must be recognized that the Forum is a "volunteer" effort without dedicated resources; that its effectiveness will rest on the "good will" of the participants; that the ultimate adoption of its recommendations may largely be a function of "peer pressure"; and that its sphere of influence will depend heavily on the involvement of all appropriate agencies. As a consequence, consideration should be given to:

1. Instituting a formal agenda for the work of the Forum, outlining specific activities to be undertaken and anticipated products.
2. Enlarging the membership of the Forum to include appropriate representatives of the Department of Housing and Urban Development, the Department of Labor, the Statistics of Income Division at the Internal Revenue Service, and additional agencies in the Department of Health and Human Services (e.g., the National Center for Health Services Research, the Office of Human Development Services, the Alcohol, Drug Abuse, and Mental Health Administration, and the Centers for Disease Control.)
3. Inviting as observers at Forum meetings representatives of the Office of Management and Budget[10] who are responsible for budgetary and information collection decisions affecting statistical programs on the elderly population.
4. Requesting formal agency signoff on Forum recommendations, with a concomitant pledge to implement suggested changes.
5. Seeking staff support from the participating agencies for activities that require background research or the development of products for use by the Forum.
6. Instituting at an early date a program to share with users of statistics in the legislative branch agencies and outside organizations information on current statistical sources, and to obtain feedback from data users on needs for and problems with information related to the elderly population.

While the Forum may serve quite effectively to improve interagency coordination and cooperation with users outside the executive branch, some further progress might also be made through greater emphasis on coordination among the many agencies within the Department of Health and Human Services responsible for programs and activities that provide statistical information relevant to the elderly population. The Administration on Aging, which has in place legislative authority to perform this function, should be called upon to enhance its efforts in this area. Although limitations on staff resources may continue to be a problem, the failure to coordinate may in the end lead to considerably greater expenditures—not only for statistics, but also, perhaps, for program services.

In the foregoing proposals related to possible expansion and strengthening of the interagency and interdepartmental coordination roles and activities of the Administration on Aging and the Forum, the question of "clout" remains largely unaddressed. Several possibilities—most notably the provision of funding for particular activities to a single agency (as was done in the case of the Survey of Income and Program Participation) or the assignment of an information collection clearance authority to a lead agency—exist. But each of these mechanisms brings problems. In the case of providing funding to single agencies, the issue of who controls content is bound to arise, and needs of particular agencies may be met even less well than at present; in the case of requiring clearance by a lead agency, which could result in the addition of another layer to the process, the benefits might well be outweighed by the costs in time and effort required. In the end, the importance of improving statistics on the elderly population, and the interest of data users and producers in addressing current problems and needs, will prove most critical in achieving better cooperation and coordination.

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[10] It should be noted that agency initiatives to foster such coordination have received favorable reviews from the Office of Management and Budget. For example, OIRA currently participates in the Interagency Committee on Dissemination of Statistics, formed under the leadership of a staff member at the Energy Information Administration when OMB disbanded its Interagency Committee on Data Access and Use.

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President's Commission on Federal Statistics: *Federal Statistics—Report of the President's Commission.* Vol. I, 1971.

U.S. Bureau of Efficiency: *Report on the Statistical Work of the United States Government.* Submitted to Congress Sept. 7, 1922.

Appendix A Organizations/individuals interviewed

Federal executive branch agencies

Office of Management and Budget

Office of Information and Regulatory Affairs

Dorothy Tella

Richard Eisinger

Special Studies Division

Gaby Lupo

Department of Agriculture

Food and Nutrition Service

Robert Rizek

Economic Research Service

Calvin Beale

Department of Commerce

Bureau of the Census

Cynthia Taeuber

Department of Health and Human Services

Administration on Aging

Donald Fowles

Howard White

Alcohol, Drug Abuse, and Mental Health Administration

David Larson

Assistant Secretary for Planning and Evaluation

Paul Gayer

Centers for Disease Control

Norman Axnick

Health Care Financing Administration

Jim Lubitz

Glenn Martin

John Parmigiani

National Center for Health Services Research

Corbin Liu

Dan Walden

National Center for Health Statistics

Mary Grace Kovar

Joan Van Nostrand

National Institute on Aging

Ronald Abeles

Shirley Bagley

Richard Suzman

Public Health Service, Office of Health Planning and Evaluation

Gooloo Wunderlich

Social Security Administration

Jane Ross

Melinda Upp

Department of Housing and Urban Development

Office of Planning, Development, and Research

Duane McGough

Department of Labor

Bureau of Labor Statistics

Sandra King

Philip Rones

Employment and Training Administration

Paul Mayrand

Office of Pension and Welfare Benefit Programs

John Turner

Department of the Treasury

Internal Revenue Service, Statistics of Income Division

Dan Holik

Marvin Schwartz

Veterans' Administration

Phyllis Thorburn

Federal legislative branch organizations

Congressional Budget Office

Nancy Gordon

General Accounting Office

Janet Schickles

Office of Technology Assessment

Robert Harootyian

Senate Special Committee on Aging

Betsy Vierck

Other organizations

American Association of Retired Persons

John Rother

Theresa Varner

Employee Benefit Research Institute

Emily Andrews

The Gerontological Society of America

John Cornman

Robert Binstock (Case Western Reserve)

Marilyn Moon (Urban Institute)

Appendix B

UNITED STATES DEPARTMENT OF COMMERCE
Bureau of the Census
Washington, D.C. 20233

March 14, 1985

MEMORANDUM FOR: Members of Forum for Statistics on Aging

From: Cynthia M. Taeuber CMT
Chairperson

Subject: Meeting, March 19, 1985

Per our telephone conversation, you are invited to participate in the Forum for Statistics on Aging (FSA) which will meet March 19, 1985, 1:30 p.m., Room 1169 (1st floor), HHS North Building at 330 Independence Avenue.

The FSA will be made up of statisticians from federal agencies who develop statistics on the elderly population. The FSA will serve as a means of:

- exchanging information (i.e., a network);
- coordinating the approach to the collection and tabulation of data on the elderly population;
- keeping the federal agencies informed about the needs for data; and
- identifying data gaps in the federal statistical system relevant to the elderly.

The agenda for the first meeting is to discuss specific recommendations for data needs for the elderly from the 1990 census. Come prepared with ideas. Dorothy Guilford from the National Academy of Sciences will discuss their project on aging and explain the inventory of data sets they will be producing.

The list below will give you an idea of the types of subjects we may want to discuss in the future:

- level of age detail that is available and creative ways we could make statistically reliable data available for the very old;
- use of data on the institutional population; enumeration problems;
- commonalities/conflicts with types of questions asked in various surveys; areas of overlap; suggestions about where money can be saved;
- bring in outside data users for presentations of problems;
- intergenerational issues; data availability; methodological problems/solutions;
- ability to do international comparisons;
- data timeliness;
- frequency of data collection;
- opportunity for combining data for interagency joint reports;
- report on SIPP, use of longitudinal data;
- report by NIA on statistical programs and research they are currently funding;

- reports by other agencies on their work;
- policy issues from the Senate Committee on Aging; etc.

This, along with the ideas you bring, should keep us entertained for awhile. I look forward to meeting with you.

CTaeuber:ja

cc: Joan Van Nostrand, NCHS
Rosalyn Bass, NIMH
Dorothy Guilford, NAS
Philip Roans, DOL
Barbara Torrey, Census
Don Fowles, AOA
Richard Suzman, NIA
Jane Ross, Social Security
Cal Beale, Agriculture
Jack Feldman, NCHS
John Mather, VA
Paul Gayer, HHS
Marian Gornick, HCFA

Lessons from longitudinal studies[a, b]

by Clifford H. Patrick, Ph.D., Veterans Administration Health Services Research Program and Duke University

I. Introduction

For over four decades, the government has supported numerous longitudinal sample surveys on a wide range of topics related to aging. Yet there continues to be a call for new longitudinal studies of aging whenever research priorities are discussed (DeFriese, Hersh, and McManus, 1985; National Center for Health Statistics, 1980). DeFriese, Hersh, and McManus (1985), summarizing priority research issues for elderly health status and risk factors, included the following: "Longitudinal cohort studies are needed of the aging process, including natural histories of diseases, the loss of ADL functional abilities and the relationship of health and functional status by disease to health services utilization." Before launching new studies, we should determine what existing studies have provided that has been useful to the research community and policymakers. While these data are useful for describing and explaining aging phenomena or processes important to policymakers, they are also appropriate for predicting events and circumstances of the elderly. Longitudinal studies incorporate invaluable information on dynamic processes of aging and changes in individual circumstances over defined time periods. As such, they should be considered national scientific and policy resources to be fostered and shared for maximum benefit to society.

Do we really need new longitudinal studies of human populations to investigate scientific issues concerning aging processes and outcomes? To answer this question, we need to determine the uses of existing longitudinal surveys and to evaluate the possibility of using other methods to reach definitive conclusions. There are several uses of temporal data that need to be identified. Longitudinal data are used to examine the aggregation of experiences over time, as suggested by Meiners (Chapter III) in terms of duration of episodes of confinement in hospitals and nursing homes, which in fact are one continuous experience of long-term care in different settings. Perhaps the most common use of longitudinal data is to make etiological inferences about the incidence or onset of an event based on characteristics at the beginning of the period and subsequent changes. Another common use is to examine the natural history of a condition or illness. Studies looking at the impact of specific treatment, such as the channeling demonstration, represent another use of temporal data on an aging population group. Finally, randomized trials to measure the impact of alternative treatments represent longitudinal data on individuals available for analysis. The Rand health insurance study is a classic experiment of this type (Morris, 1983; Newhouse, 1974). Each of these types of longitudinal studies has contributed valuable information on aspects of aging in American society.

Within this brief paper, such an enormous undertaking as analyzing each of these uses is not possible; clearly, longitudinal data are appropriate to examine such policy issues as the natural history and onset of conditions, including disease entities, activities of daily living, widowhood, and poverty. By examining a policy-oriented hypothetical longitudinal sample survey based on general principles, an overall impression of the issues can be gleaned and valuable lessons on planning future longitudinal surveys can be learned. This paper begins where such inventories as those of Migdal, Abeles, and Sherrod (1982) end. It discusses in broad terms survey planning and execution, analytical issues, and the lessons we should have learned from past experience with surveys. Several of the key issues are also discussed in papers by Fienberg and Tanur (1986) and by Fienberg, Martin, and Straf (1985). The paper attempts to indicate the advantages and disadvantages of longitudinal surveys compared to other methods of acquiring knowledge of the aging process and life cycle events such as time series of cross-sectional data. The paper concludes with recommendations regarding future longitudinal surveys.

II. Defining longitudinal sample surveys

Conceptually, longitudinal data are used to study individual change in a dynamic sense. This may be done prospectively or retrospectively. Because we are interested in the possibility of new funded surveys, a longitudinal sample survey is defined narrowly in this paper as a prospective field study in which the characteristics of interest of each person in a sample population are surveyed over time to determine what changes in selected variables have occurred and why (Nesselroade and Baltes, 1979). As Fienberg and Tanur (1986) indicate, "questions of process can *only* be answered with longitudinal data."

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[a] Contents are the opinions of the author and not those of the Department of Health and Human Services or the organization he works for.

[b]

Longitudinal survey data may be derived from cohort studies, from rotating panels, or from field experiments. In each type, the sample subject is resurveyed to elicit repeated measurements on selected items of interest. This narrow definition precludes such valuable data sets as the Continuous Work History Sample and Medicare public use files, which are administrative records, as well as aggregate time series from the Census Bureau, National Center for Health Statistics, and Bureau of Economic Analysis, which are relatively inexpensive to collect and analyze compared to true longitudinal sample surveys. This paper also excludes clinical trials, a type of longitudinal study that is not a true survey.

