Cause of Death as a Contemporary Problem

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WHAT uniquely characterizes cause of death as a contemporary problem? Four broad answers can be given to this question. The first is that, more than ever before, data—including vital statistics data—bring problems and issues to the attention of the public, inform public policy, and are invoked in public debate of policy issues. The second characteristic is the growing disjuncture between cause of death and cause of poor health—that is, the growing gap between mortality data and morbidity data as a way of delineating the health profile of a modern population. A third is the growing problem of establishing a specific cause of death for our increasingly elderly population. A fourth characteristic is the effect on cause-of-death data of advances in data collection, in medical reporting, and in medical diagnosis.

Today, mortality data are used to set policy agendas, to target government resources, to justify governmental actions, and to monitor the consequences of government action or inaction. We live in a sophisticated data-consuming society where much of the strategy of government action involves calculating the economic, social, and political costs of alternative courses of action. In this environment, cause-of-death statistics are very important at not only the national but also at the state and local levels.

Despite the amply documented limitations of quality and completeness of the mortality data from death certificates, the strengths of the database continue to make it unique.[1] No other health data source

1. Harry M. Rosenberg, "Improving cause-of-death statistics," *Am. J. Public Health*, 1989, *79*, 563–64.

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exists that is as universal in coverage, as standardized, uniform, and timely as mortality data from the vital statistics system. Mortality data continue, therefore, to be a key database for epidemiologic, demographic, and historic research and increasingly for public policy. To illustrate the use of cause-of-death data for public policy, examples are presented from both the national and the state levels of government.

POLICY AND BUDGET RELEVANCE

Federal agencies watch the numbers that may have implications for their budgets. For example, early in the Clinton administration, an urgent call was received by the National Center for Health Statistics (NCHS) from the Office of the Secretary of the U.S. Department of Transportation, which was preparing a letter to the Secretary of the Department of Health and Human Services. The letter dealt with accident prevention. The Transportation Secretary's staff had heard on the radio that AIDS had surpassed accidents as the leading cause of death among men aged twenty-five to forty-four years. Was this true, they asked? The reply from NCHS staff, based on the agency's published mortality statistics,[2] indicated that for young males, HIV infection was the leading cause of death; and for young females, cancer; but NCHS was able to confirm that for males and females combined, the leading cause remained accidents (though only by a few hundred deaths). Thus, accident prevention would remain, for a time, a high priority of the federal government. Mortality data, then, identify and communicate in a credible way some of the nation's most serious health problems and have consequences in terms of the level of public funds directed at problems like AIDS and accidents.

Cause-of-death data correlate with the allocation of federal funds for biomedical research and training at the National Institutes of Health (NIH).[3] We can show that at NIH, for example, federal funding generally reflects the ranking of leading medical causes of death in the United States and tends to focus on the health problems

2. National Center for Health Statistics (NCHS), "Annual summary of births, marriages, divorces, and deaths: United States, 1992," *Monthly Vital Statistics Report*, 1993, *41*, no. 13.

3. National Institutes of Health, NIH Data Book 1992: Basic Data Relating to the National Institutes of Health (Bethesda, Md., 1 September 1992). In 1991, the National Cancer Institute led those institutes with disease or disability-oriented missions, receiving $1.7 billion; the National Heart, Lung, and Blood Institute received $1.1 million; and National Institute of Allergy and Infectious Diseases received about $900,000.

of young adults, persons aged twenty-five to forty-four years. In this analysis, excluded from the leading causes are deaths from trauma such as accidents, homicides, or suicides because NIH programs do not embrace these areas.[4] Diseases that cut short productive life, those that are most devastating in terms of their impact on family life, and those whose treatment has the greatest promise of prolonging life are perceived as the highest priorities. Hence the rankings of budget obligations for research and training reflect such assessments of the impact of the diseases represented by mortality. For young adults, the leading cause-of-death combination is HIV infection plus influenza and pneumonia, followed closely by cancer, then heart disease plus respiratory diseases, then diabetes plus chronic liver disease and cirrhosis plus kidney diseases, with stroke ranking last. The correlation between outlays for research and leading medical causes of death is very strong; indeed, the rankings would be the same except for the primary ranking of infectious diseases as a cause of death due to AIDS, which accounts for 90 percent of the deaths in this cause-of-death grouping. While the institute within NIH most directly concerned with AIDS, the National Institute of Allergy and Infectious Diseases, ranked third in budget obligations, the funding of this institute during 1982–1991 almost quadrupled, expanding more than twice as fast as that of the other NIH agencies concerned with diseases and disabilities. In the late 1990s, this strong correlation between budget obligations and causes of death suggests, perhaps too strongly, a degree of rationality in the government's commitment of resources to biomedical research and training. It does show that NIH budget allocations are consonant with the mortality profile of the young adult population of the United States.

Another example of the use of mortality data in the area of policy and planning is a federally promoted program called "Healthy People." The concept was first presented in the late 1970s in a report called *Healthy People: the Surgeon General's Report on Health Promotion and Disease Prevention*[5] and was further developed and elaborated in the

4. NCHS, "Advance report of final mortality statistics, 1991," *Monthly Vital Statistics Report*, 1993, *42*, no. 2, supplement.

