The Compression of Morbidity Hypothesis: Promise and Pitfalls of Using Record-linked Data Bases to Assess Secular Trends in Morbidity and Mortality

CYNTHIA L. LEIBSON, DAVID J. BALLARD, JACK P. WHISNANT, and L. JOSEPH MELTON III

Mayo Clinic and Foundation, Rochester, Minnesota

DECREASED MORTALITY AMONG ELDERLY INDIVIDUALS over the past two decades has resulted in unprecedented increases in longevity after 65 years of age in the United States (Metropolitan Life 1990). Within the health profession, this development has served as a source of both pride and concern. The concern arises from the fact that much of medical research has focused on reducing case fatality and improving long-term survival among persons affected with disease. To the extent that these advances have been unaccompanied by reductions in the incidence of disease, the proportion of time that individuals spend in ill health may actually be increasing. As outlined by Fries (1989), a preferable direction for health care policy would be toward the promotion of continued declines in premature mortality, while simultaneously postponing the onset of disease and disability. The appropriate path for achieving this goal is unclear, however, because there is little information on whether any approaches have succeeded in the past.

Unfortunately, the task of discerning secular changes in age at onset of morbidity is not an easy one. There are multiple domains of morbidity, ranging from evidence of pathology through impairment and func-

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Finally, the potential of this natural laboratory for population-based epidemiologic studies was fully realized in 1966 with the extension of the Mayo Clinic diagnostic and surgical indexes to incorporate all sources of medical care used by the local population in and near Rochester, including the Olmsted Medical Group, the Olmsted Community Hospital, the Rochester State (mental) Hospital, the Federal (prison) Medical Center, the University of Minnesota Hospitals, the Minneapolis Veterans Administration Hospital, all of the small hospitals in surrounding counties, and the very few private general practitioners with offices in the area. These non-Mayo Clinic records are available for use in approved research studies and have been indexed for the time period extending from 1935 to the present.

Potential Promise of Medical Record Linkage Data for Revealing Secular Trends in Morbidity

Enumeration of the Population

The REP essentially provides a survey of the Olmsted County population. In a recent community blood pressure survey, 2,147 individuals 35 years of age or older, who had lived within the Rochester city limits for at least one year, were selected through random digit dialing. Every individual selected in the survey had a medical record on file within the REP (Phillips et al. 1988). During any given three-year period, most local residents will have at least one medical care contact. About half of the population is seen annually within the Mayo medical system alone. For example, the total number of different Olmsted County females aged 65 through 74 years seen at Mayo and its two affiliated hospitals at least once from 1984 through 1986 was 105 percent of the estimated population in 1985 (as would be expected, this figure is greater than 100 percent because of some immigration). The rate of contact is even more frequent if all service providers are considered. Consequently, the REP can be used to draw random samples of community residents across time. Although this capability has not yet been used to examine trends in the prevalence of morbidity in the general population, the National Institute on Aging recently funded a REP study to investigate secular trends in age-at-onset and survival and trends in comorbidity and dis-

ease complexity, using non-insulin-dependent diabetes mellitus as a disease model.

Completeness of Case Ascertainment

The ascertainment of disease within the population that is afforded by the REP is typically more complete than what could be obtained through most hospital-based studies, retrospective surveys, disease registries, or administrative data. The reason is partly that the diagnostic index includes medical as well as surgical diagnoses and outpatient, death certificate, and autopsy data in addition to inpatient information. Moreover, the population surveyed includes both institutionalized and noninstitutionalized individuals. The more complete ascertainment afforded by the REP is especially evident among the elderly. For example, incidence rates for a number of diseases (epilepsy, amyotrophic lateral sclerosis, multiple myeloma, brain tumors) were previously thought to decline among the oldest age groups. Population-based data from the REP demonstrate, instead, that incidence rates for these diseases continue to rise with increasing age (Kurtzke and Kurland 1983; Kyle, Nobrega, and Kurland 1969). The high proportion of earlier stages of disease, and the longer survival rates reported for Rochester and Olmsted County relative to some other community-based studies, support the belief that the REP records linkage system provides an extraordinarily complete ascertainment of most serious diseases within the community. Of particular importance here is the observation that REP incidence rates are often stable over time, whereas others report increasing rates (Lucas et al. 1988). The discrepancy usually stems from higher Rochester rates in earlier time periods, emphasizing the necessity for consistency of case ascertainment over time for discerning secular trends in disease incidence and prevalence.