Existing sample surveys generally fall into two classes. First, longitudinal surveys of nationally representative samples attempt to indicate how the U.S. population has aged and its characteristics changed. The longitudinal surveys of social and economic phenomena such as education, income, wealth, employment, and retirement decisions typically have been based upon national samples which are representative of the U.S. population. These are frequently based on the sampling frame of the Current Population Survey (CPS). Examples of nationally representative longitudinal studies focused on social issues include the Retirement History Survey, the Michigan Panel Study on Income Dynamics, the National Longitudinal Survey (NLS), the Survey of Low Income Aged and Disabled, and the Survey of Income and Program Participation (SIPP) (Duncan and Morgan; Irelan et al., 1976; Irelan and Schwab, 1979, 1981, and 1982; Kasprzyk and Herriot, 1984; Nelson, McMillen, and Kasprzyk, 1984; Parnes, 1979; Riccobono et al., 1981; Tissue and McCoy, 1981).

These surveys have been planned and directed primarily by social scientists. Directed at social issues, their analyses delve into a wide range of topics, including demographic, health, and other characteristics which are thought to influence income, work, and retirement patterns. The health data are based on self-assessment and are considered by some to be less reliable than those found in health surveys. The results have been invaluable in broadening understanding of social issues and aging. In addition to these, the First National Health and Nutrition Examination Survey (NHANES I) Epidemiologic Followup Study is creating a longitudinal data base. This study is picking up an existing nationally representative population observed originally in the NHANES I sample (Cornoni-Huntley et al., 1983). The followup study will gather recent information on survivors and determine cause and date of death of decedents, as is done in many of the longitudinal sample surveys.

Second, longitudinal surveys of people in a given setting have not attempted to be representative of the U.S. population so much as to uncover underlying risk factors and parameters of the aging process which might be replicated elsewhere. These studies for the most part focus on the natural history of disease. Examples of this type of longitudinal study include the Framingham Heart Study, the Alameda County Study, the Tecumseh Study, the Evans County Study, the Baltimore Longitudinal Study, the Duke Longitudinal Survey, the Honolulu Heart Study, the Washington County Study, and others supported by the National Institutes of Health (Alexander, 1974; Branch and Jette, 1981; Dawber, 1980; Gordon et al., 1974; Greulich, 1985; Kagan et al., 1974; Kannel and Gordon, 1980; Manton and Woodbury, 1983; McGee, 1973; Napier et al., 1972; Phillips et al., 1974; Rogot, 1974; Scheuren, Chapter II).

While the health surveys usually contain some information on socioeconomic and demographic characteristics of subjects, the key hypotheses and bulk of the data are health related and include physiological and related biomedical parameters. Though they are not nationally representative, analyses of these studies are a major factor in the growth of prevention programs. The previously mentioned surveys are only a few of the existing studies and indicate the tremendous resources which have been provided for longitudinal studies of the social and health characteristics of the aging population at both local and national levels. Whether future longitudinal studies will start with a national sample, as social surveys have traditionally done, or begin with local samples which are nonrepresentative of the U.S. population but which can be replicated at other sites depends on the goals of the study and involves tradeoffs to be considered early in planning.

III. Longitudinal survey planning and execution

Let us assume that we intend to initiate a new longitudinal sample survey. Initial planning strategies for the survey include goals, study design, sample size, sampling frame, survey instrument, response rates, and analyses of whether the study is to be done only once or repeated over time to create a longitudinal data base (Nelson, McMillen, and Kasprzyk, 1984). Therefore, only those planning and execution strategies which are concerned with the longitudinal nature of the survey are discussed herein.

Probably the most critical planning decision involves the goal of the survey. This requires clear articulation of the hypotheses to be tested by data which the study generates. Is the goal of the study to describe changing behavior or conditions associated with aging, such as retirement, financial resources, and health changes; to explain such dynamic behavior, e.g., decline in activities of daily living (ADL's) based on changing household and individual characteristics; or is it to predict changes and future distributions of individuals in certain states, such as admissions to nursing homes or hospital intensive care units as a consequence of declining ADL or disabling morbidity, all of which have policy ramifications? Is information needed which cannot be collected, at possibly much less expense, through ongoing Federal activities such as the Current Population Survey, the National Health Interview Survey (NHIS), or departmental administrative records? (See Rogot et al., 1983; Scheuren, Chapter II.) The answer may be no if the goal involves behaviors or other relationships which are believed to change over time, especially as a result of the individual's aging (Damon, 1965; Duncan and Morgan; Manton and Woodbury, 1983; McGee, 1973; Motley, 1978; Nesselroade and Baltes, 1979). The paper by

Meiners (Chapter III) offers an excellent example of the types of temporal changes in individual circumstances involving alternative long-term care arrangements of individuals and insurance coverage which have policy ramifications.

The goals of the survey to a large extent dictate the sampling methodology which will be employed. To study rare events will require a larger starting population, longer and more meticulous followup, and greater efforts to reduce attrition, all of which serve to increase the cost of the study. To study the incidence and risk factors of a chronic condition, one must consider the timeframe of development of the disease in individuals with diverse characteristics. To study retirement decisions and adjustments, information on individuals before and after retirement is required. The experiences of past studies should be used to determine design considerations such as sample size, response rates in any one wave, and rates of loss from wave to wave as well as over the entire study.

Policymakers need analyses of longitudinal tracking on crucial aging issues such as work, income, and retirement conditions; living and social support arrangements; means-tested program participation; health and disease dynamics; and individual environmental factors which are subject to temporal fluctuations. If our goal is simply to look at changes in aggregate levels or average changes in some set of variables for the population and if the changes occurring over time in individual circumstances are not crucial to the hypotheses tested or goals of the study, a longitudinal sample survey is probably a costly, inefficient method to use to collect needed data. However, if we are interested in the individual dynamics of sequential episodes and natural histories of events, then a longitudinal sample survey is the most appropriate vehicle for analytic input to aging policy.

In the current political environment, a new longitudinal study of the elderly which has multiple goals or outcomes probably has a better chance of surviving Federal review processes, since several agencies with their particular interests and objectives for the study probably will be needed to provide funds and justification. Such a study would need to specify clearly why separating differences in individual aging patterns, intercohort differences in risk factors and other characteristics, and period effects is crucial to the goals and policy ramifications of the survey. A longitudinal health survey of the elderly would probably want to combine the goals and funds of the National Institutes of Health, the National Center for Health Services Research, and other Public Health Service units, the Health Care Financing Administration, and Office of Human Development Services (OHDS), all within the Department of Health and Human Services (DHHS), and the Veterans Administration and would be carried out by the National Center for Health Statistics (NCHS) using either the NHIS or NHANES sampling frame. A longitudinal study of income, work, and retirement would probably want to combine the interests and goals of the Social Security Administration (SSA), other DHHS agencies such as HDS, and the Department of Labor, with the Census Bureau conducting the survey using the CPS sampling frame.

Ideally, the multiple goals of a new longitudinal survey would be determined as differential outcomes influenced by individual behavior patterns and risk factors amenable to policy changes. The design would utilize an existing sample such as is found in the SSA Continuous Work History Sample, the Census Public Use Sample or CPS, the NCHS NHIS or NHANES, though NHANES has no subjects over age 75. The sample would be linked to their existing administrative records, e.g., SSA and Medicare, and tied into the National Death Index for followup of lost cases. Subject nonresponse rate and attrition would be minimized through interwave contact via postcard and the administrative record linkage. After a followup call to overcome initial nonresponse on any item, a hot deck estimation procedure would be utilized to derive a value to replace the missing response. Items which consistently showed high nonresponse rates across waves must be considered for deletion from the survey instrument and analysis because of the likelihood of biased responses. Special care must be taken in long-term surveys where the interpretation of questions and responses can change over the course of the study due to technological or societal factors, especially in the health field, with the adoption of new diagnostic methods and changing concepts of disease entities.

There are several studies which provide alternative design strategies for conducting such studies. The Retirement History Survey (RHS) and SIPP provide two examples in the social area. The two surveys differ in several important aspects which will be discussed, as will examples from other studies, throughout the paper. While both were developed from the CPS sampling frame, the goal of RHS involves the answer to questions with a longer timeframe of action, such as determining why individuals retire early, what proportion of their income before retirement is replaced after retirement, and how laws governing retirement and pensions affect people's behavior (Irelan et al., 1976; Irelan and Schwab, 1979 and 1981). Thus, the RHS sample interviews at 2-year intervals, the same as in the Framingham Heart Study (Dawber, 1980), seemed appropriate when the RHS study was being planned in the 1960's.

The RHS involved an initial sample of 11,153 men and unmarried women ages 58–63 in 1969 who were to be interviewed every 2 years until 1979. While it now appears to have been a strategic mistake not to include married women in the initial sample, wives of married respondents were asked a battery of questions in the initial wave. The survey was linked to administrative records on individual earnings to provide a rich source of economic data on this aging sample. Unfortunately, the National Death Index did not exist for followup until the final year (1979) of the study. The matched information has been provided on data tapes through the National Archives to the research community.

An unusual feature of the five followup waves is the replacement of a decedent by the surviving spouse as a full participant in the survey from the wave following the death of the husband until the end of the study. As a result, in any wave following the initial survey, each observation may take on one of six indicators: (1) original sample person responding in this wave; (2) died, surviving spouse responding as replacement of original subject in the survey; (3) died, no surviving spouse; (4) institutionalized; (5) noninterview for reason other than 1–4; and (6) disappeared or lost to followup. These varying categories provide detailed temporal information on aging couples and widows which would not otherwise exist. The RHS samples must be analyzed with care to take account of these dynamic features of the sampling strategy, however.

The goal of SIPP, on the other hand, involves short-term, means-tested program information such as monthly income flow, wealth, and program eligibility and utilization (Kasprzyk and Herriot, 1984). Because of this, a more complicated sampling procedure was initiated to reach this goal. Basically, about 20,000 households drawn from Current Population Survey samples representing the U.S. noninstitutionalized population are interviewed every quarter over the 2-year life of each SIPP panel (Kasprzyk and Herriot, 1984; Nelson, McMillen, and Kasprzyk, 1984). The panel is considered the key feature of SIPP, with a new panel established each January. Each sample panel has been divided into four rotation groups, one to be interviewed in each month of the quarter to enhance the sample size. Since each interview asks for recall information over the past 4 months, there are 7 months of recall data in total with each quarterly wave of the survey. By matching individual wave data, monthly analysis of the full sample provides results needed to achieve the study goals of SIPP (Kasprzyk and Herriot, 1984). SIPP has had roughly an 80 percent attrition rate in the 1984 panel, with losses of about 5 percent in the first two waves and about 2 percent in the following waves. Item nonresponse is estimated using the hot deck procedure.

Unfortunately, the planning of SIPP also involved several administrative moves of the project before the study was housed in the Census Bureau. This may partially account for what I consider a major problem in the study. Two years (eight quarters) per respondent appear to constitute an extremely short period for observing income and program participation, especially since most of the questions asked are not repeated from one wave to the next. Since the elderly comprise a large proportion of the government's means-tested programs and their income and health can change rapidly, a larger sample of elderly households and a longer period of observation, with repeating questions on their health status within a panel across waves, also would appear from the research and policy perspectives to have been advisable in planning SIPP.

