

PLANS FOR THE 1986 NATIONAL MORTALITY FOLLOWBACK SURVEY

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INTRODUCTION

Knowledge about the mortality experience of a population serves multiple important purposes. It provides insight into the epidemiology of disease and the potential avenues for prevention, treatment, and care, guidance on areas fruitful for research, data for the study of demographic trends, and serves other purposes. Thus, the study of mortality contributes to national and State health policy formulation, program planning and evaluation, biomedical research design, and related objectives.

The fundamental source of our knowledge about mortality in the United States is the cooperative State-national vital registration system. When a death occurs, a death certificate is filed with the local vital registrar who is an officer of the State. To compile national data on all deaths, the National Center for Health Statistics (NCHS) under a cooperative agreement with all of the States, secures copies of the death certificates or computer tapes containing agreed upon data. The only source of comprehensive national mortality data is the NCHS file.

Because the death certificate is a legal as well as a demographic document, and is required to be filed for every death, there must be limits on the items which must be included on the record. Much information concerning mortality which would be of value must be omitted from the death certificate.

A valuable method for enlarging and enriching knowledge about the mortality experience of the population of the United States is the mortality followback survey. The National Mortality Followback Survey is based on a representative sample of all deaths occurring in the United States in a specified year. An inquiry is mailed to the person listed on the death certificate as the informant; this is the individual who provided the personal and family information about the decedent, and is usually the next of kin or other close relative. To secure information from nonrespondents further efforts are made by telephone or personal interview follow-up. Information may also be sought from institutions used by the decedent and from health care providers.

Two valuable characteristics of the followback survey method provide its unique qualities. (1) The universe from which a representative national sample is drawn is all deaths that occur to residents of the United States. This universe is readily available from no other source than NCHS. (2) The flexibility to inquire into specific aspects of mortality permits investigations relevant to current policy and program issues. At the same time the limitations of the method must be recognized. All responses are from a proxy respondent, and in some cases there may be no survivor who is sufficiently knowledgeable about the decedent. In addition, the emotional context of an inquiry about a recent death may limit or color the information furnished.

Prior mortality followback studies. Four national mortality followback surveys were conducted by NCHS in the 1960s. The method employed was a mail questionnaire, with follow-up mailings to nonrespondents, and a personal interview for residual nonrespondents where feasible. The mailing to the informant named on the death certificate occurred

about three months after the death. A random sample was drawn in each of the 12 months from the death certificates provided by the States. The sample in the prior surveys ranged from one in 260 deaths to one in 330 deaths.

The most common subjects of the prior followback surveys produced data on the use of hospital and institutional care in the last year of life, and on socioeconomic differentials in mortality, particularly income and education. Other subjects investigated included expenditures for health care in the last year of life; health insurance coverage, operations performed, and in one year the smoking practices of the decedents. (Table A)

Plans for the 1986 survey. Plans are currently being made for the National Mortality Followback Survey (NMFS) to include a sample of deaths which will occur in 1986. The remainder of this paper describes the process and current state of these plans.

The planning process. The initial task in planning the 1986 survey was the identification of the most relevant subject-matter focus of the survey. What aspects of mortality most needed inquiry that were suitable to the followback method? Four criteria were applied in the consideration of possible topics:

1. The relevance of the subject matter to broad public health concerns, and to the policy and programmatic issues and interests paramount in the U.S. Public Health Service and in the U.S. Department of Health and Human Services.
2. Capitalizing on the uniqueness of the population.
3. The likelihood of the results being valid, reliable and generally useful.
4. The impact of the nature, length, complexity, and sensitivity of the content on response rates.

In the process of weighing possible content areas, steps taken included: 1) a study of the types of mortality statistics currently available; 2) an analysis of recent mortality experience and trends; and 3) a review of the major policy and program priorities of the Public Health Service for which mortality data have relevance. All of these steps were viewed in light of the nature of the followback survey method. Out of 18 general topics initially identified, preliminary determination of three broad topics was proposed, and a fourth was added later in the development process. Before proceeding further, we obtained a general reaction to the proposed content and methods from persons who would fall into the circumstances which would make them potential respondents. This step was achieved by holding a very useful informal meeting with members of a bereavement group affiliated with a hospice in the Washington area where a member of their family had recently died.