Ascertainment of Exposure

Longitudinal surveys intended to study the process of aging have typically obtained contemporary lists of diagnoses, signs, and symptoms, thereby providing little information about the underlying processes of disease (Fozard, Metter, and Brant 1990). The REP enhances an appreciation of the natural history of disease to the extent that, for studies of most chronic diseases, it affords access to decades of medical record documentation prior to onset. The potential importance of this documen-

the individual to seek care and the propensity of the physician to assign a diagnosis, the REP is less suited for retrospective determination of long-term secular trends for those conditions that are likely to have become medicalized over the period of study (e.g., alcoholism, obesity, and depression).

Rates of diagnosed disease are affected not only by whether a condition is defined as pathologic but also by how much pathology needs to be present before it is considered a disease (Fozard et al. 1990). An example of the impact of changes in diagnostic criteria on secular disease trends is provided by a REP study demonstrating that the introduction of new, and more stringent, National Diabetes Data Group criteria for diabetes mellitus in 1979 resulted in an apparent drop in incidence and, as a consequence of selecting for more severe cases, a reduction in survival (Melton et al. 1983). Such a study was possible because the REP affords access to original patient data, a requisite for discerning the impact of changes in diagnostic criteria.

Changes in Disease Presentation

In order for a condition to be assigned a diagnosis, the individual must come into contact with the care delivery system. The decision to seek medical care is affected by the manner of disease presentation. As illustrated in the third level of figure 1, of those individuals affected with the disease, only a proportion exhibits signs and symptoms. This proportion is subject to secular changes in cultural attitudes and changes in the medical knowledge base among both lay persons and professionals. As an example, it is likely that the ascertainment of cancer has become more complete with increased emphasis on and education about cancer's early warning signs.

Of those affected individuals who are not or never become symptomatic, a certain fraction may still be recognized as having the condition. Such individuals exhibit some biologic marker for the disease that can be detected with diagnostic screening. The proportion of individuals with a biologic marker who are recognized reflects historic shifts in the focus, intensity, and prescriptive status of screening programs. A number of REP studies have reported rising incidence rates for a variety of diseases coincident with the advent of increased clinical surveillance for those diseases: for example, breast cancer (Ballard-Barbash et al. 1987), cervical cancer (Dickinson et al. 1972a), non-insulin-dependent diabetes

(Palumbo et al. 1976), and primary hyperparathyroidism (Heath et al. 1980).

Changes in Access to Care

The proportion of individuals who seek medical care is subject to changes in access to care (Andersen and Newman 1973) (figure 1, level 4). A REP study of access bias associated with the rare and frequently asymptomatic condition of sarcoidosis emphasizes that the more frequent and thorough the contact, the greater the likelihood that a condition will be recognized and assigned a diagnosis (Hennessy et al. 1988).

Potential biases due to changes in access to care over time are relatively minimal in the REP because of both the unusually high ratio of resources per county resident and the stability of the community socioeconomically and demographically. Nevertheless, temporal changes in the volume and intensity of care have occurred. Changes in access brought about by Medicare's Prospective Payment System likely contributed to an observed decline between 1980 and 1985 in the proportion of Olmsted County residents aged 65 through 74 years who were hospitalized at least once during the year (Leibson et al. 1991).

Changes in Diagnostic Technology and the Medical Knowledge Base

The completeness of disease ascertainment reflects changes in the capacity and propensity to assign a diagnosis (figure 1, level 5). Improved diagnostic technology has resulted in a lower likelihood of asymptomatic cases escaping detection. The impact of such improvements on incidence rates is exemplified by a REP study of abdominal aortic aneurysms, which showed that an increase in incidence over the time period 1951–1980 was mostly caused by the detection of small, asymptomatic aneurysms following the introduction of ultrasonography in the late 1960s (Melton et al. 1984). Similarly, a rise in the incidence of carpal tunnel syndrome followed the introduction of a technique that increased the proportion of positive electromyograph (EMG) examinations among symptomatic individuals. Because a positive EMG confirms the clinical diagnosis, the rise in incidence was most likely the result of increased diagnostic sensitivity (Stevens et al. 1988). Moreover, the detection of both symptomatic and asymptomatic cases has likely increased over time

with expanding application of technologies such as EMG and ultrasonography.

Observed trends in disease incidence are also affected by changes in the medical knowledge base. Improved understanding of etiology can lead to the development of effective therapies and cures. Evidence suggests that physicians are more likely to assign a diagnosis once a cure or a treatment becomes available. REP studies showed a marked rise in incidence rates for otosclerosis following the introduction of stapedectomy (Pearson et al. 1974) and a marked rise in incidence rates for proximal femur fractures following the introduction of hip pinning (Melton et al. 1982).