Longitudinal surveys conducted in one location have involved goals and planning that have required long-term commitments of Federal resources. For example, the Framingham Heart Study has collected detailed medical examination and other data every 2 years since 1948. The goal of this study has been to determine the natural history and risk factors for heart disease. The study population was composed of a sample of over 5,000 volunteers ages 30–59 years as of January 1, 1950, in Framingham, Massachusetts. To date, about 4 of every 10 in the original population have died. Spinoff studies of children of the original sample members have also been undertaken which examine the relationship between genetic and environmental factors in the development of heart disease (Branch and Jette, 1981; Dawber, 1980; Gordon et al., 1974; Kannel and Gordon, 1980; McGee, 1973).

Among the policy-relevant questions related to aging which can be addressed with the Framingham data base are the development of medical conditions, health care arrangements, changes in economic and social characteristics, and changes in family composition over time. The socioeconomic data are not the strength of the study because this information is not as detailed as in the social surveys. The original Framingham sample, in conjunction with other longitudinal surveys sponsored by the National Institutes of Health (NIH), provided much of the programmatic information used to determine the major risk factors for cardiovascular diseases, including smoking behavior, cholesterol levels, and high blood pressure (Kannel and Gordon, 1980). These analytical outcomes were possible because the longitudinal observation of individual changes in health and concomitant factors was dictated by the original goals of the study.

The Baltimore Longitudinal Study of Aging (BLSA), an intramural project of the National Institute on Aging, presents an interesting contrast to these studies. Begun in 1959, the study has followed 650 healthy male volunteers ages 20–96. The goals of the study were to determine what older adults are like physically and mentally and to determine what can be done to keep them healthy and productive as they age. The sample of volunteers was not intended to be representative of the U.S. population, but rather the upper end of the health spectrum. Each subject visits the Gerontological Research Center in Baltimore to have a medical examination and to be asked survey questions. Those age 70 and over do so annually; those aged 60–69 do so every 18 months; and the remainder do so every 2 years. The study has added 500 women to try to develop information on the aging problems of females. A significant finding from the BLSA is: many physical functions, including cardiac functions and electrolyte balance, remain constant over time in the aging adult, while ability to metabolize glucose declines (Greulich, 1985). The finding could be obtained only through the long-term observation of healthy individuals.

Not every longitudinal survey has been successful, however. The Departments of Housing and Urban Development (HUD) and Health, Education, and Welfare (DHEW) longitudinal study of the housing adjustments of older people never progressed beyond the pilot study. Newman (1981) states the primary issue of this discussion clearly: "The sampling plan, survey design, and analysis strategies for this study of housing adjustments are driven by the principal goal of the research—to examine the relationship between major changes in people's lives as they grow older and the adjustments they make in their housing environments in response to these life events." Yet the proposed study failed, apparently for lack of funding beyond the pilot stage, a serious blow to research on the life cycle demand for housing.

Having seen possible alternatives, assume we decide to initiate a 5-year longitudinal survey of the population age 55 and over in six annual waves, using NHIS as the nationally representative sampling frame, but with a sample of long-term care patients included also. Our objective is to determine the natural history and costs of disability. Our survey instrument combines questions taken from existing studies as well as those suggested by expert consultants from academia and government agencies.

By starting with a sample of both healthy and morbid subjects, we are able to trace movement into and out of the disability state of interest by individuals of different initial socioeconomic and health characteristics, including different types and levels of insurance coverage, which allows us to appreciate the range of individual heterogeneity and the associated dynamics of the processes of becoming sick, then disabled, and recovering or dying. Each new wave in the study would find that individuals would either remain in the same state as in the previous wave, change states, or drop out. Using the National Death Index and administrative records, we could trace decedents and other nonrespondents. Characteristics of the subjects such as ADL level or work history could be used to determine if there were consistent correlates or predictors of the likely move into and out of the disabled state from one wave to the next.

An integral part of the planning must involve the dissemination of information. The information may be either published results or raw data on computer tapes. Data tapes of the national surveys, especially the social surveys, have been made available to the research community through such distribution networks as the Inter-University Consortium at the University of Michigan, the Duke University Aging Center, and the National Archives.

While the nationally representative surveys have generally provided data tapes to the research community through archival distribution networks, the longitudinal health surveys conducted in local areas through NIH funding have not generally provided public data tapes for distribution through an archival system, which would have enabled the wider research community to analyze the study information. Even though these survey data are federally funded and maintained in most cases, the program managers often seem to treat the information as if it were proprietary. This situation needs to be corrected to achieve both systematic exploration of the data on aging and a replication of existing studies to obtain maximum societal benefit from the Federal investment in these studies.

Because the original researchers have invested so much of themselves in the data and know the collection and recoding procedures, they should have an opportunity to review and analyze the data as soon as they are available. However, within a year of the production internally of an initial data tape from each wave, there should be a public use tape and code book provided to a national archival system. In addition, the Federal agencies funding such surveys should set up a small grants program to encourage full exploration of the data in a timely fashion, as the Department of Education (then DHEW) did with the National Longitudinal Survey (Riccobono et al., 1981). In the past, data have been made available on a wave-by-wave basis without linking sampled individuals across waves; such linkage of responses from the same individual across waves is necessary if the research and policy communities are to derive the full benefits of the longitudinal nature of the study.

Publication beginning with the baseline cross-sectional data from these surveys can serve as the beacon for studies of the ongoing temporal changes. For instance, a concerted effort was made to present the initial information from the RHS in a single volume which could be used to plan and execute future studies using additional years of data as they became available (Irelan et al., 1976). These data have provided the basis for numerous studies over the last decade, both within the Social Security Administration and by academic researchers (Anderson and Burkhauser, 1983; Clark and Sumner, 1985; Irelan and Schwab, 1982; Keith, 1985; Motley, 1978). From the success of this program, it is clear that both the presentation of the baseline data and the preparation of public use data tapes need to be included in planning longitudinal surveys.

The SIPP survey, for example, has plans for cross-sectional and longitudinal data files and publications (Nelson, McMillen, and Kasprzyk, 1984). Quarterly and annual cross-sectional reports and data files of each wave will be issued along with special topic reports which explore only cross-sectional relationships. Six types of longitudinal reports are also being planned. A longitudinal microdata file will provide monthly response data over a calendar year for each person in the sample. Such elaborate early planning of the data products is to be commended and will facilitate the planning of research by outside groups which contemplate using SIPP. For instance, the information requested by Congress, under Public Law 98–21 Sec. 201(d), on the adverse impacts of raising the retirement age might be provided using the SIPP longitudinal data.

The goals of each survey tend to define the nature of the sampling methodology, including the sample design, instruments, and periodicity which each uses. These alone cannot guarantee the success of the study, however, as indicated by the fate of the HUD-DHEW study mentioned earlier. There are surveys that sample the same individuals every 2 years for 10 or more years, those that sample quarterly for 2 years, and those that sample annually. Some follow only the original sample, one picks up a new sample every year with a rotational design, and one replaces decedents in the original sample with their surviving spouses. One has failed to survive the pilot stage; another has been transferred among agencies in the last decade and has begun with a sampling design which, on the surface at least, does not appear to provide sufficient temporal data on elderly individuals to provide policymakers with adequate information.

Clearly, the planning process must identify well-defined goals to ensure the support necessary for completion of data collection, preparation, and dissemination. This has been the experience of RHS and other successful surveys. The example of an ideal sample survey was meant to convey broad issues to be considered in planning a new longitudinal study.

IV. Analytical issues

While data collection and dissemination are extremely vital to these studies, data analysis must be an integral part of the study planning as well. The value of longitudinal data on individuals needs full appreciation. There is a tendency for analyses to deal with information from these surveys as either means or aggregates rather than as individual observations and as if the information were static rather than dynamic (Fienberg and Tanur, 1986; Manton and Woodbury, 1985). It is not enough to report what proportion of subjects became disabled or institutionalized, changed jobs, or retired from one period to another.

Such information is often available in repeated cross-sections. This use may negate the value of the longitudinal nature of the study (Damon, 1965; Goldstein, 1979; Manton and Woodbury, 1983). Rather, the analyst must look at the individual diversity and inherent time dimension in the data set and how changes in one characteristic or condition are associated with changes in another. It is unclear whether this type of analysis occurs so infrequently because the methods are too sophisticated for many analysts or because the methods are inadequate to test the hypotheses dealing with individual changes over time for which these studies were designed and funded (Cole and Grizzle, 1966; Cook and Ware, 1983; Darby and Fearn, 1979; Elbers and Ridder, 1982; Hearne, Clark, and Hatch, 1983; Hoem, 1983; Kalbfleisch and Prentice, 1980; Kalton, 1983; Lancaster and Nickell, 1980; Mansour, Nordheim, and Rutledge, 1985; Singer, 1980; Stasny and Fienberg, 1985; Ware, 1985). Nonetheless, more analyses need to look systematically at the temporal changes in individuals in different strata to analyze the concomitants of aging and major risk factors.

Several statistical issues are important to consider in analyzing longitudinal sample surveys. Obviously, this paper cannot explore them in detail. Longitudinal studies can provide needed information about individual patterns of change over time which are critical to aging. Generally, these cannot be determined using only cross-sectional samples because of the confounding of age, period, and cohort effects (Fienberg and Mason, 1985; Ware, 1985). Analyses can take the form of descriptive statistics, explanatory analyses, or predictive equations, for which there are a multitude of statistical techniques. These studies are a form of repeated measures design for which an array of statistical methods have been developed. These methods are designed to take into account the problems associated with individual and item or measurement response errors (Cole and Grizzle, 1966; Ghosh, Grizzle, and Sen, 1973; Goldstein, 1979; Greenlees, Reece, and Zieschang, 1982; Griliches, Hall, and Hausman, 1977; Hearne, Clark, and Hatch, 1983; Hunyh and Feldt, 1980; Jensen, 1982; Koch et al., 1980; Mansour, Nordheim, and Rutledge, 1985). Longitudinal samples may provide better estimates of covariates within subjects than can be derived from cross-sectional studies with the same total number of observations (Cole and Grizzle, 1966). A major concern for both the researcher and the policymaker is the ability of the survey to represent the true population (Fienberg and Tanur, 1986). Stochastic techniques, including Markov models, need to be applied to these data sets to take advantage of the individual heterogeneity of the observations and the dynamic structure of the information (Goldstein, 1979; Stasny and Fienberg, 1985; Hoem, 1983; Kalbfleisch and Prentice, 1980; Singer, 1980). For example, in their analysis of 5 years of long-term care data, Lane et al. (1985) found that the Markov model yielded a superior forecast of long-term care services than either the moving average growth model or regression analyses.

The gain in knowledge of aging processes and related factors to be derived from longitudinal sample surveys compared to other available information sources goes beyond the purely statistical, methodological issues. Though aggregate time-series analysis may provide statistically accurate information on trends in the mean values of certain measures of interest, it masks such crucial information as: Who might have entered or left the sample over time? What are the characteristics of the extremes in the distribution? Are factors of interest normally distributed? Are the relationships between the independent and dependent variables consistent across percentiles in the distribution?

While cross-sectional microanalytic studies can answer some of these questions, they cannot indicate the dynamics of who survives or how the relationships of factors of interest change over time for those survivors and how they are different for decedents. These are key questions which make individual heterogeneity seen in longitudinal surveys and analyzed using appropriate models irreplaceable from both research and policy perspectives. Alexander (1974) succinctly points out the advantages of these studies of individuals over time. Longitudinal studies permit analysis of individuals which can be used to indicate if there are patterns which differ among individuals. These studies also enable one to identify the survivors or the returning examinees and compare them to the nonreturnees to identify differences and potential biases of survivorship, which is not possible in cross-sectional studies and aggregate time series (Gehan and Siddiqui, 1973; Laird and Olivier, 1981; Manton and Woodbury, 1983). Longitudinal studies also make it possible to identify the cohort effects which occur in succeeding generations, such as health. As Damon (1965) noted, "Longitudinal studies in adult life, though expensive, laborious, and long-lasting, are...indispensable. It is no longer a matter of refining or confirming what we think we know about aging from cross-sectional studies. What we think we know may be in serious error."

