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Design of the 1986 National Mortality Followback Survey: Considerations on Collecting Data on Decedents

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Synopsis

The first National Mortality Followback Survey in 18 years was conducted by the National Center for Health Statistics on a national probability sample of adult deaths in the United States in 1986. Data were collected on (a) socioeconomic differentials in mortality, (b) prevention of premature death by inquiring into the association of risk factors and cause of death, (c) health care services provided in the last year of life, and (d) the reliability of certain items reported on the death certificate. In addition to demographic characteristics of the decedent available from the death certificate and the questionnaire, information was secured on cigarette smoking practices, alcohol use, food consumption patterns, use of hospital, nursing home, and hospice care, sources of payment for care, duration of disability, and assistance with activities of daily living.

A rich body of data was collected for analysis. In a large pretest, response was received from 87.3 percent of the next of kin of the decedents. The pretest included several methodologic studies to increase the level and quality of response in the main survey. Response rates were compared for data collection by mail, telephone, and personal interview. A test of certified mail and first class mail was conducted. Response to two forms of different lengths was compared. An experiment was also conducted on the effect of inclusion of boxes for a "don't know" response. A public use data tape is available from the National Center for Health Statistics.

KNOWLEDGE ABOUT DEATHS, their amelioration, or postponement is of consuming interest to public health professionals, medical practitioners, and the general public. The core of our knowledge about this topic derives from the data collected in the State-Federal cooperative system of registration of births and deaths. Not available from this system however, is information on important characteristics of the decedent that may have affected mortality, such as patterns of lifetime behavior, experi-

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ences with health services before death, socioeconomic status, the complex influences of the environment, and many other aspects of life which affect when and how we die.

To increase knowledge about factors affecting mortality, and in light of its unique access to death records for the nation, the National Center for Health Statistics (NCHS) undertook the 1986 National Mortality Followback Survey. Patterns of behavior and other factors which may be associated with mortality were investigated in a nationwide probability sample of all deaths of persons 25 years of age and older. The source of information was the next of kin of the decedent.

This was the first National Mortality Followback Survey to be conducted by NCHS in 18 years. Four earlier surveys were conducted in the 1960s and provided data on the use of hospital and institutional care in the last year of life (*1,2*), socioeconomic differentials in mortality (*3*), expenditures for health care in the last year of life (*4*), health insurance coverage (*5*), and the smoking practices of decedents (*6,7*).

To determine the topics to include in the 1986 survey, the following steps were taken. Major mortality patterns and trends in the United States were reviewed, the types of mortality statistics currently available were examined, the major health policy issues of concern to the Public Health Service (PHS) and the Department of Health and Human Services (DHHS) were considered, and the earlier national mortality followback surveys were studied. All of these issues were then considered in the light of the strengths and limitations of the followback method. A tentative proposal for areas of information growing out of this process was studied by officials in NCHS and by a consulting group of officials from PHS, DHHS, and other agencies selected to advise in the survey. It was decided to focus the 1986 survey on four general topics: (*a*) socioeconomic differentials in mortality, (*b*) prevention of premature death by inquiring into the association between risk factors and cause of death, (*c*) health care services provided in the last year of life, and (*d*) the reliability of certain items reported on the death certificate.

Given the breadth of these issues and their relevance to the mission of a number of Federal agencies, it was determined to make the survey a cooperative effort. A consulting group composed of representatives designated by 19 agencies and offices was named. These agencies include the Office of the Director and six Institutes of the National Institutes of Health, Office of the Administrator and the three Institutes of the Alcohol, Drug Abuse, and Mental Health Administration, Office of the Deputy Assistant Secretary for Health Promotion and Disease Prevention, Centers for Disease Control, Health Resources and Services Administration, Administration on Aging, Social Security Administration, and Veterans Administration. These agencies contributed suggestions for survey content, reviewed survey materials, aided in financing the survey, and are sharing the analysis and use of the results of the study.

