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The Quality and Utility of Death Certificate Data

Despite the impressive strides in health information, mortality statistics are the only source of data at the national, state, and local level that is consistently available and that satisfies the basic criteria of coverage and continuity. The historic role of death certificates both as legal documents and public health records has long engendered an awkward balance between their legal purpose and content, and the procedures for their use and application on a community level. Whatever accommodations users have accepted, they tend to assume that mortality information is accurate. But is it? Percy, Stanek, and Gloeckler¹ examine the question of accuracy in the case of cancer mortality in this issue of the Journal.

Neither the accuracy of the reporting as defined by the study methods nor the interpretation of the results appears to be very heartening. The study determined that only 65 per cent of the observed underlying causes named on the death certificates fell into the groups that were defined as indicating good agreement. Using site-specific cancer as categorized by the three-digit ICDA codes, the study found substantial variability in accuracy of underlying cause among the separate site-specific cancer categories. In discussing the sources of disagreement, the study identified the physician or coroner as the most common source for discrepancy, and concluded there is a need to raise the level of awareness of physicians and coroners to pay greater attention to entries of cause of death.

While this detailed cancer specific study is largely directed toward epidemiological applications, it raises a number of broader issues about the quality, use, and evaluation of current cause of death information.

Any measure of "accuracy" used to evaluate death certificate information is wholly dependent on the performance requirements determined by a specific user. An epidemiologist following a relatively rare disease will have an exacting requirement for accuracy, whereas the community health planner may well be satisfied with the relative rank or magnitude of a disease specific entity. The epidemiologist will use the death certificate as a point of departure; and the planner will use it as an appropriate end point.

Upgrading the system and its accuracy is a variable thing, since the death certificates serve such diverse user audiences. On the one hand, access to the certificate becomes a major obstacle to the epidemiologic clinician, or disease specific investigator who would not rely on the certificate except as a starting point for a detailed study. This situation is illustrated in the cancer mortality findings in that site-specific cancers appearing in the poor accuracy groups (Groups 2-4) are relatively rare. Any rigorous study of rare phenomena would invariably turn toward a comprehensive case finding approach without sole reliance on either hospital or death records.

On the other hand, to the community health planner, the intended use of mortality data may be to characterize time trends in broad disease groupings and demographic shifts. Using larger aggregations of specific 3-digit ICDA groupings will tend to lessen errors in accuracy. The proportional mortality (Table 8) of Percy, Stanek, and Gloeckler give some assurance that the hospital and death certificate results are

much more consistent when based on aggregate categories. Agreement is measured by a comparison of the separate marginal distributions of hospital reports and death certificate data. In practice, health planners would be using data based on both aggregated ICDA categories and groups of individuals. Accuracy is a different matter for the aggregate data user.

Measurement of the accuracy of reporting is, in any case, dependent on the methodology employed. Percy, Stanek, and Gloeckler present a methodology that places a number of restrictions on reported cancer diagnoses to be eligible for the study. Such restrictions include using certificates with mention only of single cancer sites, mention of cancer on both hospital and death certificates, and defining two measures of agreement which employ arbitrary performance levels to define accuracy groupings. As in the case of many large scale studies, it is difficult to evaluate the sensitivity of the measures, or the impact of the exclusions and conditions imposed by the design to facilitate the conduct of the study.

Recent developments in the indexing of death certificates and coding do offer alternative opportunities to support more studies of accuracy and evaluation. Developments in linkage and follow-up ability will become major adjuncts to quality and accuracy studies.^{2,3} In the course of the past decade, the need for a National Death Index in the United States has been recognized and efforts have been intensified to produce such a system.⁴ Such an effort is sizable. The National Center for Health Statistics has recently announced the upcoming implementation of the Index providing researchers with a central source for identifying the probable fact of death for queried persons and the death certificate number and state of occurrence.⁵

Undoubtedly better access to tracking deaths will engender greater use of mortality data. This will expose more investigators to the limitations of the data and the attendant ambiguities on the entirety of information on the death certificate. The types of incongruities seen in the cancer study will become more conspicuous as diverse studies are facilitated through the use of the Index.

Such exposure can be turned to good purpose. A reporting system with an appropriate evaluation form can facilitate gathering user-experience on quality and accuracy of items on certificates. A feedback loop from Index users may quantify problems in age reporting, birth-death matching, and ethnic identification, as well as cause of death reporting.

Further refinements in assigning and coding causes of death introduced because of the changes in rules or in technology will also affect the use and accuracy of mortality data. The decennial revision of the ICDA classification scheme attempts to keep classification abreast of current medical knowledge. The revision process requires compromises and the resultant revised rules of classification in turn directly affect time series mortality data. Ratios of the effect of coding change in successive revision for certain specific diseases can be quite large. In the change from the ICDA 8th to 9th revision, the comparability ratios ranged from .18 to 3.8 with 1.00 being the standard comparability ratio indicating no effect on a specific disease category. As ex-

pected, most of the specific ratios are not dramatically different from the standard, indicating little effect. Often the rationale and effect of the periodic revisions are not fully appreciated by the user, and can cause embarrassment when revision effects are not recognized.