Modeling appears to be useful in analyzing individual longitudinal survey sample data because it can deal with attrition and nonresponse (Kagan et al., 1974). The analysts of the health surveys appear to have a tradition of using the individual data to derive results based on the dynamic nature of the study (Damon, 1965; McGee, 1973). Social scientists are beginning to take advantage of these temporal data (Anderson and Burkhauser, 1983; Elbers and Ridder, 1982; Manton and Woodbury, 1985; Stasny and Fienberg, 1985). Some examples may help to illuminate several important analytic concepts. For instance, Pugh and Neibauer (1980) tested a microsimulation model using mortality data from RHS to validate parameters of the model that originally had been estimated using cross-sectional data. Lancaster and Nickell (1980) used data on individuals over time to analyze factors associated with the duration of unemployment. Using a likelihood model with a hazard function, they demonstrate a key point: "It seems in practice very difficult to distinguish between the effects of heterogeneity and the effect of pure time variation.... A more promising direction of research is a detailed study of a cohort of individuals with an attempt to determine how their policies and experiences change as their unemployment extends." Elbers and Ridder (1982) take this analysis further by showing that "it is possible to distinguish between time dependence and sample heterogeneity" when the model has observed explanatory variables in the hazard function. Analysts of existing longitudinal surveys, SIPP for instance, might consider models of this genre to take advantage of the individuality of the participants in these surveys.

When analyzed as temporal observations of heterogeneous individuals using appropriate techniques, these surveys are the richest source of information on aging in man (Manton and Woodbury, 1983; Singer, 1980). The results provided to policymakers and researchers cannot be acquired by using either aggregate time-series analysis or cross-sectional methods. While other types of studies may be cheaper initially, the potential gains through savings in lives and program costs from the analytic results derived from longitudinal studies of aging and related factors clearly indicate that these longitudinal sample surveys have been productive and have provided unparalleled knowledge of the behavior and conditions of the aging American population (Dawber, 1980; Irelan and Schwab, 1982; Kagan et al., 1974; Kannel and Gordon, 1980; McGee, 1973; Phillips et al., 1974; Rogot, 1974). Each is a major policy issue with tremendous personal and social costs.

V. Conclusions and lessons for future longitudinal studies

The future of any longitudinal sample survey is precarious in a period of high Federal deficits, domestic program budget cuts, and laissez-faire attitudes. The trials and tribulations of SIPP as it migrated from one organization to another before finding a permanent home at the Census Bureau and the aborted HUD-DHEW longitudinal survey should be sufficient proof of that. Higher level administrators who do not appreciate issues such as sample heterogeneity may argue for the use of aggregate data, even though such data may result in misleading analyses and misdirected policies. The availability of cross-sectional surveys such as the National Health Interview Survey and the Current Population Survey ensure that data will be at hand on many issues that a dynamic survey would address. Therefore, it is essential to utilize existing longitudinal surveys, including RHS, NLS, SIPP, BLSA, and Framingham, as fully as possible to study facets of aging which are relevant to research and policy. It is also important that, when temporal data are necessary in the future, the samples from such studies as NHIS, NHANES, and CPS continue to be given strong consideration as the basis, as is being done in the NHANES I Followup Survey (Cornoni-Huntley et al., 1983).

Since longitudinal studies involve costly surveys which require large initial samples, considerable resources for followup, and an appreciation of analytic techniques, the lessons to be learned from past studies are extremely important. Longitudinal sample surveys have both relative advantages and disadvantages compared to other data sets. In the data collection and dissemination phase, they are similar in many respects to cross-sectional surveys except for the temporal loss of respondents; this loss requires starting with a larger baseline sample, holding the study team together, and taking changing technical and social measurements into account in the questionnaire and in the analysis. This is necessary to ensure that the terminal sample size is adequate for statistical estimation purposes and that the measured items are equivalent.

Longitudinal surveys provide precise details of individual changes in behavior and other characteristics over time, but this greater specificity of information than is possible through a single study with recall questions is exacted at a cost of maintaining the original sample minus dropouts. The population lost to followup also can provide invaluable information on the heterogeneity of the survivors and decedents that is not available in other data. The information provided can be used with a great deal of confidence for research and policy-related issues in aging where individual distinctions, such as risk factors for certain diseases or characteristics which determine program eligibility, are important. Among the important issues for which longitudinal information is now available to researchers and policymakers are streams of income, wealth, and assets; health status, disability, and long-term care arrangements; retirement and employment; living arrangements under changing family and household structure; risk factors for death and illness, especially from chronic diseases; and adjustments to changing personal circumstances and social conditions (Alexander, 1974; Irelan and Schwab, 1982; Kagan et al., 1974; Kannel and Gordon, 1980; Manton and Woodbury, 1983; McGee, 1973; Newhouse, 1974; Phillips et al., 1974; Quinn, 1979; Rogot, 1974; Tissue and McCoy, 1981).

Given the success of previous studies and limited resources, what lessons can be learned from the existing studies with regard to committing more resources to new longitudinal survey samples? Perhaps the most critical element in the planning of a study is identifying the goal of the survey in the context of an important, long-term policy issue which will justify the commitment of funds and personnel over an extended period. In the past, numerous health and social programs have been able to do this. Yet, one recently planned longitudinal sample survey (the HUD–DHEW study of the housing adjustments of the elderly) has failed in the pilot stage because of inadequate support to continue the study. Another (SIPP) has gone through administrative purgatory and appears to have a design that does not utilize information on the behavior of individuals as fully as it might have.

The heterogeneity of individuals should be emphasized as important to policy. The analysis must take advantage of the inherent time dimension and individual diversity of the observations. The survey instrument must be planned with the analysis of the collected data and the goal of the project in mind. For example, SIPP has a very elaborate analysis plan. The baseline analyses of RHS suggest that a wide array of papers was anticipated. Even though there were plans for analyses of RHS, there have been more papers published than would have been planned because the public data files have been analyzed by the wider research community. The external benefits derived from making the data available to the public cannot be estimated beforehand, but should not be minimized. Public use data sets should be a part of the data preparation and analysis plans for every longitudinal survey.

Alternatives to initiating new longitudinal studies, such as using cross-sectional or aggregate time-series data, do not provide information on the same level as longitudinal sample surveys do. As discussed earlier, static analyses of such data can be misleading regarding dynamic events and behavior. For most policy-related issues, agencies need to know the specific characteristics of individuals to determine "who wins" and "who loses" when a policy change is considered.

The possible alternative of using linked administrative and census records has a number of positive features, including a much lower program cost, and could be used effectively if the variables of interest are found within an administrative data set (Rogot et al., 1983). For the elderly population, this could involve Medicare data sets and Social Security files. However, to provide public use data files may be impossible if the data set contains certain legally restricted administrative information (e.g., Internal Revenue Service data) or does not contain information essential to the study (see Scheuren, Chapter II). Thus, it would seem that there may continue to be a need for these surveys as long as the Federal Government has programs which deal in different ways with persons of different characteristics.

The future of longitudinal studies for aging policy is not as bright as it should be for several reasons. These studies are seen as extremely costly, which they are in the short term. However, the potential benefits in terms of the potential program savings often far outweigh these costs. The political time horizon in a period of severe budget constraints would tend to prohibit planning and executing any new longitudinal sample survey. Nonetheless, the results of past surveys have provided invaluable data for health and social policies and programs after years of planning, fieldwork, and analysis.

In summary, there are six lessons we should have learned from past longitudinal sample surveys:

1. Longitudinal surveys should be used to examine dynamic events where changes in individual characteristics and outcomes associated with aging are the issues under study.
2. New longitudinal sample surveys should start with an existing data base such as CPS or NHIS, be linked to administrative records, and use the National Death Index for followup of nonrespondents.
3. Expert consultants from academia and government agencies should be involved early in the planning process to ensure that the survey instrument and methodology are appropriate to achieve the goals of the study.
4. Analyses should use methods, including stochastic models, which deal with the temporal and heterogeneous nature of the observations in such surveys.
5. When used appropriately, longitudinal sample surveys provide information for the research community and policymakers which cannot be acquired by other types of studies. Therefore, these data sets should be considered as valuable research and policy resources and be made available in well-documented public use tapes through a national archival system.
6. Cross-sectional data and aggregate time series are useful for comparative static analyses, especially where mean and total values are the measures of interest; to use longitudinal data for such studies is inefficient and may be inappropriate when the numbers are too small.

In the final section, recommendations for future longitudinal studies are presented.

VI. Recommendations

There are several recommendatons which naturally flow from the discussion in this paper. These include the excellent recommendations on data sharing made by the Committee on National Statistics (Fienberg, Martin, and Straf, 1985). These recommendations are intended to stimulate further discussion of the value of longitudinal sample surveys in relation to other methods used to obtain statistics needed to analyze problems in an aging society.

Recommendations in the area of planning and execution include:

1. Any new longitudinal sample survey should justify its longitudinal nature and hence higher cost by showing how temporal dynamics of heterogeneous individuals are necessary to the research or policy issues which otherwise might be addressed by either aggregate time-series or annual cross-sectional data to attain the goals of the study.
2. Ongoing cross-sectional studies, such as the CPS, NHIS, and NHANES, should be explored as sources for establishing new longitudinal studies of aging and the aged.
3. All federally funded surveys should routinely be linked to appropriate administrative records and the National Death Index. This will require legislative mandate to make such records available for research purposes.
4. SIPP and the NHANES I Followup Study should follow the same individual for longer continuous periods to capture more behavioral and health changes due to aging that are likely to be seen by following each cohort longer.
5. The socioeconomic risk factor data in ongoing longitudinal health surveys should be expanded if it can be done within the goals of the study and without disrupting established relationships between the subjects and the survey staff.
6. Longitudinal studies should be well documented and computer-readable copies and codebooks archived in a nation-

ally recognized distribution network within a year of the first data runs of the study.

7. The academic research community should be involved early as advisors in the planning of any new longitudinal surveys.
8. Administrative records expunged of personal identifiers should be linked to survey data on a continuing basis to strengthen the subjective data and extend the temporal coverage of individuals in the survey, as RHS has done.

Recommendations in the area of analysis include:

1. Analyses of longitudinal data should employ methods appropriate for exploring hypotheses concerning temporal dynamics of heterogeneous populations, such as the application of models involving hazard functions and Markov processes.
2. Statistical techniques involving repeated measures should be utilized and refined for longitudinal surveys involving nonrandom nonresponse.
3. Dissemination of public data sets to the research community should be given a higher priority by the Federal agencies responsible for maintaining longitudinal local studies so that fuller exploration of this information can proceed in a manner similar to that which has occurred with the information from nationally representative surveys.
4. Analyses should compare results of longitudinal sample survey data collected in the different local studies to demonstrate the consistency of the results of these surveys as input to social and health policies.
5. Analyses should compare results of longitudinal sample survey data and similar cross-sectional and aggregate time-series data to demonstrate the value of the longitudinal sample survey data for policy and research.