The questionnaire covered the following areas: demographic characteristics (age at death, sex, race, marital status); duration of hospital care; nursing home care; hospice care (institutional and at home); sources of payment for health care; out-of-pocket expenses for health care; assistance received with activities of daily living; duration of disability; food intake patterns; cigarette smoking practices; alcohol consumption; level of education; income and assets; and occupation and industry.

Specific areas investigated included these:

1. The epidemiology of rare cancers. The cancer sites studied included male breast, nasopharynx, small intestine, liver among young women, oral cavity among young men, and endocrine glands. These are concerns that have received little attention in the past due, in most part, to their rarity.
2. Characteristics of coronary heart disease deaths of those under 45 years and the contribution of family history to such deaths. Identification of risk factors, both familial and environmental, are being evaluated.
3. The relationship between lifestyle characteristics and mortality from alcohol abuse. Focus will be on drinking patterns and both alcohol-related causes of death and other causes of death not thought to be associated with intake of alcohol.
4. Vasectomy and subsequent mortality with em-

phasis on deaths from atherosclerotic heart disease. This sample provides a cost-effective opportunity to examine relations between vasectomy and heart disease and other causes of death.

Among other issues which the data permit investigators to examine are the following:

1. Are death rates higher for certain occupational groups?
2. For what causes of death are there long periods of disability?
3. For what causes of death are mortality rates higher for blacks?
4. Is oral contraceptive use related to liver cancer deaths in young women?

Survey Method

The U.S. Bureau of the Census served as the data collection agent for NCHS. The data collection procedure adopted for use in the survey consisted of the following steps.

1. A questionnaire was sent by first-class mail to the informant named on the death certificate. The mailing occurred about 6 to 7 months after the death. A postage-free return envelope was included.
2. Ten days later a letter was mailed to all informants, thanking them if they had returned the questionnaire and reminding them to do so if they had not.
3. One month after the initial mailing, a second copy of the questionnaire was sent to nonrespondents by first-class mail with a postage-paid return envelope included.
4. Four weeks after the second mailing, a telephone or personal interview was initiated to reach the nonrespondents. If one mode was unsuccessful—for example, if no phone number was located or no one was at home on repeated personal visits—the other mode was attempted.
5. Questionnaires were mailed to all health care facilities where the decedent spent one or more nights during the last year of life. These facilities were identified from the inquiry to informants, the death certificates, and the other health care facilities used by the decedent. Authorization to provide the requested information signed by the questionnaire respondent was included whenever possible.

The main survey was an investigation of approximately 18,500 deaths. It was a national probability sample of about 1 percent of all deaths of persons 25 years of age and older in the United States in 1986. There was oversampling of deaths in the black and American Indian populations, of deaths of young persons, and of young persons who died because of ischemic heart disease, asthma, and rare cancers.

Table 1. Response rates by race, sex, and age of decedents and by natural and external causes of death

Characteristic	Number questionnaires mailed	Percent with responses (weighted)
All decedents	1,360	87.3
Race:		
Black	316	83.5
Nonblack	1,044	87.9
Sex:		
Male	697	87.0
Female	663	87.6
Age:		
Under 55 years	183	79.6
55–64 years	185	88.2
65–74 years	361	88.4
75–84 years	371	87.7
85 and older	260	89.6
Cause of death:		
Natural causes	1,282	87.8
External causes	78	79.3

Minitest Procedure and Findings

Survey design is enhanced when, at an early stage, a sample of persons who correspond to the potential respondents react to the ideas being considered. In the mortality followback survey this step was achieved by a discussion at a hospice with nine members of a bereavement group who met regularly following the recent death of a family member. An early draft of the questionnaire was filled in and discussed, and proposed procedures were jointly reviewed.