In order to assure that the mortality followback survey was responsive to the work of the National Center for Health Statistics, fit in with the Center's other surveys and data gathering activities, and met the technical standards of the Center, a work group of NCHS personnel was organized. This work group reviewed the statement which analyzed the proposed subjects of the survey. In addition, the Work Group reviewed the preliminary draft of the questionnaire.

Although NCHS is a general-purpose health statistics organization, there is also a vigorous program

Table A. Previous Mortality Followback Surveys: Date, Scope, Topics Covered, Sample Size, and Informant Response Rates

Date	Topics	Sample Size	Final Response Rate Percent
1961	Institutional care, Place of death, Income, Usual activity, Education	5,154	93 ^{a/}
1962-63	Institutional care, Residence history, Household composition, Education, Income	10,822	92 ^{b/}
1964-65	Institutional care, Health insurance coverage, Cost of care and sources of payment, operations, Household composition, Assets, Income	10,408	91 ^{c/}
1966-68	Smoking habits, Household composition, Income, Assets	19,526	95 ^{d/}

^{a/} Source: (NCHS, 1965)
^{b/} Source: (NCHS, 1969a)

^{c/} Source: (NCHS, 1969b)
^{d/} Source: (Enstrom, 1980)

of cooperation with other agencies and organizations in the Public Health Service, in the Department, throughout the Federal government, with State and local agencies, and with the private sector. From the outset, planning for the 1986 NMFS contemplated a cooperative arrangement with other agencies. To further this objective, a Consulting Group of Federal personnel was organized. It consists of representatives named by 19 agencies and offices; these include the Office of the Director and six of the institutes of the National Institutes of Health, the Office of the Administrator and the three institutes of the Alcohol, Drug Abuse and Mental Health Administration, the Office of the Deputy Assistant Secretary for Health for Health Promotion and Disease Prevention, the Centers for Disease Control, the Health Resources and Services Administration, the Food and Drug Administration, the Health Care Financing Administration, the Administration on Aging, the Social Security Administration, and the Veterans Administration. These agencies contributed suggestions for survey content, are reviewing survey materials, will share in the analysis and use of the results, and aid in financing the survey.

Out of this planning and development process, agreement was reached on the four major topics of the 1986 survey: 1) socioeconomic differentials in mortality; 2) the potential for prevention of premature death by inquiring into the association between risk factors and cause of death; 3) health care services provided in the last year of life; and 4) the reliability of selected items reported on the death certificate. These subjects will be discussed in a later section.

Survey methods. Tentative plans call for a survey of 20,000 deaths, approximately one percent of all deaths in a year. The topic areas selected for the

survey appear to have the most significance for deaths occurring at ages 25 and over.

A pretest of 1,500 deaths occurring in 4 States will be conducted in early 1985. Consideration is being given to several inquiries into survey methodology as a part of the proposed pretest of the survey.

a. Follow-up methods The initial contact attempt for informants in the 1986 NMFS will be made by first class mail. This attempt will be made about 3 months after the death. An address correction will be obtained for use in subsequent followups. Ten days after the initial mailing, a postcard will be mailed to all persons whether or not a questionnaire has been returned. The postcard will thank persons who have already mailed their questionnaire and will ask persons who have not yet mailed their form to please do so. Dillman (1978) reports that typically the reminder postcard is "...followed by a response burst that almost equals and occasionally surpasses that achieved by the first mailing." Dillman believes mailing one postcard to all persons whether or not a form has been received is cost effective in that there are administrative costs associated with determining whether a form has been received or not. Two weeks after the postcard is mailed, nonresponders will be mailed a second questionnaire, one-half by certified mail and one-half by first class mail. The use of certified mail has been demonstrated to be cost-effective (Heberlein, 1978). It is believed that the use of certified mail conveys the impression of increased importance to respondents. The mail carrier is required to obtain a signature from someone in the household.

Because of the absence of a clearly indicated procedure for followups after the second mailing, we are considering an experiment in the pretest. For one-half of the non-respondents there will be a telephone contact followed by personal interviews for nonresponses; one-half will receive a personal interview only.