In summary, longitudinal sample surveys have been extremely valuable in expanding knowledge of social behavior, health changes, and other individual responses to aging. Longitudinal studies should not be considered either obsolete or too expensive to be used now. The recommendations in this paper are broad and should be widely applicable, though they do not attempt to address the specific details of a given study. In today's environment, we must have information to determine the value of policy-related issues such as retirement age changes, pension and insurance proposals, disease prevention activities, and health service utilization; we must have longitudinal sample surveys.

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State data issues for an aging population[a,b]

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The collection and analysis of data for an aging population depend heavily on activities of agencies at the State and Federal level. States are both producers of data and users of data. States have considerable discretion in setting policies for collecting, analyzing, and disseminating administrative data. At the same time, States are heavily involved in cooperative relationships with Federal agencies in producing and using data. Federal statutes, regulations, contracts, informal agreements, and financial support define, to some extent, State data efforts. Federal relationships vary by agency, but generally provide guidelines, technical assistance, and, in some instances, financial support. This paper reviews the availability and collection of current State data and examines the quality, timeliness, and special data problems. Needs for additional data and necessary changes in the process of data collection and analysis at the Federal and/or State levels are identified. States are also consumers of State data, but primarily utilize the Federal reports of State and substate data. Where State officials have identified data needs and Federal activities that would be of value, these are noted within each section of the paper.

This paper examines State data needs and activities in five areas: population, vital statistics, social services, aging, and Medicaid health services. These areas were selected because they are the primary State program activities related to the aged. Population data centers and vital statistics programs produce data about the aged in the population from administrative records and other sources. Social services, aging, and Medicaid are the three largest State programs which provide services to the aged, as well as other groups, and consequently have administrative data relative to their programs. States also have data on health and social service providers and facilities, but these were not included in this paper because of limitations of time and scope.

Methodology

This paper is based on materials from a number of sources. First, the paper is based, in part, on findings from an eight-State study of State Medicaid, Social Service, and Supplemental Security Income programs that was completed by the Institute for Health and Aging (formerly the Aging Health Policy Center) in 1983 for the Health Care Financing Administration. This study collected data from interviews with State officials in eight States: California, Florida, Massachusetts, Missouri, Pennsylvania, Texas, Washington, and Wisconsin. These States have about one-third of the Nation's elderly and are believed to represent a cross section of States in terms of geographic, administrative, political, and historical characteristics. Second, telephone interviews were recently conducted with State officials in five of these same States (California, Florida, Missouri, Texas, and Wisconsin) to identify current State activities and problem areas. Finally, members of other State, Federal, and private agencies were interviewed, and documents and reports on data problems were collected. The analysis of the issues and recommendations are the responsibility of the author and are drawn from a synthesis of these materials.

Need for State data relative to the aged

The needs for State data are extensive. States are the primary users and producers of their own State and substate data. Such data are needed by State governments to make estimates of revenues and expenditures in preparing budget allocations. Most State agencies (e.g., those responsible for Medicaid, social services, Supplemental Security Income, aging, mental health, health planning, income maintenance, housing, employment, and transportation programs) use State population data in preparing budget estimates and program planning. Health and social service programs must take into account previous patterns of utilization and expenditures and those changing sociodemographic and economic factors that affect annual or monthly rates of eligibility, utilization, and expenditure. Since the number of individuals who are 65 years and over (and especially the number 85 and over) is a major predictor of utilization and expenditure, there is a vital need for detailed State and substate data by age and disability status.

County and city governments need the same type of data for their own planning and budgeting purposes. Not only do State and substate agencies need data for planning and budgeting, but also State data are needed for monitoring State trends and program efforts. Vital statistics and program service data are used to measure program outcomes.

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[a] Contents are the opinions of the author and not those of the Department of Health and Human Services or of the organization she works for.

[b]

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Many other users of State data, especially population estimates and projections, are found in the public sector and private sectors. These public agency users include: the regional, State, and local planning commissions; health planning agencies; commissions on aging; area agencies on aging; county health and social service agencies; transportation agencies; and many others. State data are used by the private sector in planning and development of health care facilities, housing programs, and other programs that serve special population groups such as the aged. These agencies are vitally interested in age-specific data, particularly for the older age groups.

State government generally is interested in data about its own State. To the extent that Federal agencies such as the Bureau of the Census produce data about a State or its substate divisions, States make use of such data. Unfortunately, many of the national studies of the aging population do not provide data on individual States. Generally, the sample sizes for the national surveys are not large enough to allow for estimates on a State-by-State basis. This includes the National Nursing Home Surveys, the National Health Interview Survey, and others. States may use national statistics collected from such surveys to compare with their own State data. Unfortunately, most States do not have comparable data on their own State to compare with national survey data, and for States to collect such data through State surveys would be prohibitively expensive. Federal data that are not disaggregated by State are of only limited use to States.

States are also users of across-State data on an aging population and programs that provide services to the aged. The national sources that compile State data on population, vital statistics, and programs for the aged are used by States to compare their own State ranking with others. Generally States compare their own State with other States of similar size or within the same geographic region because of the wide variations across States.

Since States are given discretion in establishing their social services, aging, and Medicaid programs, there are 50 different State programs that represent natural experiments that can be examined. Each State has its own program data, and the various State statistics represent the only primary data source which must be utilized to build a data base for the 50 States. National surveys of the population are not a substitute for data on the State programs and their target populations produced by the State programs. Because of the many needs for State data, there is a strong rationale for maintaining and strengthening the existing State data efforts.

Population data by age

Federal and State population data activities

The States and Federal Government are actively involved in population data activities. The Bureau of the Census (BOC) has been actively collecting population statistics for the country since 1790. The BOC reports population data by age, sex, race, living arrangement, education, geographic mobility, fertility, voting patterns, and other characteristics. The BOC reports data from the decennial census by age categories up to age 85 for the total population in the United States and for States, counties, and cities. During the periods between the decennial censuses, the BOC prepares annual State population estimates and periodic projections which provide detail on age and other characteristics. The BOC estimates State and substate data by age category up to age 65; however, further age detail is not given for the category 65 and over.

In 1969, a Federal-State Cooperative Program (FSCP) for Population Estimates was established and has continued to operate since then. Each State designated a single State agency (State data center) to carry out the responsibility for making statewide population estimates. The establishment of the FSCP had the effect on local agencies of eliminating some of their efforts and/or shifting their emphasis to subcounty areas such as census tracts (U.S. Bureau of the Census, 1978).

The FSCP was designed so that State agencies would work jointly with the BOC in preparing population estimates for small areas such as counties and metropolitan areas on an ongoing basis. These estimates are computed using uniform BOC procedures for data collection and standardized methods for estimation. The figures are accepted by the Federal Government as the State's official population estimates. State data centers are also involved with data collection activities for the BOC decennial census. The role of the BOC under the FSCP is to provide technical assistance, computer assistance, and training to State agencies as appropriate.

Many State agencies make special estimates and projections for State and substate areas in addition to the estimates prepared with the BOC. State agencies may also develop estimates for subcounties (e.g., cities, incorporated and unincorporated areas, and census tracts). In 1975, a survey by BOC found that almost 70 percent of the State agencies that were involved in population estimates or projections made estimates for counties, and 75 percent made estimates for cities. In addition to State programs, other agencies are involved in making population estimates and projections. Over 140 agencies nationwide were estimating the population down to the census tract and 156 agencies were making estimates for other small geographic subdivisions, such as traffic zones or planning areas, which are often composed of census tracts (U.S. Bureau of the Census, 1978).

Methods for population estimation

The BOC and the designated State agencies participating in the FSCP have developed a number of methods for making estimates of the State and substate population. Most States have adopted standardized methods recommended by the BOC (U.S. Bureau of the Census, 1985a).

Most States use a combination of the Ratio-Correlation Method, used in 46 States, and the Administrative Records Method, used in 48 States (U.S. Bureau of the Census, 1985a). The Ratio-Correlation Method uses multiple regression equations for variables that are transformed by calculating ratios of percentage shares in a later year to an earlier year (U.S. Bureau of the Census, 1985b). The Administrative Records Method looks at Federal tax data to measure the net intercounty migration of the population under 65 years of age, birth and death statistics, and Medicare enrollees (U.S. Bureau of the

Census, 1985b). Other States (14 in number) use a Component Method whereby the figures are averaged with the estimates made by one or both of the two other methods, depending upon their accuracy relative to the most recent census (U.S. Bureau of the Census, 1985a). The Component Method II examines net migration through school enrollment or differences between the actual school-age population and the population predicted on the basis of births. Another technique which is used for making population estimates is the Housing Unit Method, which makes estimates of residential housing based on building and demolition permits; certificates of occupancy; electric, gas, or water meter connections; or field surveys (U.S. Bureau of the Census, 1978).

The methods States use to make estimates and projections for State, county, and subcounty areas vary considerably. They include the different standard approaches described previously with additional modifications. For example, in three States, a unique method is used to calculate a figure which is then averaged with that derived using one of the methods described earlier. California uses a Component Method based on changes in the addresses listed on driver's licenses. Changes in the number of housing units are included in Florida. Individual income tax returns are used to estimate the population 18 and over in Maryland (U.S. Bureau of the Census, 1978). While significant improvements have been made in standardization, State agencies have a great deal of discretion in the decentralized system for population estimates.

Components of population estimates

The components of State and substate population estimates also vary across State jurisdictions. Each State makes policy decisions about what to include based, in part, upon the needs of users, the financial costs, and other factors.

Age detail—Age is a critical factor in population estimates. As noted earlier, BOC does not make population estimates with age detail within the category 65 and over for counties or cities except at the time of the decennial census. Some States develop their own data, which include each year of age up to the age of 85, while other States develop an age detail using 5-year or 10-year increments. Other States compute the total population for State and substate areas but do not make detailed estimates by age.

In some States, the data are disaggregated (i.e., broken down) into a number of components which include age, sex, and race. Income, education, place of residence, household size, marital status, living arrangement or household status, occupation, and other factors may also be specified. These characteristics may also be cross-tabulated by age, sex, and race. Unfortunately, such data are not generally prepared in the population estimates.

Changes in the patterns of mortality and morbidity in the aged population make the category of 65 years and over less meaningful than one that is more precise, such as reporting for each year of age or in 5-year categories. Age-detailed data at the State and substate levels are critical for planning, budgeting, and making policy decisions. In order to improve the availability of data, age detail for State and substate population estimates and projections should certainly be developed voluntarily. Strong consideration should be given to mandating that such data be compiled by both State and Federal agencies on a yearly basis. Such action would require a statutory change at the Federal level and financial support for these activities.

Disability data—A major gap in the population data is the lack of statistics on disability rates for State and substate areas. Although the decennial census collects data on the number of individuals who are institutionalized, data on disability levels for the institutionalized and noninstitutionalized elderly are not collected. The National Center for Health Statistics has conducted the National Health Interview Survey since 1957. This survey collects data on disability by gathering information about the number of restricted-activity days for individuals during the year and the number of days individuals are confined to bed. These indicators can be used as a proxy measure for the rate of disability in the general population. These data were collected in 1969–70, 1973–74, 1980–81, and most recently in 1984 (National Center for Health Statistics, 1984b). Unfortunately, the sample size of the survey is too small to make estimates or projections of disability in State or substate areas. The most recent State data on disability rates were available from the National Health Interview Survey conducted by the National Center for Health Statistics (1978), where the sample size was large enough to make State estimates.