It is often difficult to estimate the extent to which changes in incidence and survival can be attributed to changes in practice style and care delivery. However, the small number of providers and the availability of the surgical index in the REP allow for historical documentation of the introduction and expansion of specific technologies. The contribution of improved technology to increased incidence is typically apparent with a greater proportion of cases characterized by earlier stages, more uncomplicated or asymptomatic disease, and longer postdiagnosis survival. The availability of the complete medical record within the REP affords the opportunity to differentiate diagnoses according to these characteristics and to calculate incidence by mode of diagnosis (Melton et al. 1984).

Changes in Death Reporting

Detection of disease and assignment of a diagnosis can also occur at the time of death (figure 1, level 6). The ascertainment of both mortality and morbidity within the REP is enhanced by a file of death certificates for all county residents deceased since 1935. The difficulties of relying on death certificate data as the sole source of information for inferring morbidity rates are well recognized (American Medical Association 1988; Galanos et al. 1989). A particularly graphic example is provided by a REP study showing that diabetes was listed as the underlying cause of death for only 10.3 percent of individuals with diabetes who died during the period 1965–1974, and was not mentioned on the death certificate in 62 percent of the cases (Ochi et al. 1985). To the extent that the problems of inaccuracy, incomplete recording, and selection bias change over time, reported trends in disease occurrence derived from death-certificate information will be affected. Such problems are mini-

mized in the REP as incidence cases can be followed through the medical record until death or the end of the study period.

Changes in Autopsy Rates

An additional opportunity for case detection and confirmation occurs with autopsy (figure 1, level 7). Compared with the national average, the percentage of deaths among Olmsted County residents that come to autopsy is very high. Recent declines in autopsy rates at the national level, however, have also been observed locally, with the peak value of about 70 percent in the 1970s having fallen to below 40 percent in the past decade (Chute, Ballard, and Nemetz 1991). Moreover, such changes are likely to cause a bias in disease occurrence rates because autopsies are not performed on a random sample of deaths. As reported in a REP study, conditions that result in sudden unexpected death (e.g., abdominal aortic aneurysm) are more likely to undergo autopsy (Nevitt 1989). Therefore, the frequency of such conditions is likely to be overestimated in autopsy-cohort studies characterized by low percentages in the proportion of deaths in the population of risk that come to autopsy (Nevitt, Ballard, and Hallett 1989). Although the REP has the capability of estimating how representative of the underlying population are the cases diagnosed at autopsy, changes in the rate as well as in the precision and thoroughness of autopsy procedure must be taken into consideration.

The Need to Assess Validity

The problems of changing definition, access, and care delivery are not isolated to record-linkage data, but exist for data obtained through interview as well. The problems can be resolved only with prospective, longitudinal investigations to detect the presence of disease with routine, periodic assessments using objective methodology. However, even the few prospective studies that have included such serial measurement (Busse and Maddox 1985; Shock et al. 1984; Svanborg 1988) have not been immune to changing diagnostic criteria and technology (Fozard et al. 1990). The potential for bias within each of these approaches emphasizes the need for a methodologic structure to assess the validity of time trends. This section has illustrated several possible sources of bias when using record-linked data bases. Some of the more important restrictions and concerns are listed in table 1.

TABLE 1
Some Methodological Concerns in the Use of Medical Record Linkage Data to Estimate Secular Trends in Morbidity

1. The population at risk must be definable, and age- and sex-specific rates must be obtainable to allow adjustment and cohort comparisons.
2. The level of ascertainment (i.e., disease recognition and diagnosis) should be consistently high:
   a. The condition should be resistant to medicalization over time.
   b. The time between onset of disease and diagnosis should be short.
   c. The seriousness of the condition should be such that medical attention will be sought.
   d. Access to care should be consistently high.
   e. The reliability and validity of diagnoses should be estimable (e.g., by re-abstracting the medical record or reexamining pathology specimens).
   f. Rates should be adjustable for confounding factors such as terminology, diagnostic criteria, technology, reporting procedures and the relative contribution of diagnoses at autopsy.
3. The capacity for follow-up must be high to assure unbiased estimates of survival.
4. There must be sufficient power, with respect to the relationship between incidence and time, to distinguish true trends from random variation.