- b. Comparison of Responses by a Proxy Respondent and by a Self Respondent There is some evidence that a next-of-kin reports with a fairly high level of reliability about decedent characteristics such as occupational status and smoking status. (Rogot, 1975) However, there are proposed items in the NMFS that may be very difficult for some respondents to report (eg. questions on the diet of the decedent). For this reason it is proposed to conduct a small study of hospice residents in which comparisons would be made between responses made by an individual about himself or herself and responses to identical items about the individual made by the next-of-kin after the individual's death.

Approximately 300 terminally ill hospice patients would be interviewed at the beginning of the pretest period using a modified pretest questionnaire. Cooperation of hospice programs would be obtained to permit the interviews and to inform the NMFS staff when death occurs. Interviews would be conducted face-to-face. Patients too ill or too incoherent would not be interviewed. After being informed of a death of a study subject, the NMFS staff would obtain a copy of the death certificate from the vital registration office. The same questionnaire used in the pretest would be mailed to the death certificate informant about 3 months after the death. A comparison of the decedent's and next-of-kin's answers would be made. It is recognized that study subjects will not be a representative sample of all United States decedents and no attempts will be made to generalize to the universe of decedents. Nevertheless, this study would provide useful insights into the reliability of survey items and procedures.

- c. Assessment of Reliability Through Reinterviews and Other Examination of Pretest Responses We propose that a reinterview for a small subset of questions be conducted for a large subsample of the pretest respondents to permit the calculation of reliability measures for those items included in the reinterview. The NMFS reinterview program will be patterned after that which is a permanent part of the National Health Interview Survey. (See (Koons, 1973) and (Poe, 1984) for a detailed explanation of this program.) Telephone calls will be made to respondents between one and two weeks following receipt of the initial questionnaire. The reinterviewer will reask a short subset of the initial question. Replies to the same question on the original interview and the reinterview will be compared. From this comparison, measures of the reliability of responses, or the simple response variance, will be calculated.

In addition, pretest items with either failed edit rates or blank or "don't know" rates greater than 5-10 percent will be examined carefully. An examination of internal consistency of response will be made.

- d. "Don't know" Responses An issue not investigated in any experiments dealing with

factual responses, as far as we could determine, is whether or not "don't know" response boxes are a good idea. On the one hand, we prefer that respondents indicate that they don't know an answer rather than either making wild guesses or leaving an item blank. On the other hand, the use of don't know boxes may result in higher item unknown rates; respondents may take the easy way out and mark the don't know box without searching their memories, checking records, etc. To test the effects of don't know response boxes, we propose that in the pretest a random one half of informants be sent a questionnaire with either no or very few don't know boxes and the other half of respondents receive a questionnaire with many don't know response boxes. In the analysis of pretest results, an item by item comparison would be made between the response distributions obtained from the two questionnaire versions. On an item by item basis we would assess whether the inclusion of a don't know box increases or decreases the reliability of responses (based on the reinterview results). Questions which have high unknown rates (including don't know box marked, blanks, and write-in "don't know"s) would be candidates for deletion prior to the main 1986 survey.

- e. Length of Questionnaire An issue of some controversy is how long the mail questionnaire can be (in terms of number of pages, number of items, and/or time required to fill), without seriously reducing response rates.

In an analysis of 98 mailed questionnaire response rates, Heberlein (1978) found no significant zero-order correlation between any of the measures of length (number of questions and number of pages) and overall response rates. When salience of the questionnaire topic and number of contacts were controlled he estimated that each additional question reduced the response rate by .05 percent. He found that "...the length of the questionnaire, in number of pages, does not affect the final response rate until the initial response, the number of follow-ups, the use of special third contact and the saliency of the topic are controlled." With all these factors controlled for, he found about a 5 percent reduction in final response for every 10 pages of questions. (In Heberlein's analysis, the average questionnaire had 72 questions on 7 pages and took less than one half hour to complete. Five percent of the questionnaires were over 22 pages long and had in excess of 230 items.)

The proposed questionnaire for the 1986 NMFS is relatively long for a self-administered instrument (about 108 items). Because of the uncertainty of the effects of such a lengthy questionnaire on response rates for our survey population, we propose to split the pretest sample and use the basic questionnaire on a random one-half of the sample and use a shortened version of the questionnaire (about 60 percent of the items) on the other half sample.

Survey topics. Focusing on the survey content, what do we expect to learn?