5. U.S. Department of Health, Education, and Welfare, *Healthy People: The Surgeon General's Report on Health Promotion and Disease Prevention, 1979*, Office of the Assistant Secretary for Health and Surgeon General, DHEW (PHS) Publication no. 79-55071 (Washington, D.C., 1979).

1989 Surgeon General's report, *Healthy People 2000*.[6] Tracking the nation's health in a more formal way than ever before, *Healthy People 2000* is a detailed delineation of national goals for disease prevention and health promotion, with quantitative objectives to improve health, to promote service, and to protect against disease and disability. How do the *Healthy People 2000* objectives relate to mortality data? About one-third of the objectives are measured using mortality data. Sometimes subobjectives are established separately for population subgroups, classified by such characteristics as race or ethnic origin. For example, an overall goal would reduce coronary disease deaths below 100 per 100,000 people, with a separate and higher rate of 115 per 100,000 African Americans.

Because information from death certificates is almost the only routinely available measure of health that is of reasonable quality and is comparable among geographic areas, mortality data are even more central to health policy at the state and local levels of government than at the national level. A recent survey of states revealed that cause-of-death data are widely used in state government.[7] The survey showed that these data were used for planning, resource allocation, regulation, enforcement, and legislation in a broad range of areas including maternal and child health, highway safety, occupational and environmental safety and health, fire safety, clean air, smoking, and programs directed to control of hypertension, cancer, and diabetes.

MORBIDITY–MORTALITY DISJUNCTURE

The second contemporary characteristic of cause-of-death statistics is the growing disjuncture between cause of death and cause of poor health. This is mainly because of extension of life in industrialized societies. Before the twentieth century, and certainly before the industrial revolution, the link between serious illness and death was a strong one. Even into the twentieth century, infectious and communicable diseases were the leading causes of death in the United States. Thus, in 1900, one of every four deaths was from pneumonia, influenza, and tuberculosis, which were the leading causes of death in the United

6. U.S. Department of Health and Human Services, *Healthy People 2000: National Health Promotion and Disease Prevention Objectives*, DHHS Publication no. (PHS) 91-50213 (Washington, D.C., 1991).

7. NCHS, *Report of the Workshop on Improving Cause-of-Death Statistics*, National Committee on Vital and Health Statistics (Virginia Beach, Va., 15–17 October 1989).

States. By 1991, only one of the ten leading causes in 1900—pneumonia and influenza—remained among the ten leading causes of death (see Table 1).[8] The three infectious and communicable diseases that were leading causes of death at the beginning of the century have all been supplanted by chronic diseases—specifically, heart disease, cancer, and stroke.

A comparison of leading causes of death for 1986–1988 with the prevalence of chronic conditions further underscores the growing disjuncture between disease and disability and cause of death.[9] The leading chronic condition is chronic sinusitis, which afflicts about 14 percent of the population, but is not life threatening. This is followed by deformities and orthopedic impairments, affecting about 13 percent of the population. Arthritis is the third leading condition (13.1), followed by high blood pressure (12.1), allergies (9.3), and deafness and other hearing impairments (8.9). Heart disease is the seventh leading chronic condition (8.2), and the first to appear on both lists. If chronic bronchitis and asthma were combined, as they are for mortality, they would have a high prevalence (9.1), ranking sixth compared with a rank of fifth for mortality. Many of these conditions are not life threatening or can be controlled by medication. As such, the modern health afflictions that burden the health care system and society are often not the same as causes of death. This disjuncture, noted by Verbrugge[10] and others, places a new emphasis on the measurement of disabilities and impairments, and the standardization of these measures is reflected in the new classification system called the "International Classification of Impairments, Disabilities, and Handicaps," which supplements the traditional *International Classification of Diseases* used for mortality and morbidity.[11]

CAUSE OF DEATH FOR THE ELDERLY

A third characteristic of contemporary cause-of-death statistics reflects the persistent difficulties of ascertaining and reporting the cause of

8. NCHS, (n. 4).

9. J. G. Collins, "Prevalence of selected chronic conditions, United States, 1986–88," *National Center for Health Statistics: Vital Health Statistics*, 1992, *10*, 182.

10. Lois M. Verbrugge, "Recent, present, and future health of American adults," *Annu. Rev. Public Health*, 1989, *10*, 333–61.

11. World Health Organization (WHO), *International Classification of Diseases: Manual of the International Statistical Classification of Diseases, Injuries, and Causes of Death, Ninth Revision* (ICD-9), vol. 1 (Geneva, 1977).