To learn the reactions of respondents to the proposed study instrument and procedures, a minitest of 34 interviews was subsequently conducted in the Washington, DC, area. After being sent an introductory letter, the informants were visited by a Census Bureau interviewer. The informant was handed a questionnaire and asked to complete it as though it had come by mail, while the interviewer waited. The interviewer then discussed the completed questionnaire to learn how the respondent reacted to the questions and procedures. Members of the survey staff attended many of these interviews.

The respondents were asked about the appropri-

Table 2. Cumulative level of informant identification by mode of inquiry

State of death	Total in sample	Original death certificate complete	Spouse identified	Required query	Funeral director: Response by phone	Funeral director: Response by mail	Total adequate identification
	Number						
Total sample	1,363	618	244	501	359	42	1,263
Illinois	843	505	111	227	107	31	754
New Mexico	85	83	1	1	1	...	85
Vermont	35	30	3	2	1	...	34
Virginia	400	...	129	271	250	11	390
	Cumulative percent						
Total sample	100.0	45.3	63.2	...	89.6	92.7	92.7
Illinois	100.0	59.9	73.1	...	85.8	89.4	89.4
New Mexico	100.0	97.6	98.8	...	100.0	100.0	100.0
Vermont	100.0	85.7	94.3	...	97.1	97.1	97.1
Virginia	100.0	...	32.3	...	94.8	97.5	97.5

ate interval after death to send the questionnaire, and most replied that 6 months was a satisfactory period. Several persons noted that an earlier date would be unsuitable, not so much because of grief, but because of the burden of paperwork after a death. Asked whether they would have completed the questionnaire if it had come by mail, most replied affirmatively. The respondents were asked about the suitability of the design of the questionnaire, and most found it satisfactory. A detailed analysis of problems encountered with specific items on the questionnaire was noted and used in revising the instruments for the main survey.

Pretest Procedure and Results

The pretest consisted of a sample 1,360 records. It was designed to include records of deaths of persons age 25 years and older, drawn from the Current Mortality Sample, a 10 percent sample of United States deaths which NCHS receives from the States within about 3 months after the death. Four States were included in the sample to provide geographic and racial-ethnic variation—Illinois, New Mexico, Vermont, and Virginia. Deaths in September and October 1984 were selected for survey 6 months later. Deaths of blacks were oversampled at a rate of 1.8 times that for whites, and all deaths from ischemic heart disease at ages 25 through 44 years were selected. A total response rate of 87.3 percent was achieved for the informant questionnaire in the pretest.

It is of interest to examine differences in response rates according to characteristics of the decedents (table 1). The difference in positive responses by race of decedent was significant, with blacks responding at 83.5 percent and whites at 87.9 percent. The response rates by sex of decedent were not significantly different. A critical value of 1.96 (0.05 level of significance) was used to test comparisons that are discussed in this paper.

When the data were examined by age of decedent, the highest positive response rates were at the older ages and the lowest, at the younger ages. Respondents for persons who died from external causes (accidents, suicides, and homicides) completed the questionnaires at a lower rate than for those who died of natural causes, but the difference was not statistically significant.

An important decision, made early in planning the survey, was to seek the means to achieve maximum response and to increase general knowledge of survey techniques by conducting several special methodologic studies as a part of the pretest. Although somewhat related studies on these questions are reported in the literature, their application to this unique study population—the next of kin of recent decedents—raised special issues. For example, much of the history we were seeking might be unknown to some of the respondents. Would the inclusion of boxes to check "don't know" (DK) make completion of the questionnaire more likely, or would it tend to offer an easy alternative to a serious effort to recall or to inquire about the answer? A split-sample experiment was included in the pretest. Half of the questionnaires contained such "don't know" boxes; in the half that lacked such boxes respondents were instructed to enter a question mark if the answer was unknown.