Using REP Data to Examine the Compression of Morbidity

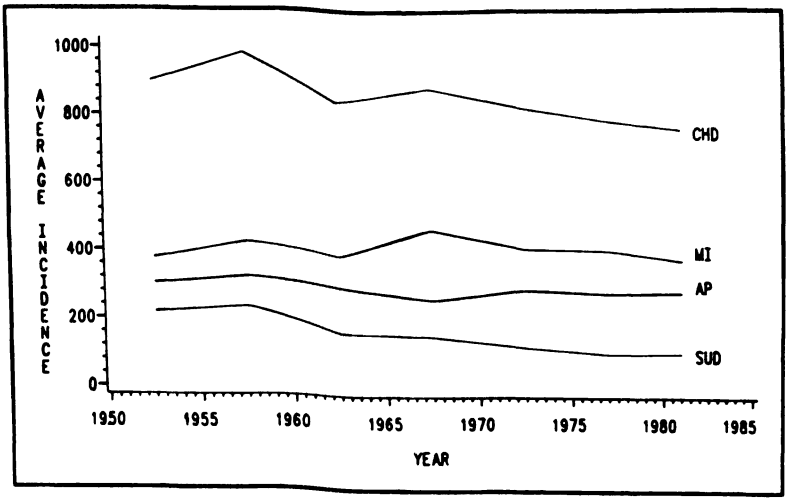
The majority of REP studies have been mounted primarily to describe the natural history of specific conditions and to investigate etiology. The relevance of the REP data base for investigating secular trends in the association between aging and disease has not been fully appreciated. The question of whether secular trends in the process of aging include a compression of morbidity depends on whether the observed increases in average age at death have been accompanied by even greater increases in the average age at onset of illness (Fries 1989). Although no studies using the REP data base have examined these issues directly, presumptive evidence is available from previously published findings, including longitudinal age-specific incidence rates for nearly 30 chronic conditions. Investigation of birth cohort effects is also possible, as time trends extend over four or five decades in many instances.

Declines in age-specific mortality observed nationally over the past few decades have also occurred in Olmsted County. Because declines in mortality at the national level are primarily attributed to fewer deaths caused by cardiovascular disease, REP data on coronary heart disease and stroke are reviewed, along with recent studies of cancer.

Coronary Heart Disease

A number of REP studies have explored the reasons for the declining coronary heart disease (CHD) mortality observed both nationally and locally beginning in the late 1960s. Data show a steady decline in the overall incidence of CHD among Rochester men between 1955–1959 and 1979–1982. Rochester women exhibit a decline between 1955–1959 and 1965–1969, but then show a 9 percent increase to 1979–1982 (Elveback, Connolly, and Melton 1986). CHD is defined in the REP studies as initially manifested by angina pectoris, myocardial infarction, or sudden unexpected death, and the different manifestations must be examined separately in order to appreciate the implications of secular trends in the incidence of CHD for the compression of morbidity issue (figure 2A,B). Age-adjusted rates show higher incidence and longer survival for angina among both males and females between 1965–1969 and 1979–1982. The contribution of increased ascertainment and earlier detection to these findings, however, is not clear. Females exhibit an increase in the age-adjusted incidence of myocardial infarction during this time period, whereas males exhibit a decrease. These changes are generally greatest in persons 50 through 69 years of age. These and other findings led Elveback et al. to conclude that declines in CHD mortality between 1968 and 1982 are largely attributable to a declining incidence of sudden unexpected death, a decrease in the 30-day case fatality rate for myocardial infarction, and improved survival after a diagnosis of angina pectoris, rather than later onset of disease (Elveback, Connolly, and Kurland 1981; Elveback and Connolly 1985; Elveback, Connolly, and Melton 1986).

This interpretation of CHD incidence and survival trends reinforces the perception, held by even the strongest proponents of the compression of morbidity hypothesis, that advances in health and medicine prior to the 1980s contributed more to increased longevity than to disease prevention (Fries 1990). This conclusion is strengthened by a REP



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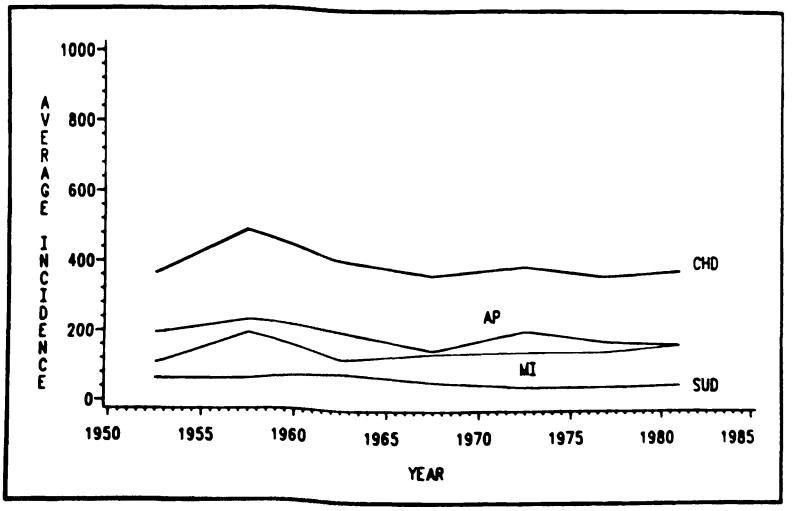

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FIG. 2. A. Average annual age-adjusted incidence (per 100,000 population) of coronary heart disease among men in Rochester, Minnesota, 1950 through 1982, by initial manifestation. AP, angina pectoris; CHD, coronary heart disease (all manifestations combined); MI, myocardial infarction; SUD, sudden unexpected death (death within 24 hours after appearance of symptoms). B. Average annual age-adjusted incidence (per 100,000 population) of coronary heart disease among women in Rochester, Minnesota, 1950 through 1982, by initial manifestation.