TABLE I

Distribution of Ten Leading Causes of Death: United States, 1900 and 1991

1900				*1991*		
Number	*Percent*	*Rank order*	*Cause of death*	*Rank order*	*Number*	*Percent*
323,217	100.0	—	All causes	—	2,169,518	100.00
40,362	12.5	1	Pneumonia & influenza	6	77,860	3.6
38,820	12.0	2	Tuberculosis	—	—	—
28,491	8.8	3	Heart disease	1	720,862	33.2
27,427	8.5	4	Diarrhea, enteritis & ulceration of the intestines	—	—	—
21,353	6.6	5	Stroke	3	143,481	6.6
17,699	5.5	6	Nephritis	—	—	—
14,429	4.5	7	Accidents	5	89,347	4.1
12,769	4.0	8	Cancer	2	514,657	23.7
10,015	3.1	9	Senility	—	—	—
8,065	2.5	10	Bronchitis	—	—	—
—	—	—	Chronic obstructive pulmonary disease (COPD)	4	90,650	4.2
—	—	—	Diabetes	7	48,951	2.3
—	—	—	Suicide	8	30,810	1.4
—	—	—	HIV infection	9	29,555	1.4
—	—	—	Homicide	10	26,513	1.2
103,796	32.1	—	All other causes	—	396,832	18.3

Note: data for 1900 are for 10 states and the District of Columbia, which comprised the U.S. death registration area.

Sources: CDC/NCHS, National Vital Statistics System, 1991.

death for elderly persons. At the beginning of the century, the life table median age at death was between fifty-five and sixty years. This increased rapidly during the twentieth century, so that today the proportion surviving to that age is on the order of 90 percent.[12] Thus, the success of medicine and public health has greatly reduced the likelihood of dying from infectious and communicable diseases. Even for those with chronic diseases, the prospect of long life has been substantially extended. By 1991, persons aged sixty-five could expect to live, on average, more than seventeen additional years, to more than eighty years total.[13]

The extension of life span in the United States represents not merely a quantitative change in the structure of mortality in the United States but a qualitative change in which mortality is increasingly a phenomenon of the elderly and is a reflection of the diseases associated with aging. The average number of reported causes increases from about 2.5 at ages twenty-five to thirty-four years to about 2.9 at ages eighty-five years old and older.[14] Translating this cross-sectional observation to a historical perspective, as the population ages, the proportion of deaths with multiple conditions increases. This trend is observed in NCHS mortality data reported in a paper published in 1986.[15] In 1917, only 35 percent, or about one in three deaths, had more than one cause reported. By 1955, more than one-half (60 percent) of all deaths had more than one cause reported. By 1990, the figure was more than 80 percent. This trend of increased reporting of multiple causes in the medical certification is consistent with basic demographic and epidemiologic trends being experienced in the United States and in a number of other industrialized countries. The increasing reporting of multiple causes results in part from the aging of the population and the consequent increase in the proportion of deaths due to chronic diseases and may in part be from improved cause-of-death reporting.

The death certificate does a reasonable job in characterizing cause

12. NCHS, (n. 4).

13. Ibid.

14. Harry M. Rosenberg, Frances Chevarley, Eve Powell-Griner, Kenneth Kochanek, and Manning Feinleib, "Causes of death among the elderly: information from the death certificate," in Manning Feinleib, ed., *Proceedings of the 1988 International Symposium on Data on Aging*, NCHS, *Vital and Health Statistics*, series 5, no. 6, DHHS Publication no. (PHS) 91-1482 (Hyattsville, Md., August 1991), 35–58.

15. R.A. Israel, Harry M. Rosenberg, L.R. Curtin, "Analytical potential for multiple cause-of-death data," *Am. J. Epidemiol.*, 1986, *124*, no. 2, 161–79.

of death for the younger population, but its precision and specificity decrease rapidly with increasing age.[16] In an NCHS study, cause of death from the death certificate was compared with responses from the 1986 NCHS National Mortality Followback Survey question about the health history of the decedent. By correlating the responses from the survey with causes of death reported on the death certificate, one could ascertain the extent to which the death certificate reflected the medical history of the decedent and whether the correlation changed with increasing age. For example, among the elderly death due to cardiovascular disease (CVD) was almost as probable for those with a history of a heart attack as it was for those without a history of heart attack. This same pattern was observed for virtually all of the conditions examined in the followback survey; that is, with increasing age there was a weakening association between the history of a serious medical problem and its subsequent manifestation as a cause of death. Thus, the link between mortality and morbidity weakened with increasing age.

Thus with the changing structure of mortality in the United States, it has become increasingly apparent that the death certificate as currently designed may not be appropriate to capture the mortality of the elderly. The present format of the medical certification of death was adopted by the United States in the late 1940s in accordance with the recommended international standard shown in Fig. 1. This form was carefully designed to standardize reporting of causes of death by helping the medical certifier (that is, the physician, medical examiner, or coroner), identify a single, unique medical condition or trauma that initiated the chain of events resulting in death. The certificate is divided into an upper part identified as part I, and a lower part, below the line, as part II.[17] In part I, the physician is asked to provide the causal chain of events beginning with the most proximate condition on line a, then on line b what caused the condition on a, then on line c the condition that caused the condition on line b. In part II are to be reported other significant conditions that are not in the causal chain. The lowest-used line of part I is to record the "underlying cause of death." The underlying cause is the basis

16. Rosenberg *et al.*, (n. 14).
17. WHO, (n. 11) *International Classification of Diseases.*

CAUSE OF DEATH		Approximate interval between onset and death
I		
*Disease or condition directly leading to death**	(a). . . . . due to (or as a consequence of)	. . . . .
Antecedent causes Morbid conditions, if any, giving rise to the above cause, stating the underlying condition last	(b). . . . . due to (or as a consequence of)	. . . . .
	(c).	. . . . .
II		
Other significant conditions contributing to the death, but not related to the disease or condition causing it	. . . . .	. . . . .
	. . . . .	. . . . .