A technological change—long in development—that offers a great potential for accuracy studies is the Automated Classification of Medical Entities (ACME) system. Starting with 1968 mortality data, the National Center for Health Statistics has used this computerized system to assign underlying causes of death.⁷ The ACME system coding rules are specific detailed, and the implementation of the underlying cause selection rules is consistent with international rules. The underlying cause of death is selected by matching the coded conditions from a certificate against the computerized decision tables and assigning a cause thereby promoting consistency that cannot be achieved by individual coder selected underlying cause.

Decision rules imply the use of the multiple cause information contained on the certificate. As in the cancer study, the underlying cause takes on a seemingly sacrosanct monolithic posture. This appearance of certainty is deceiving, of course. The rules for cause of death coding are responsive to the complex chain of events. Here, too, arbitrary decisions are required. But computerization can be used to vary decision trees, and examine the sensitivity of cause of death to decision rules in a facile manner. In addition, multivariate analysis can explore the more complete use of information contained on the death certificate. These suggestions are not novel, but wider recognition of increased access through computerization and software can facilitate the study of accuracy from an information analysis perspective.

Despite the promise of additional technology and greater ease in access to data, expectations for the use of mortality data to support detailed studies of health patterns and disease causation from our national death registration system as currently constituted are unrealistic. In 1978, the United States recorded a final complete count of 1,927,788 resident deaths.⁹ An estimate of the number of physicians, coroners, and medical personnel who contributed to the medical information is not available, but assuredly it is large. Since the turn of the century, formalized efforts to improve registration have been in place and constantly expanded. The registration system now, as well as then, is dependent on a long chain of individuals and arrangements in the 50 states and the territories of this country.

Efforts to maintain and improve the system encompass a variety of educational programs, self-improvement programs, and quality check procedures on local, state, and national initiatives. However, the diverse nature of the participants and their degrees of autonomy lead to an unevenness in the level and continuity of quality assurance efforts. The official authorities in vital statistics methodology have delineated the deficiencies, procedural problems, and efforts to evaluate the quality of mortality data;⁹ however, appendices and technical tracts do not automatically command attention by so wide a range of users. Furthermore, the dual nature of the legal and public health content of death certificates is a fundamental, inherent limitation.

A balanced view of accuracy of cause of death data lies somewhere between the assumption of complete truth in mortality information, and the assumption that cause of death accuracy should be expected to satisfy rigorous and specific criteria exactly consistent with detailed medical history gathered from follow-up studies. At the same time, it should be recognized that although accuracy assessments and quality studies have been a traditional activity, many contemporary and authoritative works on the quality of medical content studies rely on references that are not recent.

Mortality statistics will undoubtedly remain our primary source for continuous monitoring of population disease patterns. Constructively what is required are not only descriptive studies of quality, but prescriptive evaluations that are sensitive to the constraints of our mortality information system. The article by Percy, *et al.*,¹ in this issue of the Journal illuminates aspects of the mortality problem, but does not fully differentiate the consequences to the diverse audience of users of mortality data, nor does it delve into the limitations in definition and methods which studies of accuracy entail. The authors are quite correct in pointing out the need for further study. The implementation of the National Death Index, and the availability of computerized data and coding systems underscore this need and provide, in part, the mechanism for meeting it. Improvement in the accuracy of data,

given the nature of the system, is another story, however, and its achievement would represent no small feat.

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Editor's Report—1980

Once again, as the year ends, a report to the readership is due. The year rounds out half a decade of editorship for me, during which time both the face and the body of the Journal have undergone some changes. The major change in content has been a reduction in papers that could be characterized as descriptive reporting of programs or events. Their place has been taken by increased numbers of epidemiologic investigations, service evaluations or other research, and analytically oriented papers. There has been no change in the proportion of papers that can be called commentaries or health policy pieces: now, as then, they constitute one out of every five or six of the articles, commentaries, and briefs which we publish. Many of the 31 editorials solicited and published in 1980 also dealt with policy matters and concerns. There has been relatively little change in the subject areas covered by the Journal in the past five years although chronic diseases and gerontological care are beginning to be seen somewhat more frequently.

During 1980 we received 697 papers, unsolicited, the largest number in these five years; after revision, we published 139 unsolicited papers in 1980. We could not have done so without the help of a host of dedicated reviewers

whose names are published on pages 326-328 of this issue. During 1980 we inaugurated a new section, Different Views, in order to accommodate controversy that would not yield to the constraints of a 400-word letter to the editor. We also published 42 letters (most of those we received) commenting on some imagined or real fault in what we had printed or on the affairs of the world.

In 1980, only four years away from 1984, the affairs of the world seem in sorry shape. If all that George Orwell foresaw has not come to pass, we are close enough to some of it.¹ Big Brother may not be upon us, but the television screen has taken over Presidential elections; in the words of William Butler Yeats,

"The leaders of the crowd:
 . . . must to keep their certainty accuse
 All that are different of a base intent;
 Pull down established honor; hawk for news
 Whatever their loose phantasy invent."²

The thought police may not have pounded us into mindless conformity, but violence, torture, and terror are abroad in the world. We do not submit to a daily Two Minutes Hate, and the planet has not quite fallen into three equally