Data on disability are needed on a State-by-State basis and for localities for the planning of health, social services, and aging programs. Age alone is not an adequate predictor of the need for health and social services because there is no abrupt change in functional status at any given age. A better approach would be to collect data on age, sex, and disability in the general population. Disability can be measured through self reports. The incidence of disability changes over time and varies across States and geographic regions (National Center for Health Statistics, 1978). Such data are essential in making projections of future needs for and costs of health and social service programs to the public and private sectors. Such data are also basic in planning income maintenance programs. Data on disability are needed nationally as well as for State and substate areas (General Accounting Office, 1979). Careful consideration should be given to how such disability data can be collected along with information about age, sex, race, income, and other characteristics. Questions about the level of disability should be included in the decennial census so that such information is collected on a regular basis.

Other data—Better State data on several demographic categories, particularly from the 1990 census, would be valuable for policy analysis and research on the aged by States and other agencies. The National State Data Center Steering Committee (NSDCSC) recommends that a question with combined race/Spanish origin be included in the decennial census and that greater detail be provided for ethnic groups within race groups (National State Data Center Steering Committee, 1984). More specific information on household relationships, especially for nonrelatives who may or may not be related to household members other than the householder, is important in predicting caregiving needs, utilization, and expenditures for the aged. Information about the number and patterns of marriages and divorces of the aged and their potential caregiver children would also be useful. The NSDCSC also recommended including an indicator for full- or part-time employment, and adding greater detail on migration by asking about the number of moves during a 5- and 10-year interval. Greater detail should be provided on income, especially nonmoney income (National State Data Center Steering Committee, 1984). Data on total health and social service utilization and expenditures would be valuable. These data would be extremely useful to States if available from the decennial census on a State-by-State basis. States could then make detailed age estimates and projections for the population by these critical factors.

Accuracy of methods

The accuracy of State and substate estimates is an important concern. In 1975, the BOC was concerned about the high number of agencies below the State level that were not using ratio-correlation techniques in making their estimates and the number using extrapolative methods that had been discredited (U.S. Bureau of the Census, 1978). The BOC evaluated the different estimation methods used by States during the 1970's and found that the accuracy of the methods was similar, but that error rates were high when compared to the 1980 census. For 1980, the methods for State estimates were refined considerably, and the new procedures improved prediction nationally. The Component Method II was found to be the least accurate, while the new Composite Method had the lowest percent error of all the methods (U.S. Bureau of the Census, 1984).

While the accuracy of estimates appears to be improving, the State and substate variations continue. A basic policy question concerns why these parameters are not standardized to a greater degree across States. One argument is that since resources and technical capability for making estimates vary across States, some variation in method should be allowed to take into account these factors and other unique characteristics of State data availability. On the other hand, an argument can be made that the comparability and reliability of data should be enhanced across the States by mandating that each State use an identical method which is selected on the basis of accuracy and financial feasibility. Although State prerogatives have already been established, the BOC should enforce greater standardization in methods and components at the State level or the Congress should mandate more uniform procedures.

Timeliness of data

Another major concern is the timeliness of data from the BOC. The BOC has developed a system for provisional county estimates which achieves a substantial improvement in the timing of the estimates by using a variation of the Administrative Records Method. The subcounty reports on population were prepared on an annual basis in the 1970's; however, these are now prepared every 2 years (Melnick, 1982). While officials in State government report that the delivery of data from the 1980 census was an improvement over the 1970 census, the need for substantial improvements still remains. Numerous revisions were made in the schedules to distribute data from the 1980 census. As a result, some confusion was created and public distrust was reportedly aroused (National State Data Center Steering Committee, 1984).

Because of the great need for more frequent data, Congress authorized the Census Bureau to conduct a mid-decade census beginning in 1985 (Storey, 1985). While plans were made to do this in 1985, financial resources to complete such a survey were not made available by either the Carter or Reagan administration (Storey, 1985). The methods and technologies are available for more frequent survey activities. Clearly, the time required to prepare data on State and substate areas could be shortened by giving greater financial resources to the BOC, and resources for a mid-decade census are needed. A mid-decade census would be one of the most valuable Federal efforts for States because it would reduce the workload of State data centers and would improve the quality and accuracy of State estimates and projections. This would benefit all State users of data, who depend heavily upon population estimations for planning and budget development.

Financial resources

The lack of adequate financial resources limits the activities of Federal and State agencies making population estimates. The amount of data available, their timeliness, how often they are collected, and the inclusion of details on age, disability, and other elements all are dependent upon financial resources and personnel.

The demand is increasing for State and substate population data of improved volume, type, and level of sophistication (National Governors' Association, 1985; U.S. Bureau of the Census, 1985c). At the same time, the capacity of the Federal and State agencies to produce such data and respond to requests is hampered by real financial constraints. The financial resources for data on population are a political problem at both the Federal and State levels, since data activities are invariably viewed as less important than providing direct services to the population. In periods of time when human service programs are threatened or actually reduced, political and public attention first is directed to protecting service programs, and less attention is given to data issues. Nonetheless, population data are fundamental to the effective planning and management of direct service programs.

The Bureau's current, periodic, and reimbursable budget for 1983 was estimated at $236.3 million, compared to $257.8 million in 1982 and $334.2 million in 1981. This was a decline of 29 percent from 1981 to 1983 (Melnick, 1982). The BOC also laid off an estimated 300 employees in 1981–82 due to budget cuts. Delays in the data analysis and publication of reports from the 1980 census created many delays for data users. These delays caused a ripple effect on the rest of the statistical system (Melnick, 1982).

Some BOC reports from the 1980 census (e.g., the 1980 census report on the older population with detailed local area data on the aged) have been canceled (Storey, 1985). The mid-decade census planned for 1985 was canceled because of the budget cuts. This census was strongly supported by State officials, who need more up-to-date data because of the dramatic increase in the pace of social and economic changes occurring in specific localities. This population survey, which would have included data on age, sex, and other demographic characteristics, would have improved the accuracy of data for State and local planning efforts (Storey, 1985). Thus, these cutbacks have created further problems for State agencies who are already having difficulty in obtaining data for making population estimates.

State agencies have also experienced problems in having adequate resources to carry out their responsibilities in the Federal-State cooperative program. Some States have reduced their data programs. Many have reduced their outreach activities, training, and dissemination of reports. The National Governors' Association staff and officials from selected States have reported problems resulting from the cutbacks. Some States have attempted to respond to the cutbacks by becoming more entrepreneurial, through selling their information to private clients.

A National State Data Center Steering Committee consisting of nine members from State agencies was established in 1983. This Committee is designed to foster communications between individual State data centers and the BOC. The Committee meets periodically to address common problems for the States such as funding levels and standardization. It publishes a newsletter and sponsors data conferences (U.S. Bureau of the Census, 1985c). These activities represent a positive direction for improving communications and formulating policy issues.

Developing adequate financial resources for collecting and analyzing population data is a major impediment in improving the quality, quantity, timeliness, and usability of data, especially data on the aged population at the State and substate levels. Some type of political action will be needed if substantial improvements are to be made, and the political decisions will, by necessity, require an analysis of cost effectiveness to justify this need.

Vital statistics

Vital statistics are data on births, deaths, marriages, divorces, abortions, and other demographic parameters. These data are important to the national data base, and collecting such data is an important activity at the State level.

Statistical activities of State health departments first started with their responsibility for vital statistics. In 1969, the National Center for Health Statistics (NCHS) developed a Cooperative Health Statistics System (CHSS) with the States (National Center for Health Statistics, 1980). The idea of the CHSS was to develop uniform definitions and standards, to collect data at the State level, and to lower costs by using a decentralized system for data collection. NCHS negotiated contracts with State agencies to collect data on vital statistics, health facilities, health manpower and ambulatory care, and health interview data (National Center for Health Statistics, 1980).

In 1978, almost all of the States had a State center which collected data on some or all of the following three programs: vital statistics, health manpower, and health facilities. A study of State statistical programs in 1978 showed that the 50 State health agencies spent $47 million (National Center for Health Statistics, 1980). Eighty-seven percent of the funding was from State sources, 10 percent from contracts with NCHS for the CHSS activities, and 2 percent from Public Health Service funds.

Guidelines defining the characteristics and functions of the State agencies were developed by NCHS in 1980 (*Federal Register*, 1980). Under the cooperative program, States designated a State agency to be responsible for State health statistics and these agencies are called State Centers for Health Statistics. During the same year, the Federal funds were eliminated for the State Centers for Health Statistics. In spite of this development, some States continued to collect data on health manpower and facilities (National Center for Health Statistics, 1982a). Delaware just designated a center in 1985 (National Center for Health Statistics, 1985a).

States have continued their vital statistics activities and the National Center for Health Statistics has continued funding for this activity. At the same time, NCHS continues to provide technical assistance to the States to support their program activities in vital statistics. The States are also asked to send representatives to periodic meetings to evaluate the standards for vital statistics.

A study by the Department of Health and Human Services (National Center for Health Statistics, 1980) found that 43 States furnished data on births and deaths, and a smaller number of States produced other types of vital statistics, including marriages and divorces, in 1980. Other States provided copies of vital records in photographic form, which were then used to prepare NCHS computer tapes. No recent study, however, has been conducted on the extent of State activities on vital statistics.

The study by the Department of Health and Human Services recommended that future work in vital statistics concentrate on improving data quality on births and deaths (especially fetal death records) and more timely reporting (National Center for Health Statistics, 1980). Because the current system is voluntary and decentralized, problems of data quality and reporting have persisted. NCHS must wait until the States submit their statistical data before publishing the State mortality and birth rates. For example, the final mortality statistics for 1982 were not published by NCHS until 1984 (National Center for Health Statistics, 1984c). In 1984, the lag time for most State vital statistics data was expected to be 2 years (Woolsey, 1985). Methods to speed reporting by States are needed to make the data more useful.

Because of the need for more timely data, NCHS conducts a 10-percent sample study each month from the death statistics. This provides monthly estimates of State death rates, and corrections to the estimates are made on an annual basis (National Center for Health Statistics, 1985a). While this sample is used to make U.S. estimates of deaths by age, sex, and race, these estimates are not made for each State. If the sample size were larger than 10 percent, it would be possible to make State estimates for sociodemographic characteristics. This is especially needed to make State estimates of death rates by age.

NCHS recently has begun to analyze multiple causes of death from the death certificates. This is especially important for the study of chronic illness patterns in the older age groups, who tend to have multiple illnesses. The National Center for Health Statistics (1984a) reported that in 1978 nearly 75 percent of the death certificates had more than one condition listed and 15 percent had more than four conditions listed. Based upon these data, a valuable report was developed for the United States describing multiple causes of death by age, sex, and race (National Center for Health Statistics, 1984a). Such reports should also be prepared and analyzed by States identifying multiple causes by age, sex, and race, since the data are available on existing birth certifications and are important for both scientific analyses and policy decisions.

While there is general support for continuing the present Federal and State cooperative arrangement for vital statistics, the major issue is the extent of Federal financial support for the collection of State vital statistics. The activities in the area of vital statistics, as in other areas of data collection, are heavily dependent upon financial resources at both the Federal and State levels. A 1981 study of State vital statistics activities found that the cost of operating the vital statistics programs was approximately $53 million (National Center for Health Statistics, 1982b). Of this total, approximately $4.5 million, or 8 percent, was paid by NCHS. The $4.5 million paid by NCHS covers approximately 29 percent of the costs that were determined to be within the scope of the Federal-State vital statistics program (National Center for Health Statistics, 1982b).

