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HISTORICAL DEVELOPMENT OF CAUSE OF DEATH STATISTICS

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FOREWORD

[Cause of death]

Cause of death statistics are the by-products of a legal process, the registration of deaths. "This paper traces the historical development of these statistics, with special attention to international efforts to develop and maintain a common classification system and coding rules." The development of procedures for designating the underlying cause of death was an especially difficult task which has had many critics, but few suggestions for alternatives. Despite the limitations of official mortality statistics on causes of death, they have served well in delineating the major public health problems over the years, and also played an important role in the conduct of epidemiological studies. Yet much can be done to make cause of death statistics more useful, particularly multiple cause of death data.

HISTORICAL DEVELOPMENT OF CAUSE OF DEATH STATISTICS

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As a background to this presentation and discussion, it may be noted that one of the earliest, if not the earliest, systematic collection of information on causes of death was the old Bill of Mortality first published in London in 1532. These bills were weekly lists of burials and included the name of the deceased, the parish in which the burial took place, and the cause of death, with particular reference to the plague. The cause of death was determined by the searcher after she had viewed the body. In the more difficult cases, the searcher consulted a physician. The searchers made their reports to the parish clerk who prepared an account of all the burials every Tuesday night. On Wednesday, the general account was made and printed. The bills were distributed on Thursday to the subscribers who paid four shillings for an annual subscription.

More than a century later, John Graunt conceived of the idea of using the London Bills of Mortality for analytical purposes. He made ingenious use of imperfect data and made a number of generalizations such as mortality in the earliest years of life being relatively high. In the absence of mortality data by age, John Graunt (1662) estimated the number of deaths among children under 5 years of age as follows: "Having premised these general Advertisements, our first observations upon the Casualties shall be, that in twenty years there dying of all Diseases and Casualties, 229,150 that 71,124 dyed of the Thrush, Convulsions, Rickets, Teeth, and Worms; and as Abortives, Chryosomes, Infants, Livergrowns, and Overlaid; that is to say, that about 1/3 of the whole dies of those Diseases, which we guess did all light upon children under four or five years old."

Despite medical progress, the diagnostic quality of the old bills did not improve. Also, interest in these bills waned. Clerks of many parishes failed to report or reported only irregularly. Even when complete, the bills gave no information about the population much beyond the walls of London.

In 1837, the Registration Act was passed with provision for the inquiry into the causes of death occurring in the population of England and Wales. In 1839, William Farr was appointed Compiler of Abstracts in the Registrar General's office, and he, probably more

than any one else, developed and analyzed mortality statistics to delineate the sanitary and health problems of the day.

The English Registration Act of 1837 served as the prototype of the first State registration law in the United States enacted by the State of Massachusetts in 1842. In the years following, births and deaths were registered in few of the largest cities and several States. In 1855, the American Medical Association adopted a resolution urging its members to take immediate and concerted action in petitioning several legislative bodies to establish offices for the collection of vital statistics. By 1900, there were 10 States and the District of Columbia which met the requirements of the U.S. Census Office for admission to the U.S. Death Registration Area. Thus, the compilation of annual mortality statistics for the United States began with a handful of States in 1900. Nationwide coverage was not achieved until 1933.

Unlike most countries, civil registration in the United States is a decentralized system, that is, the responsibility for the registration of vital events is in the hands of the individual States. There is no national registration office as such and the States have complete autonomy with respect to registration matters. The system is loosely coordinated by the National Center for Health Statistics which is responsible for the setting of standards and guidelines and for the national compilation of vital statistics.

In almost every country, a family member or relative is required to appear before the local registrar to register the death. The local registrar records certain personal particulars and information about the death. If the registration law calls for information on causes of death, the hospital in which the death took place or the physician in attendance is required to forward the information to the local registrar.