* This does not mean the mode of dying, e.g., heart failure, asthenia, etc. It means the disease, injury, or complication which caused death.

Fig. 1. International form of medical certification of cause of death. Source: WHO, ICD-9.

for most tabulations of cause-of-death published by the United States and by other countries.

The underlying cause is defined by the World Health Organization (WHO) as "(a) the disease or injury which initiated the train of morbid events leading directly to death, or (b) the circumstances of the accident or violence which produced the fatal injury." It is the condition on the death certificate believed to be most important for public health. To quote from the *International Classification of Diseases, Ninth Revision*: "From the standpoint of prevention of deaths, it is important to cut the chain of events or institute the cure at some point. The most effective public health objective is to prevent the precipitating (that is, the underlying) cause from operating."[18]

The basic assumption in the design of the medical certification of death is that the medical certifier can identify a linear sequence of conditions initiated unambiguously by a single medical condition or trauma. Although this assumption may be true for many of the countries of the world and for deaths at younger ages, it is questionable

18. Ibid.

for a society where death is preponderantly a phenomenon of the aged. For the elderly, the underlying cause of death is less the result of a clearly defined etiological path than the random result of a more generalized deterioration of the capacity for life, or, as R. R. Kohn described it, "an accumulation of diseases."[19]

In sum, the third characteristic of contemporary cause-of-death data is that mortality of an increasingly large segment of the population, the elderly, is probably not well captured by a death certificate designed to reflect the simpler, more linear morbid process of younger decedents.

ADVANCES IN MEDICAL SCIENCE AND TECHNOLOGY

A fourth contemporary problem is the impact on cause-of-death data of changes in methods of data collection, changes in medical terminology, and changes in medical diagnostic techniques. The impact of changes in data collection is illustrated with a recent study of trends in diabetes mortality.[20] Historically, death rates from this sixth leading cause of death in the United States remained relatively unchanged until the late 1960s, when a decade-long reduction of about one-third began. However, from the mid-1980s, the risk of dying from diabetes began to increase gradually, at a rate of about 1 percent per year. Then, between 1988 and 1989, the NCHS annual mortality report noted that the death rate from this cause increased in just one year by about 14 percent, creating a sensation in the diabetes community and a good bit of public awareness when reported by the media. The NCHS report did communicate some reservations about the large increase: "Although there was a very large increase in age-adjusted death rates for diabetes mellitus between 1988 and 1989 and a very large decrease for atherosclerosis, there are no known reasons for these changes. They may reflect, in part, changes in

19. R.R. Kohn, "Cause of death in very old people," *J. Am. Med. Assoc.*, 1981, *247*, no. 70, 2793–97. Kohn recommended that the cause of death for the elderly be reported as "senescence" when "deaths in debilitated members of the aged population cannot be ascribed to a disease process that would cause death in a middle aged person."

20. L.S. Geiss, P.J. Smith, W.H. Herman, H.M. Rosenberg, M.S. Eberhardt, W. Schramm, C. Friedman, "Increased diabetes mortality in the late 1980s: epidemic or artifact?" presented at the Eighth National Conference of Chronic Disease Prevention and Control, 17–19 November 1993, Kansas City, Missouri.

the way in which physicians report causes of death on the death certificate."[21]

In the United States, about once every ten years the content and format of vital records used by the states are modified, resulting in revised certificates. The revisions, which are the result of an extensive and complex deliberative process involving researchers, state vital registration officials, epidemiologists, and others, are intended to respond to new data needs and new legal requirements. The goal of the revision process is to achieve a consensus on changes that will be reflected in a model certificate called the "U.S. standard," which is recommended for implementation by all of the states in the same data year, most recently 1989.[22] The revised certificates include the certificates of live birth, marriage, divorce, and death, and the reports of induced termination of pregnancy and spontaneous termination of pregnancy, or fetal death.

The revision process may result in major or only minor changes in the forms. Thus, effective 1989 the standard birth certificate and the report of fetal death were modified in a major way to provide additional information on risk factors associated with the pregnancy outcome, complications of labor and delivery, method of delivery, and abnormal conditions of the newborn or fetus. Changes were also made to the death certificate, where emphasis was placed on changes that would improve the accuracy of reporting cause of death. One result was expansion of instructions to include two examples of properly completed medical certifications. In the first example, the causal sequence in part I shows that the decedent died of a heart attack, having had a reported history of heart disease for an estimated five years before the acute myocardial infarction. In part II, the other significant conditions include chronic obstructive pulmonary disease, smoking, and diabetes. The second example was a death resulting from a motor vehicle accident.

The revision of the death certificate resulted in a second change to the medical certification: the addition of a fourth line to part II

21. NCHS, "Advance report of final mortality statistics, 1989," *Monthly Vital Statistics Report*, *40*, no. 2, supplement (Hyattsville, Md.: Public Health Service, 1992), p. 7.