States have argued that they should receive 50-percent Federal funding for vital statistics activities. The 1980 study of the Department of Health and Human Services mentioned earlier recommended that the Federal share be at least one-third of the in-scope costs. In spite of this recommendation, the Federal share of funding was estimated to be 26 percent for fiscal year 1986, the same level as in the previous year (Woolsey, 1985). While it is consistent with cost-containment efforts to attempt to control the budget, it is also necessary to maintain a minimal level of funding for these program activities. The Federal Government should pay its fair share of the costs, at least one-third of the Federal-State vital statistics program, and the budget should keep pace with inflation if the program is to remain viable, and certainly if the program is going to be improved.

Social services

Social services have been provided by government for many years in the United States. The Federal Government assumed a greater role in the early 1960's and then, in 1975, the Title XX Social Service program was established (Gilbert, 1977; Lindeman and Pardini, 1983). This program was organized as a Federal and State partnership until major changes were made in the program in 1981. The 1975 legislation required States to provide at least one service for each of five program goals: economic self-support; personal self-sufficiency; protection from abuse, neglect, and exploitation; prevention of inappropriate institutionalization; and arrangement for appropriate institutional care (Lindeman and Pardini, 1983). States were given wide discretion in the number and scope of services provided, but the services were targeted to those with low incomes. States were required to conduct specific planning and reporting activities, including development of a Comprehensive Annual Service Program Plan (CASP) and preparation of quarterly and annual reports for the Social Services Reporting Requirements (SSRR).

With passage of the Omnibus Budget Reconciliation Act (OBRA) of 1981 (Public Law 97–35), the program changed to the Social Service Block Grant (SSBG) and no State matching funds were required. Federal funds were reduced from $2.9 million in 1981 to $2.4 million in 1982. In 1983, the Federal allocation based on State population was limited to $2.5 billion, and it was raised to $2.7 billion for 1984 (*Federal Register*, 1983). Thus, Federal funding did not keep pace with inflationary increases during the period 1981–84. As the level of funding was reduced, Congress also removed various requirements, including those for the CASP and the SSRR. States were also allowed to select the types of social services provided, and the requirements for information and referral or protective services were removed. Only minimal requirements for overall planning and community involvement in the planning process were maintained by the legislation (Lindeman and Pardini, 1983).

Lindeman and Pardini (1983) and others at the Aging Health Policy Center conducted a survey of the social service programs in eight States (noted earlier) to examine the impact of these changes in 1982 and 1983 after passage of OBRA in 1981. Only two of the eight States maintained their social service programs at 1981 funding levels during 1982 and 1983; the remaining six states reduced the budget for their programs. One State reduced the number of eligibles, two reduced the number of services, three reduced the units of services, and two increased the client fees.

The Title XX program was criticized prior to the OBRA 1981 changes because data about its programs and clients were so poor and incomplete. In many States, the program planning and reporting of expenditures and recipients were simply viewed as a bureaucratic exercise. The program did not require States to submit detailed data on the number of recipients or provide breakdowns by age, sex, race, or income. Utilization data by service were also not requested or required. The Federal reporting requirements were not specific enough to bring uniformity to the program. Uniform definitions of program services were never established at the Federal level and States developed their own unique approaches to the definitions and provision of services. No penalties were imposed on States for failure to comply with reporting requirements.

After the adoption of the SSBG, the data reporting became more problematic, although, to some extent, State planning activities may have improved as States struggled to make budgetary decisions that would target the use of their limited resources (when the Federal program budget was reduced by about 20 percent) (Lindeman and Pardini, 1983). Some of the States in an eight-State study sample were in the process of upgrading their fiscal and program data systems. Others, however, placed no emphasis on attempting to correct a problem situation (Lindeman and Pardini, 1983).

Some States such as Texas have developed sophisticated client and provider information systems for social services that include all recipients. The Texas system provides detailed data on the number of services and costs for each individual client. It also provides data by age and other demographic characteristics by county. This system has been accomplished because all private provider agencies under contract are required to report this information in order to receive payment for services. Other systems, such as California's social service program, use the county as the primary service delivery and data reporting agency (Harrington et al., 1983). It is more difficult to manage such a decentralized system and to assure uniform and accurate data.

Even though some individual States have developed reasonably good reporting and evaluation systems for their State social service program, reporting to the Federal Government continues to be poor. States are no longer reporting SSRR data, but are now required to prepare pre- and postexpenditure plans for the Federal Government in a format of the State's own choosing. These expenditure plans must provide two components: (1) a description of services and attributes, and (2) a description of the characteristics of persons served (Office of Human Development Services, 1983). In 1985, the Office of Policy Coordination and Review in the Office of Human Development Services, Department of Health and Human Services, reported that a few States were reporting detailed data, but many States were just sending in brief lists of the types of services offered (Office of Human Development Services, 1985).

The Office of Human Development Services (1983, 1984) prepared an analysis of the preexpenditure reports submitted by States. The preexpenditure data vary considerably by State in terms of the types of information contained, the level of specificity, and the range and definitions of services offered. Cost-of-service data were available for 42 States. Although some general data were provided by the States, these data were much too general to provide a basis for any reliable or accurate conclusions.

In 1982, the American Public Welfare Association (APWA) developed a proposal for the Office of Human Development Services to establish a voluntary program for reporting aggregate State data on social service expenditure programs for three groups: developmentally disabled and mentally retarded, child welfare, and social service block grants. The APWA was funded for an exploratory design and study of the feasibility of developing such a national data-base system. Aging was not included because the Administration on Aging had a contract with the National Association of State Units on Aging to collect data on aging programs.

State data from the Voluntary Cooperative Information System (VCIS) was analyzed by the American Public Welfare Association (1984). APWA found that only 43 States provided data on services and recipients for 1981–82. Data from only 31 States were usable; the remainder was not included because the data were for points in time rather than cumulative and data from some small States were reported to represent less than 90 percent of the total SSBG-funded program. VCIS data were derived from a combination of actual and estimated figures. Few States reported unduplicated counts of recipients. While the VCIS did provide a useful summary of reported data, the problems noted before are serious.

In summary, the need for a standardized minimum aggregate data set to be collected and reported by the States is evident. The most critical aspect of this would be to develop a standard set of service definitions that could be used across States and across programs (e.g., social services, aging, and Medicaid).

Although States are willing to provide some information to the Office of Human Development Services and APWA, the problems in quality and accuracy are so overwhelming that the data become meaningless. On the other hand, a mandate for improved State reporting systems would require a statutory change in the SSBG legislation. It probably would also necessitate providing Federal funds for States to make improvements in their data information systems. As long as Congress and the Administration continue to constrain the SSBG program budget (which has been declining in terms of real dollars), resources will not be available to develop adequate reporting systems for the program. Because data are not available on what the program provides, who the beneficiaries are, and what the impacts and outcomes of the SSBG program are, funds for social services are extremely vulnerable to future Federal and State cuts. The issue is whether or not the need for data about the program outweighs the cost of designing and implementing a reporting system to the Federal and State Governments.

State aging services

The Older Americans' Act (Public Law 89–73) was established in 1965 to provide Federal funds for social and recreational programs for the elderly. In 1972, the Federal program added funds for social and nutritional services. The Social Security Act amendments of 1967 expanded the definition of eligibility and prohibited tying eligibility to income (Lindeman and Pardini, 1983). Since these programs were intended for all of the aged, State and area agencies which administer these programs have minimal and sometimes nonexistent reporting on recipients, utilization, or expenditures. No Federal data reporting system was required and a voluntary system was not established initially.

A survey of States in 1982 and 1983 found the State programs and their data systems to be in disarray (Lindeman and Pardini, 1983). No Federal data system for State and area agencies on aging was required nor were such data available. The only data available were in the States, and the State data were primarily for expenditures by fiscal year. Some States such as Missouri eliminated their data reporting system on the aging program because of financial reasons.

The problems of data are similar to those in the social service system, where no uniform definitions of services and providers have been developed and used by States. Thus, even available data collected by State surveys were not useful because of problems in different State service definitions and incomplete information (Lindeman and Pardini, 1983).

In 1981, the National Association of State Units on Aging (NASUA) established a voluntary data reporting system. The NASUA system collected data from State units on aging (SUA's) and from 660 area agencies on aging (AAA's). The data collected include service and client information from service providers (usually contractors). Data are being compiled for fiscal years 1980–84. The data include the services and the dollar amounts spent by type of service from Federal, State, and private sources. In 1981, NASUA had a 94-percent response rate from the SUA's and an 84-percent response rate from the AAA's. Since 1982, the survey has used a rotating stratified random sample which includes one-third of the AAA's per year but all of the SUA's are surveyed annually (National Association of State Units on Aging, 1985). In addition to data on administration, staffing, policies, and revenues, data are also collected on the types of services provided, the units of service, the percentage of funds spent on the service, and the recipients' characteristics in terms of sex, race, and the proportions who are age 75 and over, low income, and living alone. No data on actual expenditures by type of service or by client characteristics are available (National Association of State Units on Aging, 1985).

The NASUA survey conducted in 1983 (National Association of State Units on Aging, 1983) categorized services into 30 different groups. In regard to client characteristics reported by the type of service, 69 percent of the agencies surveyed reported some statistics for the number of recipients age 75 and over. Seventy-seven percent of the agencies reported on the proportion of low-income clients. In general, only about 60 percent of the agencies had client-based data (National Association of State Units on Aging, 1985). As noted earlier, the NASUA data base reports on only one-third of the AAA agencies each year.

The data compiled by NASUA are valuable for examining issues related to program policy and budgets for State and area aging agencies. This data information system should be maintained because it is the only source for data of its type. This data base, however, is extremely limited in providing a description of aggregate client characteristics across States, and does not allow for a comparison of client characteristics to program utilization and expenditures.

A basic aggregate data base for an aging program should, at a minimum, recognize the importance of collecting data for the different ages within the overall category of aging. The data on the program should also include demographic data by age, sex, race, income, education, marital status, and other factors. Service definitions should be developed for every different type of service that may be used and these services should be grouped into categories where aggregation is desired. The service definitions should not be limited to only 30 categories unique to the aging program. Uniform definitions of service providers should also be developed that would be used across programs (i.e., social services, Medicaid, and others) and data should be reported by service and by providers of services. The data should include services provided, providers, utilization, and expenditures, as well as quality outcome measures for the program.

The findings from the voluntary NASUA survey show how inadequate the current data collection activities of State and area agencies are. As long as the Federal Government does not require mandatory client reports on utilization by type of service, the data reporting activities will, no doubt, remain problematic. Historically, the States have had weak data reporting systems for the aging programs. These activities have deteriorated even further with the reductions in reporting requirements. Only additional Federal funds and mandatory requirements are likely to change the current patterns.

Medicaid data

The Medicaid program was enacted in 1965 to provide health care services to the poor. The program provides Federal matching funds for State programs. The Medicaid program requires the States to provide certain mandatory services and allows for some optional services. Services are provided to those who are eligible for Aid to Families with Dependent Children and those aged, blind, and disabled who are eligible for the Supplemental Security Income program. The legislation gives the States a great deal of discretion in managing the programs as long as the minimum benefits and eligibility requirements are met.

In 1972, Congress authorized funding to provide incentives to States to design, develop, and install Medicaid Management Information Systems (MMIS's) and provided 90-percent Federal funding for this activity. Congress also provided 75-percent Federal funding to operate the systems after they were established (General Accounting Office, 1982). The MMIS programs provide data for claims processing to providers and detailed data on recipients, services, utilization, and expenditures based on billing data. The general system design established for the MMIS programs allowed considerable variation in its characteristics across States, and that approach is still used to maintain a decentralized system (Sawyer et al., 1983).