In the United States, the mortician or undertaker, and not the family member is responsible for notifying the local registrar of the death. The death certificate which he files is a combined legal and statistical form which also includes the medical certificate of causes of death. It is the responsibility of the physician last in attendance to complete the medical certificate of causes of death. If the death occurred without medical attention, the case is referred to the medico-legal authority. Also, if death resulted from violence, or if foul play is suspected, the coroner or medical examiner reviews or investigates the case.

The undertaker is responsible for obtaining from a family member the personal particulars about the decedent and other information called for on the death certificate. He also obtains from the physician in attendance at death a completed and duly signed medical certificate of death. Upon filing the death certificate with the local registrar, the undertaker receives a burial permit

or a burial transit permit if the remains are to be shipped to another State.

This, in brief, is the death registration procedure in the United States. The registration practice differs somewhat by country, but official mortality statistics on causes of death are generally derived from the death record filed in compliance with the registration law. This law usually requires that a death certificate be filed before a burial permit can be issued for the legal disposition of the body.

Cause of death statistics are, by and large, by-products of a legal process, the registration of death. However, not all countries are able to produce cause of death statistics because their medical care system does not extend to a large part of its population. For these developing countries which represent more than one-half of the world population, lay reporting of causes of death is a possible source of cause of death statistics. Paramedics are being used in India, for example, for collecting by interview with family members information on causes of death. Feasibility studies have been made in other areas with some measure of success, but more developmental work is needed. However, there is little to be gained by collecting data and compiling statistics on causes of death until there is a reasonably complete death registration coverage in these countries.

The international development of cause of death statistics may be traced back to William Farr. In the first annual report of the Registrar General published in 1839, there is an oft quoted statement of Farr which is as follows: "The advantages of a uniform statistical nomenclature, however imperfect, are so obvious that it is surprising that no attention has been paid to its enforcement in Bills of Mortality. Each disease has in many instances been denoted by three or four terms, and each term has been applied to many diseases; vague, inconvenient names have been employed, or complications have been registered instead of primary diseases. The nomenclature is of much importance in this department of inquiry as weights and measures in the physical sciences and should be settled without delay".

At the first International Statistical Congress held in Brussels in 1853, Farr and Marc d'Espine of Geneva were requested to prepare a classification of causes of death applicable to all countries. It may be said that this marked the beginning of a remarkable international cooperation and collaboration in field of disease classification.

The present system for compiling cause of death statistics dates back to 1893 when the classification of causes of death was adopted by the meeting of the International Statistical Institute. This classification was prepared by Jacques Bertillon and was a

synthesis of the English, German and Swiss classifications based on the principles proposed by Farr. The Bertillon Classification of Causes of Death was adopted by several countries and a number of cities.

In 1898, the American Public Health Association proposed that the classification of causes of death be revised at decennial intervals to keep abreast of medical progress. The first revision conference was then convoked by the French Government in 1900. The first revision of the International List of Causes of Death was adopted by the conference. Also adopted were a medical certificate form for reporting the cause of death and the rules for selecting the cause of death for primary mortality tabulations.

The International List of Causes of Death (renamed the International Classification of Diseases in 1948), the medical certificate of cause of death, and the rules for selecting the cause of death for statistical purposes are the basic tools for the production of cause of death statistics. Each of these instruments are subject to review and modification at each revision conference. To date, there have been 10 decennial revision conferences. The last, or the Tenth Revision Conference, took place in 1989 in Geneva.

From 1900 to 1948, the revision conferences were held in Paris at the invitation of the French Government. The International Statistical Institute was responsible for the preparatory work for the First to the Sixth Revisions. From the Third to the Sixth Revisions, the International Statistical Institute shared the preparatory work with the Health Section of the League of Nations. At the Sixth Revision, the World Health Organization assumed the responsibility for the Sixth and future revisions.