Socioeconomic differentials in mortality. Over the years there have been great reductions in mortality among all segments of society. However, in spite of the recent gains there still remains great variability in

death rates between individuals with differing social and economic status. For example, the death rate for black infants in the U.S. in 1981 was nearly twice the rate for white infants. Those with lower social and economic standing still have relatively shortened life spans compared to those individuals who have higher social status and more economic means at their disposal. A national study of socioeconomic status and its relationship to mortality has not been reported in twenty years. The latest reported national study was the 1962-1963 NCHS Mortality Followback Survey.(NCHS 1969a) Kitagawa and Hauser's classic study which used death certificates and Census schedules to investigate differential mortality experience and measures of socioeconomic status reported on 1960 data.(Kitagawa, 1973)

The 1986 survey will examine the relationship between mortality and education, occupation, income, assets, race and other socioeconomic factors.

Risk factors associated with premature death. The NMFS will permit inquiry into the association between mortality at various ages from causes of premature death and the risk factors hypothesized to be significant for those causes of death. The mortality followback survey in 1966-68, for example, showed that nonsmokers had an age-adjusted death rate from cancer of the respiratory system that was 43 percent less than the rate for current smokers.(Enstrom, 1980) Using the unique universe of a sample of all deaths in the U.S. in one year, the followback study could reaffirm the existence of a relationship between risk factors and mortality which have been hypothesized or documented, and could develop current national data on the degree of the association and variation among subgroups. The risk factors which may be included are diet, smoking, use of alcohol, immunization against influenza and pneumonia, occupational exposure, exercise, and adherence to medical advice. The followback study could also serve the very useful purpose of examining new hypotheses on the existence of risk factors or could provide insight into hypotheses not yet tested. Participating agencies are being invited to suggest hypotheses for investigation. Thus, further enlightenment on the potential for reducing premature death will be obtained.

To obtain a population base (denominator) for the risk factors identified, the mortality followback survey is being coordinated with plans for a supplement on health promotion and disease prevention in the 1985 National Health Interview Survey conducted by NCHS. Insofar as feasible, common questions will be asked on risk factors among a sample of the adult, civilian non-institutionalized population of the U.S.

Care in the last year of life. Two-thirds of all deaths in a year occur at ages 65 years or older. Many of the decedents have experienced multiple illness and chronic and disabling conditions. The nature of the health care and social support which they receive is of concern to the individual, the family, and society. The sources of financial support for this care have important social consequences.

Even less is known about health care in the last year of life of younger persons. Inquiry will be made regarding the nature and sources of health and social care received during the last year of life. Such information can provide guidance in planning and management of health care resources and community services. Inquiry will be made on the use of hospital and other institutional care, the use of home care services, the use of hospice care, medical encounters, the occurrence of disabling conditions, the sources of

payment for care, and related issues. All institutions providing health care to decedents in the last year of life will be contacted by mail to obtain admission and discharge dates, diagnoses, and names and addresses of other institutions providing health care that the decedent used in the last year of life. The identity of these institutions will be obtained from the next-of-kin questionnaire and the death certificate (in addition to the institutions themselves.)

Reliability of items reported on the death certificate. The primary source of data on mortality is the death certificate. Analysis of mortality experience relies on the items reported on the certificate. Thus, the reliability of these reports is critical. Inquiry will be made on specific items on the certificate to determine reliability, including age, race, ethnicity, occupation, and marital status.

An issue of particular concern is the quality of the information on cause of death. The NMFS will not include this issue as NCHS is planning a pilot study of methods to undertake such an evaluation.

Other issues for future studies. In examining the potential content of the 1986 survey, it became clear that the possible subjects of inquiry were far too extensive to be encompassed in one survey. It is expected that NCHS will conduct mortality followback surveys on a regular periodic basis.

The process of selecting subjects for the 1986 survey identified a number of content areas for possible future study. These include: a study of infant mortality, conducted simultaneously with a natality study in which the birth and death records are matched (NCHS periodically conducts Natality Followback Surveys); a study of the external causes of death -- accidents, suicides and homicides --(in 1980, deaths from these causes accounted for 54 percent of all deaths at ages 1 through 44); epidemiologic studies of specific causes of death; social support of the dying; the experience of a lingering death; the experience of survivors; financing care of the dying; and other issues.

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