Source: Reprinted with permission from Elveback, Connolly, and Melton 1986.

study of the prevalence of significant coronary artery disease. Secular changes in the prevalence of coronary disease were estimated with a review of autopsy records of all persons over 30 years old who died and went to autopsy in Olmsted County from 1950 through 1979 (N = 5,558). The study adjusted for historic changes in autopsy rates by cause of death. Ten percent of tissue specimens were reexamined to correct for changes in reporting. The findings show a secular increase in significant coronary artery disease for all age groups, except for the 30- through 49-year-old age group, which showed a nonsignificant decrease (figure 3). The authors suggest that, despite the improved survivorship and declines in mortality for patients with coronary heart disease, as of 1979 there was no decline in the progression of atherosclerosis during life (Elveback and Lie 1984).

Stroke

Although mortality rates from stroke exhibit steady declines since 1900 in the United State (Havlick and Feinleib 1979), data from the REP suggest that much of the decline prior to 1950 may be artifactual because

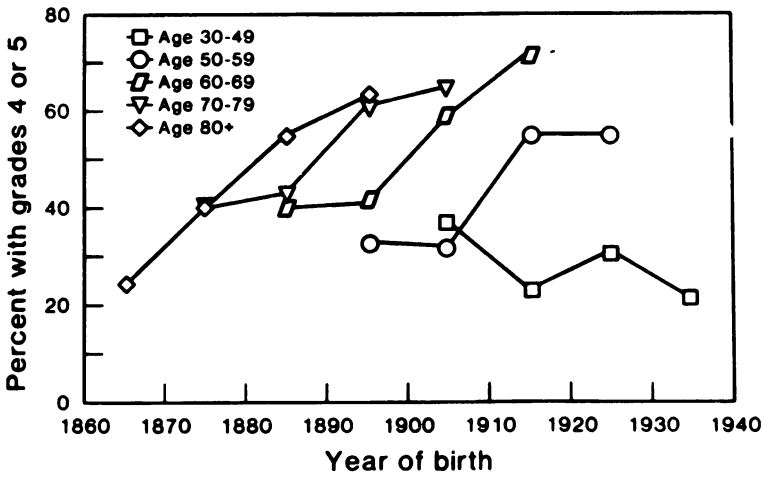


FIG. 3. Percentage frequency of grade 4 and 5 stenoses by decade of birth and age at death, corrected for underreporting in the records.
Source: Reprinted with permission of the American Heart Association, Inc., from Elveback and Lie 1984.

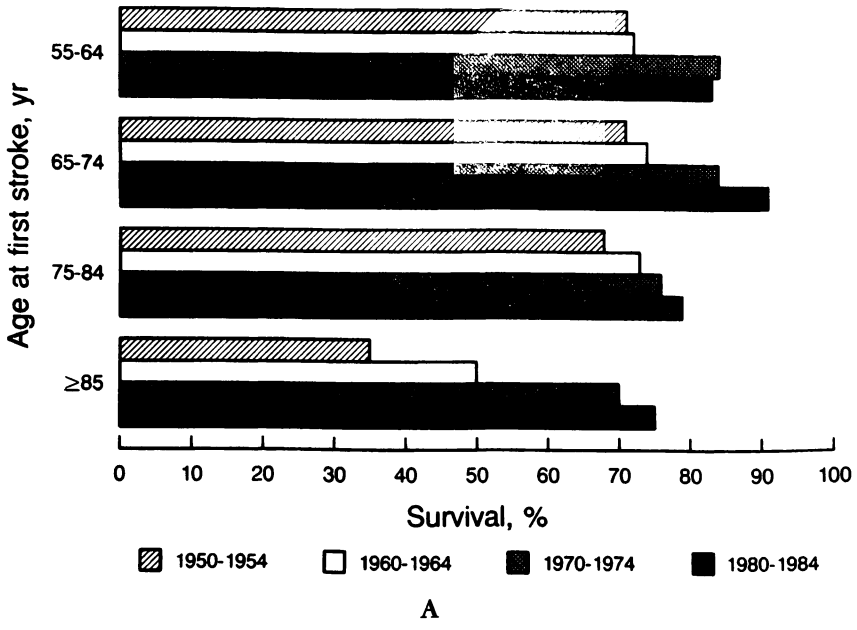
of revisions in coding and changes in the precision and accuracy of reporting cause of death (Homer, Whisnant, and Schoenberg 1987). Following 1950, however, the observed decline in mortality appears to be caused by both increased survivorship following first stroke and declining incidence of stroke associated with improved recognition and control of risk factors like hypertension (Broderick et al. 1989; Garraway and Whisnant 1987).