The major focus of these revision conferences has been on the classification of diseases. The first revision of the International List of Causes of Death was comprised of some 179 categories of diseases and external causes of death. The number of rubrics had increased to 200 by the Fifth or the last revision of the International List of Causes of Death. At the Sixth Revision when the classification was expanded into a combined morbidity and mortality classification, the number of categories increased to 1010. This number was more or less maintained until the Tenth Revision when the number of rubrics was doubled to 2032. The number of categories in the Tenth Revision is 10 times that of the International List of Causes of Death. The expansion of the ICD resulted first from the accommodation of the needs for medical care statistics. Then, the needs of various medical specialties were catered to in the Ninth and Tenth Revisions. A big change in the Tenth Revision was brought about by providing additional rubrics for use of physicians and hospitals in billing for medical care services.

There is little question that the recent revisions of the International Classification of Diseases are much too detailed for the classification of causes of death. This may be demonstrated by the size of the tables devoted to the most detailed cause of death list published in the Vital Statistics of the United States. In 1939, the last year of the Fifth Revision of the International List of Causes of Death, the table on each cause of death took up 4 pages. In 1948, when the combined mortality and morbidity classification was adopted, the same table increased to 14 pages. When mortality data were tabulated by the Ninth Revision in 1987, the table on each cause of death took up 142 pages! Almost all the cells in this table showed zero or small frequencies. When the Tenth Revision comes into effect, it may be expected that the "each cause" table will take up over 250 pages unless the zeros and small frequencies are suppressed.

Traditionally, official mortality statistics have been compiled on the principle that a single cause must be attributed to a death. This cause has been variously labelled as the cause of death, the primary cause, the principal cause, the fundamental cause, and the basic cause of death. The wording of the present medical certificate is the underlying cause of death, that is, the disease that started the sequence of events leading to death.

To obtain this statistic, a medical certificate form was designed to collect the necessary medical information. The medical certificate that was proposed at the time of the First Revision of the International List of Causes of Death simply called for the Cause of Death and for a Contributory Cause of Death, that is, a disease associated with the death but unrelated to the Cause of Death. These two items of medical information, the Cause of Death and the Contributory Cause of Death are equivalent to Parts I and II of the current medical certificate form.

If the medical certificate form had been filled out properly, the cause of death to be tabulated would be that reported as the Cause of Death. Because the mode of dying, symptoms and complications were frequently reported as the cause of death, it was decided that these entries could not be accepted as the primary cause of death. There were also instances where more than one disease or condition were entered as the cause of death. Another kind of problem arose when the primary cause of death was given as a nonfatal or some ill-defined condition and a serious or fatal disease was entered as a contributory cause. Because of these problems, the medical certifier's statement of cause of death was not accepted and the joint cause rules were applied to all the terms reported on the medical certificate without distinction as to the primary or contributory cause of death.

In the hopes of clarifying the intent of the medical certificate, the wording was modified slightly at each revision conference. The

decennial tinkering with the wording did not bring about the desired results. In 1925, Dr. T.H.C. Stevenson, Medical Statistician of the Registrar-General's Office of England and Wales submitted for the consideration of the Health Committee of the League of Nations a medical certificate form which subdivided the item on the cause of death into four parts for the reporting of the sequence of events leading to death. Of historical interest is the fact that William Farr, who was Stevenson's predecessor at the General Register Office almost a century before, had called attention to and discussed the importance of the chain of events leading to death.

The medical certificate submitted by Stevenson was recommended for International use by the League of Nations. This form was adopted by England and Wales in 1927 and by Canada in 1935. In the United States, the new medical certificate was incorporated into the 1939 standard death certificate, but no change was made in the method for selecting the primary cause of death. It was not until the Sixth Revision Conference in 1948 that this new medical certificate and the International rules for coding the underlying cause of death were adopted by the signatory nations of the World Health Organization. In accordance with WHO Regulations No.1, the use of the ICD and the International rules for classifying causes of death is binding on countries unless they enter a formal reservation.