In 1978, a General Accounting Office report about MMIS's found that the Department of Health and Human Services was approving State systems that were not meeting the program's need for data (General Accounting Office, 1982). Congress passed the Schweiker amendment in 1980, which required most States to install a computerized MMIS program. In 1981, 35 States operated approved systems at a cost of $214 million and 21 States (12 of which already had approved systems) spent $48 million on system design, development, and implementation (General Accounting Office, 1982). Since 1980, the Health Care Financing Administration (HCFA), which is responsible for the Medicaid program, has developed performance standards for the MMIS program and has carefully monitored State progress.

The Federal Medicaid reporting requirements are complex and include several different types of data. States must submit

Form 2082 annually and Form 120 monthly to report the number of recipients by specific eligibility category (including the aged, blind, and disabled) and by service category.

States still employ nonstandardized coding, processing, and file structures (Sawyer et al., 1983). These problems are compounded in States that have decentralized Medicaid programs, such as New York, which has allowed county-based MMIS systems with cross-county variations (Sawyer et al., 1983). Some States have problems in the accuracy of their reporting of recipients by county. For example, in California, when a recipient moves from one county to another, the recipient generally receives a new identification number (Harrington et al., 1983), leading to duplicate counting of recipients. If States were required to use social security numbers as identification numbers, then there would be less chance for duplicate counts of recipients.

In 1983, six States still were not filing annual reports on Medicaid and two did not file monthly reports. Thus, HCFA has had to estimate the missing data using a weighted linear extrapolation method and aggregate data from other sources (Sawyer et al., 1983). Problems with missing and unreliable data are extensive (Heinberg and Adler, 1982).

Data on the number of individuals who are eligible for the Medicaid program are generally not available. Since States are required to report only on the number of recipients (users), they have not reported the number of eligibles to HCFA. Although some States do have data on the number of eligibles, such data are not reported by the States to the Federal Government. Information about the rates of utilization for the number of individuals who are eligible are not available by State from a national source.

One problem with Medicaid data on the aged is that many aged individuals are also in the disabled category. Those individuals who are categorized as disabled before they reach age 65 generally remain in that category after age 65 because the benefit level under the Supplemental Security Income (SSI) program is higher for the disabled than for the aged. According to the Social Security Administration, 21.8 percent of the 2 million disabled in the SSI program are also 65 and over (Social Security Administration, 1983). Thus, the number of aged Medicaid recipients is undercounted. State Medicaid programs are required to report data on actual age of recipients (for those aged 65 and over) on the Federal 2082 forms. Unfortunately, these data have been found to be incomplete and inaccurate for many State reports for the period 1978–83.

An added problem is that State Medicaid data on the number of days of care in hospitals and nursing homes are not reported accurately, especially for Medicaid recipients who are also Medicare beneficiaries. These data are critical in understanding patterns of utilization. In 1985, data about the days of care are going to be made available by the Health Care Financing Administration only after a substantial period of cleaning and editing of the State data from the 2082 reports. These data are still not considered to be very accurate. In the future, the States should make greater efforts to improve the accuracy of data on days of care.

Another problem is that State Medicaid data systems generally are not linked with the Medicare billing data, which are produced by fiscal intermediaries under a Federal system. Since 12 percent of the aged who use Medicare also are on Medicaid, this information is critical in determining the total expenditures for individual Medicaid recipients (Sawyer et al., 1983). The total days of care and expenditure data for these individuals (called crossover cases) frequently are inadequate because a large portion of the services and expenditures per illness episode are actually reported only by the Medicare program. Claims data for crossover cases generally are sent to Medicare for payment, and then Medicaid may pay the remainder not covered by Medicare. Medicaid data for these individuals are frequently incomplete.

Medicaid data on the MMIS are generally reported as the bills are submitted. Thus, data are reported at the time of payment rather than when the services are rendered. This makes analysis of the policy changes difficult and makes certain types of analyses difficult.

More importantly, State Medicaid data are reported to the Federal Government only in an aggregate form rather than for any individual or group of individuals, such as the elderly. Thus, while arithmetic means can be calculated, measures of central tendency and dispersion cannot be calculated and many important questions cannot be answered (Heinberg and Adler, 1982).

HCFA established a project for five States during 1980 and 1981 that would create uniform person-level data by grouping all billing data for individual recipients. This project created a National Unit Record Medicaid Data Base (tape-to-tape data) with uniform files from 100 percent of all State claims. Such data allow for tracking of utilization and expenditure patterns for individual recipients rather than simply reporting totals for the State by service or eligibility categories (Heinberg and Adler, 1982). Unfortunately, such data are not otherwise available.

One approach toward solving some of these Medicaid data problems would be to require all States to use a standardized format that specifies a minimum data set from its MMIS program similar to that created for the National Unit Record Medicaid Data Base on the tape-to-tape data. Such data from the billing records could then be sorted for each recipient and actual utilization and expenditures reported for unduplicated counts on a monthly and annual basis. This would eliminate the need for the 2082 and 120 forms and would put data into a more usable format. The advantages of such a system would be the ability to: (1) take a comprehensive look at special groups such as the institutionalized aged; (2) conduct distributional analyses; (3) look at Medicare crossover recipients; (4) make accurate cross-State comparisons; (5) analyze provider participation and recipient access; (6) link Medicaid with Medicare and other data sources; (7) conduct small-area studies or special studies by services; and (8) analyze cross-tabulations by age and other demographic characteristics (Heinberg and Adler, 1982). By merging Medicaid with Medicare data for individual recipients, a greater understanding of utilization and expenditure patterns of the aged could be gained. This system could also include the actual birth date of all recipients so that age patterns could be studied in relation to utilization and expenditures. Finally, if such data reporting systems were required, the extensive activities undertaken by many State agencies to produce estimates and projections for Medicaid planning and budgetary purposes would be substantially reduced.

Summary and conclusions

State data systems for population, vital statistics, social services, aging, and Medicaid are all designed as decentralized State programs. The Federal Government has primary responsibility for technical assistance, coordination, analysis, leadership, and dissemination of data. It also has some financial responsibilities. States are given a great deal of discretion not only in the design of their health, social service, and aging programs but also in the development of data reporting systems for those programs. Even in the area of population estimation and projection at the State level, which involves highly technical methodologies, State agencies are given considerable latitude in the methods used and the components included. Medicaid MMIS is the most highly developed data reporting system in any of the health and social service programs at the State level due to its large payment system to private providers; however, even it has many problems. The quality of State data on the population, Medicaid, and vital statistics has improved over time, while the social service data have deteriorated and the aging data remain poor as a direct result of the change to Federal block grants to States and the failure to employ detailed program reporting requirements. While the voluntary systems (e.g., the APWA and the NASUA surveys) can provide some useful information, these systems are not satisfactory for aggregate client data or for utilization and expenditure data.

Two major consequences of the current State data systems are that data are frequently not comparable across States and quality is variable. Definitions of service categories, utilization, eligibility groups, and client characteristics all vary within and between the State programs. The element definitions, formatting conventions, timeframes, and data types all vary. Some States may even have decentralized systems at the county level that make data collection and analysis even more difficult. The programs are, for the most part, not mandated to report client-based data. When client-based data are available, these are almost invariably in the form of aggregate statistics, thereby limiting their usefulness.

The limitations in the current data systems for basic population and program data for all age groups pose a serious problem which grows as the demand for data by policymakers, purchasers, consumers, government analysts, researchers, program managers, and private businesses increases. The technology in data information systems has improved exponentially during the last decade as the country has had an information revolution. The data capacity of the public sector has not kept pace with the growth in technology.

A more rational and effective data system can be achieved through the development of a national data base for all States using administrative records (vital statistics, social services, aging, and Medicaid) and other sources (e.g., population estimates using standardized methods). No other source is available to replace the type of valuable information that States are able to produce from administrative records. National surveys generally do not have adequate funds to collect data from a large enough sample to provide State and substate data.

States are the producers of State administrative data and the primary users of the State data. States probably use Bureau of the Census State and substate data from the decennial census more than other data sets because most State agencies need such data, especially those on age and income, for program planning and budgeting. While States occasionally use data from national sources that are not disaggregated by State, these are not considered to be as valuable as State data. States use their own program data for describing, explaining, and predicting their program activities and budgets. States also compare their own State program data with those of other States. The data produced by States on social services, aging, and Medicaid must be improved before such cross-State data will be very valuable to States. Unless improvements are made in national data on States, States will probably not be extensive users of Federal data.

States have the technical capacity to improve their State data reporting systems. In order to improve the State systems, a number of changes are needed. Such systems must be uniform and standardized in terms of their data elements, definitions, formatting, timeframes, and types of data (Rice, 1983). Methods for collecting, cleaning, coding, calculating, and preparing the data must also be standardized. Ideally, data systems should be linked across programs (i.e., population, social services, aging, Medicaid, and vital statistics) at the State level and with other data at the Federal level (i.e., Social Security and Medicare data). The data systems should not only serve as payment mechanisms but be effective as tools for management and evaluation. Standard methods should be developed to ensure access and privacy. Methods for making corrections and updating are important. More importantly, some ways to assure quality and timeliness are vital.

The ideal administrative data system would have both aggregate and individual client data. The systems described have focused primarily on aggregate cross-sectional data because they are available. Individual client data would allow for different types of policy analysis and research over time. Such data could build a continuous history for individuals over time and allow for distributional studies of eligibility, utilization, access, and expenditures by programs. If such data could be linked across programs (e.g., for social services, aging, Medicaid, and Medicare), studies of cross-program and policy issues could be conducted. These data would be of great value for describing, explaining, and predicting program activities. It would be difficult to build such a detailed data system by any other method. This type of system would not necessarily cost more than the data systems already established in the Medicaid and Medicare programs, but would require uniform definitions, coding, formatting, and data collection across programs and across States. Costs would be incurred in establishing data systems for social services and aging in States which do not have such systems.

Voluntary State data systems have not proven effective. The mandatory reporting system established by Medicaid, in spite of its many deficiencies, is far more effective than the social service and aging data systems. If States are not mandated to report, they will not have a real incentive to improve their systems. If mandatory requirements are established, some type of real penalties would have to be developed for States that fail to comply with the basic requirements. Such penalties should have both intermediate and severe sanctions that can be invoked for noncompliance. Mandatory reporting requirements by the Federal Government would require statutory changes within each program.

The most difficult aspect of designing a rational system is in obtaining the political support from the President and Congress to make these changes. Data systems do not have natural organized political constituencies, except perhaps those who are directly involved in data collection activities. Policymakers would be more sympathetic to imposing mandatory Federal reporting requirements on the States if States could be provided the financial resources for such activities. Given the current fiscal crisis and the large budget deficit at the Federal level, the likelihood of giving substantial financial resources to States to develop improved data systems is low. State governments continue to have their own financial limitations and generally do not view the establishment of a national data base for State data as a high priority, and certainly not one they would be willing to finance without Federal support.

The most important factor relative to data quality, timeliness, accuracy, and detail is to provide adequate financial resources for the programs at the Federal level. In order to justify additional Federal expenditures to improve State data systems, some cost effectiveness would have to be demonstrated. No study has looked at the direct and indirect costs of the voluntary, decentralized, and chaotic systems that currently exist. The amount of waste, duplication, and ineffectiveness resulting from the complexity and fragmentation in the existing systems has not been documented. The financial costs and personnel hours consumed by the use of manual systems or inadequate computerized systems also need to be examined. The indirect costs to the public and private sectors due to poor planning and management, waste, and inefficiency are another consideration. Although it is clear that the current data systems at the State level are not satisfactory, an analysis of the cost effectiveness of redesigning and improving the systems is needed before policy recommendations for change will be taken seriously.

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