These two observations provide apparently conflicting evidence for the compression of morbidity. We attempted to examine directly the net effect of reduced frequency and increased survival with a reanalysis of existing data. Preliminary results of this analysis are provided in table 2 and figures 4 to 6. Compression of morbidity could occur in the presence of improved survival if accompanied by a relatively greater increase in the age at onset of first stroke. As shown in table 2, median age at onset increased with each decade from 1945 through 1984. This increase, however, may merely reflect the aging of the overall population at risk of stroke. Therefore, we applied the Rochester age- and sex-specific incidence rates for each decade to a standard population (U.S. 1970 whites) and then calculated the percent of incidence cases in each age group. No secular increase was evident in the proportion of incidence cases above either age 64 or 84 years. This observation is supported by the absence of any significant interaction between age and five-year time period in a Poisson regression model investigating the effects of sex, age group, and five-year period on the natural logarithm of

TABLE 2
Trends in Age at Onset of Stroke Among Residents of Rochester, Minnesota

Decade	No. of cases	Median age at onset	Percent at or above age 65[a]	Percent at or above age 85[a]
1945–1954	504	69	73.4	12.2
1955–1964	617	72	70.7	11.9
1965–1974	625	73	68.2	7.8
1975–1984	717	74	71.2	9.1

[a] Age- and sex-adjusted to 1970 U.S. white population.



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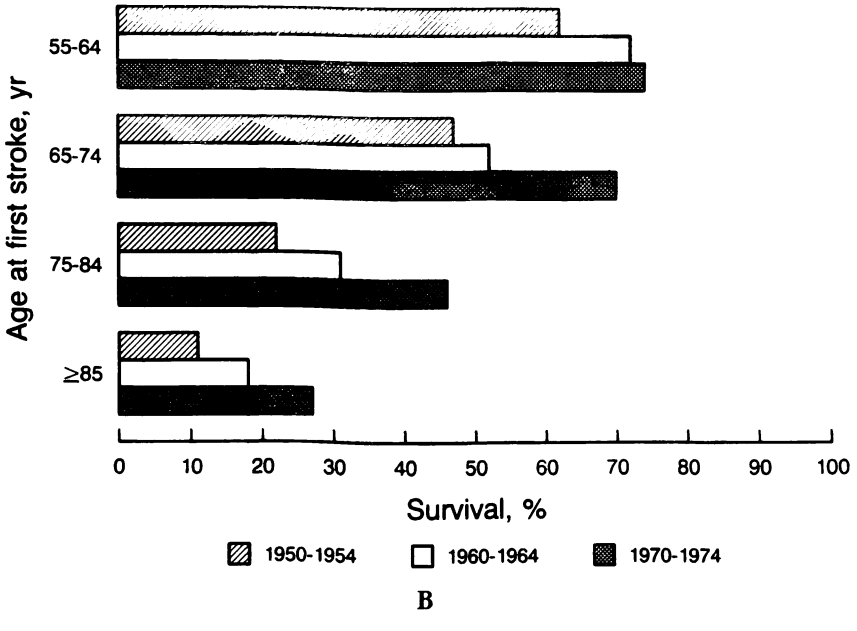

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FIG. 4. A. Age-specific 30-day survival following first stroke for selected quinquennia of stroke from 1950 through 1984. B. Age-specific 5-year survival following first stroke, given 30-day survival, for selected quinquennia of stroke from 1950 through 1974.

the incidence rate of stroke, from 1945 through 1984 (Broderick et al. 1989).

A corollary of the compression of morbidity hypothesis is the compression of mortality, which predicts that, as average life expectancy approaches the upper limit of longevity, the impact of disease prevention and medical intervention on survival will decrease with advancing age (Olshansky, Carnes, and Cassel 1990). This was not yet evident with the most recently available stroke data, as there were dramatic improvements over time in both 30-day and five-year survivorship among the oldest age group (figure 4A,B).