Although the present medical certificate form appears to be different from the formats of the past, it is basically still the same two part form with some modification in the wording. Instead of attempting to identify the primary or principal cause of death as such, the current medical certificate provides a framework for tracing the sequence of events leading to death, and thus point to the underlying cause of death, or the cause of death in the old terminology.

The present coding rules for selecting the underlying cause of death are much more comprehensive and complex than the five general rules proposed by Bertillon in 1900. However, the objectives of the coding rules and the manner of achieving them are basically the same. A significant addition to the current coding rules is the provision to ascertain the causal relationship between the diseases reported in the sequence of events in Part I.

The general rules proposed by Bertillon were employed by various countries from 1900 to 1948. In the United States, the Manual of Joint Causes of Death was used until the Sixth Revision of the ICD in 1948. This Manual included a series of priority tables taking two diseases at a time based on decisions made over the years in applying Bertillon's rules to death certificates filed in the United States. The use of the Joint Cause Manual was discontinued in 1948 when the International rules for selecting the underlying cause of death were adopted.

The joint cause rules of Bertillon and the subsequent revisions were criticized because they did not take into consideration the opinions of the medical certifier. The big selling point of the International rules for selecting the underlying cause of death of death was that the opinion of the medical certifier would be accepted in coding the underlying cause of death. This turned out to be only partially true. The medical certificate as completed by the medical certifier was accepted so long as the medical certificate was completed properly.

The following is the general rule for the selection of the underlying cause for primary mortality tabulations:

A. Any condition entered in Part I of the International Certificate of Cause of Death is to be preferred to the condition entered in Part II, and

B. Of the causes entered in Part I, the underlying cause which was the starting point (i.e., the last stated condition in Part I) in the sequence of events leading to the direct cause of death, is to be selected. However, there is the following proviso: "In order to obtain consistency in statistical tabulations and to minimize the effects of vagaries in reporting or of omission of required medical information, there are exceptions to the general rule". This statement is followed by a series of exceptions to the general rule and by the supplementary rules for use where the exceptions cannot be applied. Whenever one of these problems arise, an arbitrary rule kicks in and the stated opinions of the medical certifier are ignored. This is not necessarily a bad practice. In fact, it will more often than not result in what appears to be a more sensible assignment of cause of death.

A serious drawback from the standpoint of the users of cause of death statistics is that primary mortality tabulations preclude the display of all the diseases and conditions reported on the medical certificate. For example, diseases like diabetes mellitus are under reported in the official mortality statistics. Nonfatal diseases are even less likely to figure prominently in cause of death statistics. This is understandable, but it is a source of dissatisfaction for those interested in the statistics of nonfatal diseases.

Any changes in the coding rules or in the ICD may affect the comparability of data. Some of the effects can be quite significant and need to be taken into consideration in the analysis of data. Use of different coding rules, systematic coding errors, and differences in the interpretation of coding rules will also affect the comparability of data between two areas. This was more of a problem before the International standardization of coding rules,

but it still needs to be considered in any comparison of data between countries.

Major revisions of the code structure of the classification of diseases and of the coding rules will produce discontinuities in mortality trends of causes of death. The effect of such breaks may be ascertained by what has been termed "bridge or dual" coding, that is, the classification of data for the same time period by the old and new classification of diseases and coding procedures. Comparability ratios are available for each decennium in the United States starting 1940. Similar data are available for England and Wales and for other countries.

When discontinuities in trend result from the revisions of the ICD, it may be possible to reconstruct the trend on the old basis, i.e., for the period prior to the revision, by a judicious grouping of the components that were split off in the revision. However, any revision changes that affect comparability of data is, at best, inconvenient and annoying. When it is not possible to adjust for, or otherwise account for the breaks in the trend, it could be frustrating. Worse yet is not to recognize the effects of revision changes and interpret them as real changes in mortality trend.