22. George C. Tolson, Judy M. Barnes, George A. Gay, Julia L. Kowaleski, "The 1989 Revision of the U.S. standard certificates and reports," *Vital and Health Statistics*, series 4, no. 28, DHHS Publication no. (PHS) 91-1465 (Hyattsville, Md., June 1991).

to provide additional space for reporting other significant conditions not in the causal chain of morbid events that resulted in death. This was recommended because many certifications were including more than three conditions per death. It was believed that an additional line would alleviate crowding and would make the report more legible and easier to complete. Most states revised the certificates for implementation beginning with the 1989 data year, but twelve states made changes a year earlier, for implementation in 1988 instead of 1989. Twenty-three states added examples to their certificates, and thirty-seven states added a fourth line to part II.

The changes in the certificate appear to have had an effect on the observed trend in diabetes mortality. Over a two-year period between 1987 and 1989, the death rate for diabetes increased from 16.2 death per 100,000 population to 19.4, an increase of 19.8 percent, and an increase of almost 10 percent per year compared with the recent historic increase of about 1 percent per year. After adjusting for year-to-year differences, death rates from states using the revised death certificates were about 21 percent higher, on the average, than from those using unrevised certificates. Among states with revised certificates, effects on the rates resulted from both the number of lines and whether examples were added, the number of lines being the more influential of the two factors. Also examined was the trend in diabetes mortality, in terms of whether diabetes was reported as the underlying cause of death or was mentioned either in part I or in part II of the certificate. Mention of diabetes anywhere on the certificate increased less than 2 percent between 1987 and 1989, compared with the almost 20 percent increase in diabetes as the underlying cause of death. Thus, the revision in the certificate did not affect whether diabetes was reported on the certificate but did shift its placement from being reported in part II as a contributing condition to part I as an underlying cause. Further support for the attribution of the 1987–1989 increase to the revision in the certificate is from the mortality trend in diabetes subsequent to 1989. Recently published data show that the rate from this cause increased by 1 percent between 1990 and 1991 and decreased slightly between 1991 and 1992.[23]

If the revision of the certificate resulted in relatively large increases in mortality from diabetes, compensating reductions in mortality from

23. NCHS, (nn. 2, 4).

other causes should have been detectable. Indeed, such compensations were observed. For instance, the long-term decline in atherosclerosis mortality accelerated during this period.[24] Such changes suggest that the revision of the U.S. Standard Certificate of Death accomplished its intent to improve the quality of medical certification. Atherosclerosis is not a precise diagnosis, and the level of mortality attributed to it decreased as a result of the change in the death certificate. The diabetes example shows, then, the sensitivity of mortality trends to changes in data collection instruments, as subtle as a change in instructions or the addition of an extra line. Inasmuch as NCHS and the states are now contemplating major changes in the way in which mortality data are collected (in particular, a change to an electronic form called the Electronic Death Certificate), it can be anticipated that a major disruption in cause-of-death trends will occur that will be attributable to these changes.

Also affecting mortality trends are physician reporting practices in the terminology used to describe a diagnosis. P. D. Sorlie and E. B. Gold, for example, showed that the reporting of cardiovascular diseases varied depending on whether the certification was completed by a physician or by a medical examiner/coroner and that these differences had major implications for geographic comparisons of mortality.[25] A study by NCHS staff shows that the way in which physicians reported mortality from respiratory diseases significantly affected long-term trends of these diseases.[26] A change in the way in which physicians reported chronic respiratory diseases that began in the late 1960s had major consequences for mortality trends from these causes. During the 1950s and 1960s mortality from emphysema and bronchitis increased rapidly, while the death rate from asthma declined. However, beginning around 1968, death rates from emphysema and bronchitis began to decrease. What was happening? Medical coders and nosologists who coded cause of death increasingly found on death certificates a new diagnosis, "chronic obstructive lung disease," or "COLD," without mention of the more specific diagnoses of chronic bronchitis,

24. NCHS, (n. 4).

25. P.D. Sorlie and E.B. Gold, "The effect of physician terminology preference on coronary heart disease mortality: an artifact uncovered by the 9th revision, ICD," *Am. J. Public Health*, 1987, *77*, 148–52.

26. M. Feinleib, H.M. Rosenberg, J.G. Collins, J.E. Delozier, R. Pokras, F.M. Chevarley, "Trends in COPD morbidity and mortality in the United States," *Am. J. Respir. Dis.*, 1989, *140*, no. 3, part 2, supplement, S9–S25.

emphysema, or asthma. To capture this new term, NCHS introduced a new four-digit subcategory, "chronic obstructive lung disease without mention of asthma, bronchitis, or emphysema," with the code *519.3.[27] The number of certificates assigned to this category increased rapidly, from 2,704 for 1969 to 28,613 for 1978.