Although survival following stroke has increased in recent time periods, this finding must be considered together with the observation that fewer persons are experiencing stroke. Figure 5 plots the incidence rate of stroke per decade for the three decades 1955–1964, 1965–1974, and 1975–1984 against the mortality rate for all incidence cases since 1935 for these same time periods. The divergence of the curves over time suggests that the age- and sex-adjusted prevalence of stroke is increasing. For purposes of these calculations, we assumed that no incidence cases of stroke left the population and that no migrants into the community had previously experienced stroke. The proportion of surviving inci-

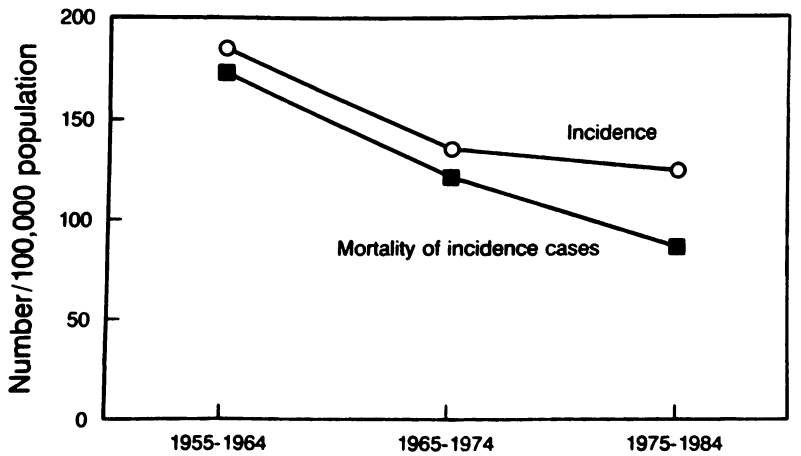

FIG. 5. Age- and sex-adjusted incidence rates of first stroke among residents of Rochester, Minnesota, for the decades 1955–1964, 1965–1974, and 1975–1984 compared with age- and sex-adjusted mortality rates for incidence cases of first stroke since 1935 for these three decades.

dence cases who were residing outside of Rochester on January 1 was 15 percent in both 1965 and 1980.

The decline in stroke incidence stabilized in the 1970s, and incidence of stroke increased 17 percent between 1975–1979 and 1980–1984. The increase was greatest among individuals at or above 85 years of age (Broderick et al. 1989). Possible explanations include an increase in the mean age of the population at or above 85 years and increased ascertainment following the introduction of computed tomography (CT). The stabilization in incidence rates of stroke for women in the early 1970s, however, preceded the introduction of CT.

Given that stroke is a fatal disease, it could be argued that a secular increase in stroke incidence is not necessarily incompatible with the compression of morbidity, if the increase is occurring among very old individuals who then die shortly after onset. To address this issue, we compared the total number of years post stroke among all incidence cases of stroke who were at or above 55 years of age and surviving on January 1, 1965 versus January 1, 1980. The age- and sex-adjusted ratios were 210 years post stroke per 1,000 population on January 1, 1965 and 230 years post stroke per 1,000 population on January 1, 1980. Age-specific analysis showed that the increase was greatest for males in older age groups (figure 6). Future analyses will investigate possible differences among subpopulations and will include reabstraction of the medical record to provide estimates of secular changes in stroke severity and comorbidity.

Cancer

The REP data base has also been employed to document secular trends for a variety of cancers. Rising incidence rates in the face of declining mortality for a number of these cancers would appear to refute the compression-of-morbidity hypothesis. However, the compression of morbidity is likely to be underestimated by retrospective reviews of record-linked data bases that fail to consider that a majority of the cultural, structural, economic, and technological changes occurring in our society have resulted in earlier, more complete disease detection (Johannson 1990). The detailed analysis afforded by the REP demonstrates that reported upward trends in cancer incidence and survival may be largely artifactual. A recent study of secular trends in pancreatic cancer reported a reduction in the time between onset of symptoms and diagnosis, but no