There are also comparative studies of the accuracy of coding of diagnostic data by various countries. These studies show that there are differences in national coding practices, but the variations in coding methods appear to be less than the differences attributable to medical certification practices. It is much easier to control coding procedures than it is to educate medical certifiers in the proper medical certification procedures.

Another problem that needs to be considered is the quality of medical certification. Studies have been made using as the basis of comparison various sources of data such as post mortem examinations, hospital and physicians' records, and other sources of medical information. Also, studies have been made where the investigators reconstructed the underlying cause sequence utilizing hospital records, including available autopsy information and comparing the results with the original medical certification. These studies have shown that some diseases like cancers of accessible sites are generally better reported than other causes of death. There is a varying lack of correspondence between the causes of death found on death certificates and the data on clinical records and autopsy protocols. The measurement of the accuracy and completeness of reporting cause of death information is a very difficult matter, and there is no way of assessing the precision and reliability of these studies.

Shortly after the Eighth Revision of the International Classification of Diseases, the U.S. National Center for Health Statistics undertook a study of automating the coding of the underlying cause of death. This computerized coding system went

into operation in the data year 1968. The advantages of the automated system of coding are the speed of operation, consistency of coding, and the complete elimination of the manual coding operation, a labor intensive procedure. A serious disadvantage is the eventual loss of knowledge and skills in coding causes of death. Unless the coding skills can be maintained, there will not be sufficient number of trained coders at the next revision to make the necessary adjustments and modifications in coding procedures in the computerized system.

Despite the recognized limitations of official mortality statistics on causes of death, they have served well the purposes for which they were intended. They have delineated the major public health problems over the years, and served as a useful data base for public health programs. The cause of death statistics have played an important role in the conduct of epidemiological studies and in studies of the natural history of disease. Although mortality statistics can never serve as a substitute for morbidity data, the absence of statistics on causes of illness for the general population has placed a greater demand on cause of death statistics.

The statistics on causes of death have not been free of criticism. The accuracy of the data has been questioned. It has also been pointed out that the need is for morbidity and not mortality statistics. Serious criticisms have been levelled at the basis of primary mortality tabulations, that is, the selection of a single cause for each death which makes it impossible to give a full view of causes of death when more than one disease is involved in the death. It has been argued that single cause tabulations were acceptable in the era when communicable diseases were prevalent. However, this no longer holds true in an aging population where chronic diseases are the leading causes of death.

A great deal of dissatisfaction has been expressed with the primary mortality tabulations, but there has been little in the way of suggestions as to alternatives. Almost invariably, it is proposed that all the information reported on the medical certificate be coded and tabulated. This has been done. The first national multiple cause tabulation made in the United States in 1918 when the primary and a contributory cause were coded and tabulated. Since then, multiple cause tabulations have been produced for the data year 1925, 1937 (unpublished), 1940 and 1955. Beginning in 1968, multiple cause tabulations have been available every year. These tabulations show clearly that certain diseases are under reported in the official mortality statistics. Aside from that, the multiple cause tabulations prepared to date have not been particularly revealing or useful because of the vagaries of reporting causes of death. Signs and symptoms, mode of dying, ill-defined terms, various manifestations of the same disease, and repeated description of the same disease in different degrees of specificity are frequently reported. Unless this "noise" is

eliminated, it is not possible to obtain an unduplicated count of diseases and conditions in the death.

Because any multiple cause tabulation made today will have to be based on the data collected within the framework of the present form of the medical certificate, it will not be possible to obtain complete information on, for example, the disease and conditions present at the time of death. It may be suggested that clinical and pathological records to which death certificates are matched be used to ascertain the most meaningful data that can be gleaned from all the records for particular purposes. The findings from such a study can then be used to redesign the medical certificate to elicit the necessary information for various defined purposes.

To date, there has been a good deal of rhetoric on the question of primary mortality tabulations. No satisfactory solution to this knotty question has yet surfaced. Changes need to be made in the present method of compiling multiple cause data if they are to serve their expected role.