As a consequence of the change in terminology, to obtain a meaningful trend in respiratory disease mortality it is necessary to add the number of deaths assigned to the new category and the number of deaths assigned to the specific diagnoses of respiratory diseases. "All COPD" increased continuously from 1950 through 1992 and today remains the fourth leading cause of death in the United States. After HIV infection, COPD is the most rapidly increasing cause of death in the United States. Between 1979 and 1991, the death rate from this cause increased by 38 percent, or by about 2.5 percent per year.[28]

Chronic obstructive pulmonary disease also illustrates how the cause-of-death classification affects the characterization of health problems and the importance of one disease compared with another. In 1978, respiratory diseases did not rank among the ten leading causes of death; they ranked eleventh, in a category called "bronchitis, emphysema, and asthma." However, in 1979, chronic respiratory diseases ranked as the fifth leading cause of death in the United States. The dramatic change in ranking was the result of the combination category, chronic obstructive pulmonary disease, formally introduced as a cause-of-death category beginning with the World Health Organization's ninth revision of the *International Classification of Diseases*, effective with the 1979 data year. To be sure, there were policy implications of the ranking both before and after 1979. Because of its low ranking before 1979, respiratory diseases did not receive priority attention among the major initiatives for disease prevention and health promotion in the Surgeon General's report *Healthy People*.[29] This has since been rectified.

Changes in diagnostic technology can affect cause-of-death trends, as illustrated by a recent study of trends in brain tumor mortality. Thus, symptoms characterizing a particular disease under one diagnostic regimen may, under a more thorough regimen, be assigned to an

27. NCHS, Vital Statistics of the United States, 1978, *2* , Mortality, part A, DHHS Publication no. (PHS) 83-1101 (Washington, D.C.: Public Health Service, 1983).
28. NCHS, (n. 4).
29. U.S. Department of Health, Education, and Welfare, (n. 6) *Healthy People 2000.*

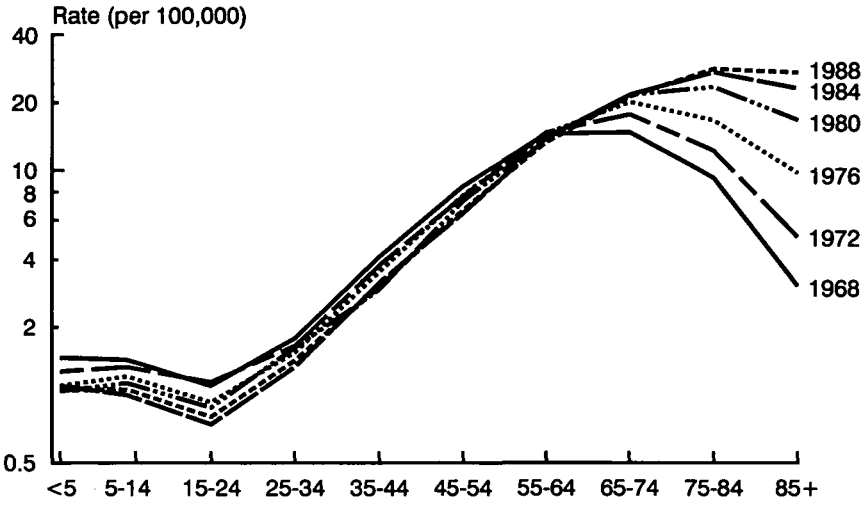

Fig. 2. All brain-tumor mortality, 1968–1988, by age and selected years. Source: CDC/NCHS, Vital Statistics of the United States, Mortality 1968–88.

entirely different disease. This may be the explanation for the recent upward trend in brain tumor mortality of the elderly.[30]

Figure 2 shows death rates from brain tumors for selected years from 1968 to 1988 by age. Each line represents a calendar year of observations. The general pattern is low rates for the population under twenty-five years, increasing for ages fifty-five to sixty-four years. Beyond sixty-five years, the pattern varies by the year of observation. For 1968, there is a sharp downturn in mortality after age sixty-five; but this pattern shifts as one moves forward in time. By 1988, the pattern of brain tumor mortality is the expected increase in death rates with increasing age characteristic of chronic diseases. Viewed over time, death rates from brain tumors increased by 50 percent for persons aged sixty-five to seventy-four years, by 200 percent for those aged seventy-five to eighty-four years, and by more than eight times for those eighty-five years old and over. For those under sixty-five years, there was little increase during this time period.

The study made two observations about these patterns of mortality.

30. B. Modan, D.K. Wagener, J.J. Feldman, H.M. Rosenberg, M. Feinleib, "Increased Mortality from brain tumors: a combined outcome of diagnostic technology and change of attitude toward the elderly," Am. J. Epidemiol., 1992, *135*, no. 12, 1349–57.

First, trends in which death rates increase sharply for the older age groups but not the younger are improbable. Exogenous forces producing changes in the risk of death most likely will operate generally on all age groups, not selectively. For example, a newly introduced carcinogen can be expected to affect all ages, not just the elderly. Second, the expected pattern of mortality seen with most diseases is increasing risk with increasing age. As such, one expects a pattern more nearly like that for 1988, not the pattern observed for 1968. The 1968 pattern suggests a severe deficit in mortality at the older ages.