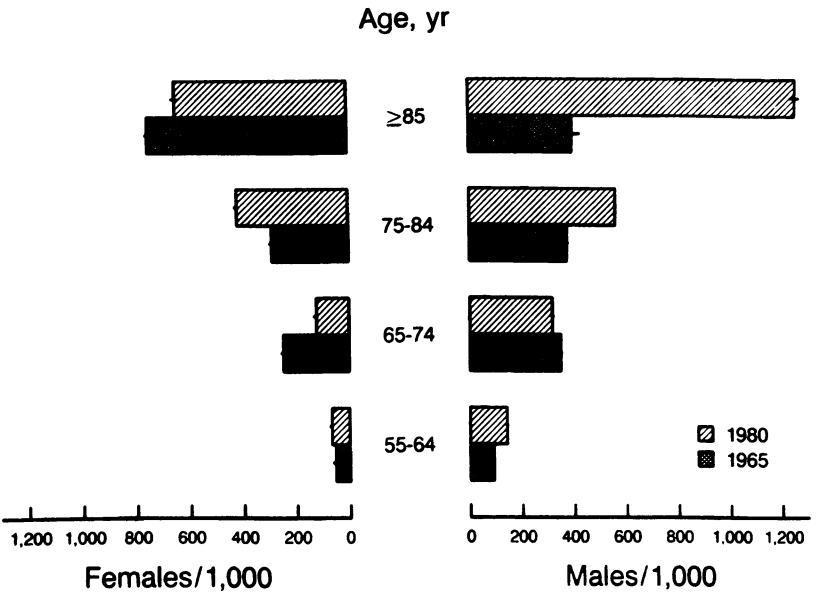

FIG. 6. The total years post stroke per 1,000 population among Rochester, Minnesota, residents on January 1, 1965 and January 1, 1980. The numerator only includes incidence cases since 1935 and excludes any individuals who on January 1, 1980 were 30 years or more post stroke. Both numerator and denominator include incidence cases not residing in Rochester on January 1, 1965 or January 1, 1980.

change in the interval between onset and death (Riela et al. 1989). Earlier detection followed the introduction of abdominal CT and endoscopic retrograde cholangiogram pancreatography, contributing to improved ascertainment and an apparent increase in both incidence and survival.

REP studies of breast cancer also attribute rising incidence rates to increased ascertainment. Review of medical records and histopathologic slides demonstrated that a rise in age-specific incidence observed among older age groups from 1935 to 1982 was primarily accounted for by an increase in less advanced disease. The prolonged survival among breast cancer patients, however, does not appear to be due solely to earlier detection, but rather to improved management of individuals first diagnosed with metastatic disease (Ballard-Barbash et al. 1987). By contrast, REP studies of cervical cancer suggest that declining mortality rates for patients with cervical cancer can be attributed to increased screening and earlier detection, although the increase in incidence observed between

1935 and 1964 is not entirely explained by increased screening (Dickinson 1972a,b).

A REP study of primary adenocarcinoma of the lung found a continued increase in incidence rates through 1984 for both males and females despite an apparent levelling off for males in the 1970s (Beard et al. 1988). Almost all diagnoses of lung cancer in Olmsted County residents extending back to 1935 could be subjected to review and potential reclassification by a single pathologist because original histology specimens were available for 591 of the 613 (96 percent) cases. Thus, it could be determined that the increase was not due simply to changes in the criteria for histopathologic classification by cell type. The analysis suggested the existence of a birth-cohort effect (figure 7). Data on later cohorts is required to determine the impact of recent changes in smoking behavior on age-specific incidence rates (National Center for Health Statistics 1990).

Secular trends that appear to support the compression of morbidity hypothesis, such as decreasing incidence of cancer and shorter survival times, may also be biased by period effects like greater diagnostic specificity, declining autopsy rates, and limited access to care. Consideration of these factors in REP studies of ovarian cancer (Annegers et al. 1979), cancer of the gallbladder and extrahepatic biliary ducts among females

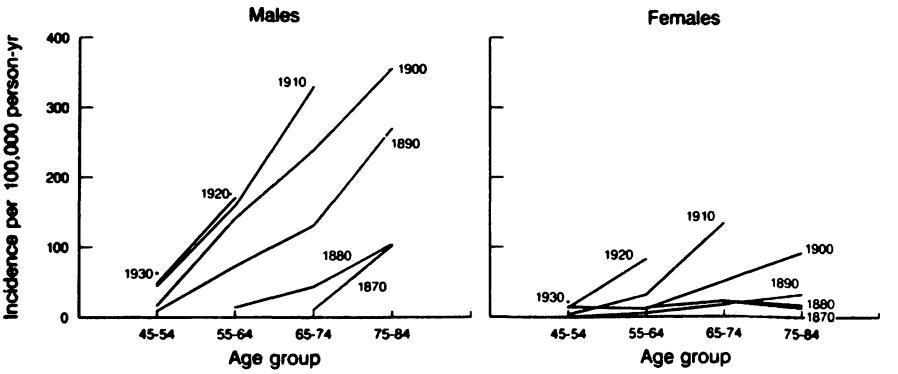

FIG. 7. Incidence of primary bronchogenic carcinoma among Olmstead County, Minnesota, men and women, from 1935 through 1984, by age group and 10-year birth cohort.

Source: Reprinted with permission of the National Cancer Institute from Beard et al. 1988.

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Address correspondence to: Cynthia L. Leibson, Ph.D., Department of Health Sciences Research, Mayo Clinic, 200 First Street, SW, Rochester, MN 55905.