As an explanation of the observed patterns, two factors were suggested. Changes in brain tumor mortality were found to be correlated with the use of the newer, more intensive diagnostic techniques, such as the improvements in the technologies of noninvasive diagnostic procedures of the head, improvements in surgical procedures of the head, and the use of CAT scan, or computerized axial tomography. A second possible factor to explain the pattern of increase in brain tumor mortality is changes in health care of the elderly during the period. With the advent of Medicare in 1968, the elderly could benefit from more complete diagnoses because the costs are not borne by the patients. Thus, deaths that, with minimal diagnostic workup, may earlier have been attributed to stroke, may, under the new diagnostic regimen, have been assigned to brain tumor. Thus, the study concluded that the trend in brain tumor mortality was not the result of greater risk, but rather of changes in diagnostic technology and a more accessible health care environment.[31]

HIV INFECTION

A review of contemporary issues of cause of death could not be concluded without discussion of the classification of AIDS. HIV infection has interest not only because of its signal importance as a public health problem, but because it illustrates the way in which the vital registration system must necessarily have dynamic attributes that allow it to properly classify and monitor changes in health that may arise from emergent diseases or public health problems. Certainly, the AIDS epidemic epitomizes a major public health problem not

31. Ibid.

previously seen, though its scope is still not at the level of tuberculosis at the beginning of this century.

With regard to the vital registration system, HIV infection went through an interesting evolution. When the disease was first seen and identified clinically, its viral origin was not established. Its main manifestations as a type of skin cancer called Kaposi's sarcoma, or as a type of pneumonia called pneumocystosis, indicated a weakening of the immune system that made the patient vulnerable to a variety of opportunistic diseases and infections. In response to questions regarding coding and classification, WHO first recommended that this new disease be classified to ICD. 279.3, unspecified immunity deficiency, then shortly afterward to. 279.1, deficiency of cell-mediated immunity. Because of evolving terminology for the condition, some of the deaths were also classified to their disease consequences, such as Kaposi's sarcoma, or pneumocystosis, or a number of specified infections (lymphadenopathy, toxoplasmosis, etc.).

By 1985, it was known that the disease was caused by the human T-cell lymphotropic virus-III/lymphadenopathy-associated virus, or HTLV-III/LAV infection, and the classification the disease by WHO as a disorder involving the immune system was recognized as incorrect. As a consequence, the Centers for Disease Control and Prevention (CDC) in 1987 established a task force developed a new classification for HIV infection. The classification was complex, as it attempted to capture in some combination the stage and severity of the disease as well as some of its manifestations. The disease was to be represented by an unused set of numbers, *042–*044, which were properly in chapter 1 of the ICD, infectious and parasitic diseases, rather than in chapter 3, which included the metabolic diseases. The CDC then promulgated the new classification for morbidity and mortality coding in the United States and in Canada, effective with the classification of illnesses and death for the data year 1987.[32]

The HIV classification has since been modified twice, first in 1988 to change the name from HTLV-III/LAV to human immunodeficiency virus (HIV) infection and make minor changes in the content of the classification, and then in 1991 to make additional changes in the content of the classification and to create an entirely new and

32. NCHS, *Vital Statistics of the United States, 1987, 2*, Mortality, part A, DHHS Publication no. (PHS) 90-1101 (Washington, D.C.: Public Health Service, 1990).

separate category for Kaposi's sarcoma (176), which had previously been classified under malignant skin cancer. The classification is once again being reviewed with a goal of simplification. Despite the many changes in the classification system with regard to HIV infection, the vital registration system has provided a sound statistical basis for assessing the character of the disease and its spread throughout the United States, from an estimated 2,943 deaths in 1984 to the 29,555 deaths in 1991, when it ranked as the ninth leading cause of death for the total population, and the second leading cause men aged twenty-five to forty-four years.[33] By 1992, HIV infection was the leading cause for this age group.[34]

The recent outbreak of deaths from hantavirus among American Indians in the Southwest is likely to result in a further change to the classification system, as the new disease apparently has systemic consequences that differ from those seen previously with infections from this virus, which is endemic in Korea and other Southeast Asian countries.[35]

SUMMARY

Four characteristics have been identified that affect the contemporary analysis of cause of death: (1) the increasing use of cause-of-death data for public policy; (2) the growing disjuncture between cause of death and cause of poor health; (3) the problem of specifying cause of death for the elderly, who constitute a growing proportion of the population and, accordingly, of mortality; and (4) the impact of technology and medical science on the temporal comparability of mortality statistics. With regard to the first issue, statistical data in general are being used with increasing sophistication throughout society. The public is exposed to all types of data by the media, and is increasingly educated in how to interpret statistics. Government at all levels increasingly uses data to help identify priorities, to choose among policy options, and to evaluate outcomes of decision making. Cause-of-death data are but a specific subset of information that are being used to understand social, economic, and health issues and to

33. NCHS, (n. 4).
34. NCHS, (n. 2).
35. Centers for Disease Control and Prevention, "Update: Hantavirus pulmonary Syndrome—United States, 1993," *Morbidity and Mortality Weekly Report*, 29 October 1993, *42*, no. 42, 816–20.

make more informed private and public choices regarding these issues. Increasing use of any data set is likely to result in better data simply because greater use results in closer scrutiny of data quality with resultant emphasis on evaluation and systematic efforts to improve quality. This is happening to cause-of-death data in the United States. The National Center for Health Statistics (NCHS) initiated major efforts through two national workshops in 1989[36] and 1991 to improve the quality of medical certification of death through better training of physicians, medical examiners, and coroners. While there is no clear evidence that the initiatives resulting from these workshops alone resulted in data quality improvement, the indicators used by NCHS to measure quality of medical certification point to continued gradual improvement in completeness and specificity in cause-of-death data.

The gap between causes of morbidity and causes of mortality is growing because advances in medical science have essentially eliminated many infectious and communicable diseases that previously caused premature death and have considerably reduced the lethality of chronic conditions that previously caused death at earlier ages. As acute conditions have moved into the background, so to speak, a variety of disabilities and impairments have moved forward as sources of illness, pain, and diminished quality of life. As a consequence, the previously clear etching in mortality statistics of a society's health has become blurred by advances in medicine, health care, and prevention. Mortality data continue to have value per se and are important to social and medical knowledge because of their availability as a uniquely continuous data set. However, increasingly, a complete and contemporary profile of the health of a society requires data on both morbidity and mortality as complementary indicators of health and social development. Not only do we need to know of what causes people die, but also what health conditions aggravate and diminish their lives and, at an aggregate level, what conditions impose the greatest health costs on the community. Increasingly, these are debilitating conditions of the elderly that may diminish life but may not cause death.

Medical description of the cause of death of an elderly person has probably never been easy; however, the contemporary extension of life has made the problem more visible and substantial than in earlier

36. NCHS, (n. 7) *Report of the Workshop on Improving Cause-of-Death Statistics.*

times. It is likely that the relatively few octogenarians of centuries past were also afflicted by concurrent medical conditions, and that even younger persons were prematurely afflicted by conditions that are now identified with advanced age. For these population groups, the description of cause of death, as a single and singular initiating event, is problematic. Instead, for them, death is multifactorial and is not readily amenable to linear description. Clearly, the traditionally designed death certificate with its emphasis on a single, underlying cause of death does not satisfactorily capture Kohn's description of an elderly person's death as due to either an "accumulation of diseases" or to "senescence." One way of dealing with the problem of mortality for the elderly is to restrict historic comparisons of mortality to the population groups believed to be more equivalent. Thus, fifty year olds may represent the elderly in a society whose life expectancy is thirty-five years, as eighty-five year olds represent the elderly in contemporary industrialized society where life expectancy is about seventy-five years. Comparisons of mortality, then, may need to be indexed for age inflation similar to comparisons of income which are facilitated by conversion into "constant" dollars, which have been adjusted for the effect of inflation.

Science and technology have profoundly affected medicine and the profile of mortality. Technology affects the way in which data are collected. Data collection forms have been modified and improved, reflecting advances in survey methodology and questionnaire design. In the case of the death certificate, small changes have been made in the latest version of the U.S. Standard Certificate of Death (slight departures from the international standard), which resulted in unanticipated breaks in trend, most dramatically illustrated by the trend in diabetes mortality. In the future we can anticipate additional disruptions in trend as data collection moves from paper to an electronic medium. An electronic medium for data collection will allow for much greater flexibility; it will allow, for example, for immediate checks of consistency between different items such as cause of death and age of decedent; it will allow querying the reporter about ambiguous responses; it will allow for in-depth exploration. In sum, it is likely to produce data of greater uniformity, accuracy, complexity, and detail than do paper forms or questionnaires. The shift from paper to an electronic medium for data collection may have almost

as profound an impact as the transition from an oral to a written tradition.

Technology and science also affect comparability through changes in terminology, nomenclature, and classification. When the terminology for chronic respiratory disease changed in the late 1960s because of diagnostic advances and changes in terminology, mortality trends were broken. And when the ninth revision of the *International Classification of Diseases* was introduced in the late 1970s, the health profile of the United States, especially in terms of the importance of chronic respiratory disease, was altered in a major way. We also showed how improvements in diagnostic technology affected trends in brain cancer mortality.

Advances in science and technology, therefore, are powerful driving forces not only in terms of the health of society, but also in terms of the measurement of health. Trends in cause of death are shaped by advances in medical science, but also by the science, technology, and linguistics of diagnosis and by the environment in which medical care is provided. To be sure, these trends, no doubt of early origin, will continue to affect not only medicine, but also data collection.

The contemporary problems in cause of death that have been described should not be viewed as impediments to the use of cause-of-death data to enlarge our understanding of social and medical history. No data set can be used effectively without an understanding of the changing social, economic, and technological context within which the data are collected and the elements in that context that impinge most directly on the data. This is as true of epidemiological and medical data as it is of social and economic data. Over time, data collection instruments become more sophisticated and sensitive; meanings change; emphases shift; and dimensions multiply.

The medical historian, the sociologist, and the epidemiologist need to be aware of the data issues prevailing at different points in time, similar to those discussed; and, undaunted, to use cause-of-death data with an appreciation of the problems of continuity over time, which likely are no greater today than in the past.