To probe the reliability of responses for both questionnaire versions, a sample of the completed questionnaires was selected for telephone inquiry in which the respondent was again asked some of the

same questions. The findings of this experiment led to the decision to exclude DK boxes in the main survey (*8*). The effects on response rates of questionnaire length and type of mailing (certified versus first class) were also tested in the pretest. There was little difference in the final response rates for questionnaire length (87.2 percent for the long form and 89.0 percent for the short) or type of mailing (84.0 percent for certified and 86.5 percent for first class) after followup of nonrespondents by personal or telephone interviews (*9*).

In all previous mortality followback surveys conducted by NCHS the field followup was conducted primarily by personal visit. To test the effects of using the telephone, another split sample test was included in the pretest. Records that failed to produce a response by mail were assigned to either telephone or personal visit followup as a primary mode. However, the alternate mode was used when appropriate. For example, if no phone number could be secured, a visit was made. If repeat visits yielded no response, a telephone interview was attempted. The response rate by telephone was 76.8 percent, and by personal visit it was 75.4 percent.

An element of concern in a followback survey is the ability to identify and reach the desired respondent. In the mortality followback survey the primary source is the person whose name and address is listed on the death certificate as the informant. In six States the death certificate form contains an entry for the name but not the address of the informant. To test the procedure for securing the address, Virginia was included in the pretest because it is one of these States. Further, it was learned that, particularly in Illinois, many certificates list a medical or hospital record as the informant rather than the name and address of the person who furnished the information to the hospital. Of 1,363 records in the pretest sample 618, or 45.3 percent, contained the needed identification in the informant entry (table 2). (Three records were dropped from the pretest before the first mailing.) Inspection of these certificates, however, showed that 244 listed a surviving spouse who could receive a mailing at the decedent's usual residence. After this step 501 records, or 36.8 percent, required an inquiry. A telephone call to the funeral director to secure the name or address or both of the next of kin resulted in 359 responses. Sometimes the funeral director requested a letter in order to reply, and 42 additional leads were furnished by this action. These steps left 100 records with no name and address of the informant. In these cases, the questionnaire was addressed to "Next of Kin" of the named decedent at the decedent's usual residence. A total of 92.7 percent of the sample were thus addressed to a named informant.

'The great majority of informants were very close relatives of the decedent. In 35 percent of the deaths the spouse provided the response, and a daughter or son replied in an additional 35 percent. The information was furnished by a sibling in 10 percent and by a parent in 3 percent.'

The great majority of informants were very close relatives of the decedent. In 35 percent of the deaths the spouse provided the response, and a daughter or son replied in an additional 35 percent. The information was furnished by a sibling in 10 percent, and by a parent in 3 percent. Other relatives replied in 15 percent of the inquiries, and a neighbor or friend in 2 percent. Thus, 83 percent of the informants were first degree relatives.

Reports by Caregivers

When no next of kin could be identified and the death occurred in a long-term care facility, a member of the staff of the facility who knew the decedent was interviewed by telephone. Twenty-four such interviews were conducted (1.8 percent of the decedents); one attempt to contact a staff person was unsuccessful. These decedents were usually older (83 percent were ages 75 and older).

Conclusion

Research into the risk factors associated with premature mortality is placing increased emphasis on the importance of lifetime habits and behaviors. This knowledge is important because it offers the individual, the health care provider, and the public health community information that can be used to reduce the risk of early death. Methodologies available to the researcher to investigate these relationships are somewhat limited. One such methodology is the mortality followback survey. NCHS is uniquely able to employ this method, given its access to the universe of death records for the nation. After an 18-year gap, NCHS conducted such a study of adult deaths in the United States in

1986. This cooperative effort with nine other public health agencies investigated a variety of risk factors for important diseases, inquired about the health care needs and services received during the last year of life, and examined socioeconomic differentials in mortality.

Results from the 1986 National Mortality Followback Survey are available in a public use data tape with detailed technical documentation that can be purchased from NCHS. The data include items from the death certificates and the survey responses. A wealth of mortality issues can be analyzed using these data, and NCHS invites inquiries regarding potential studies and analyses.

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Factors Influencing Intentions of Pregnant Women to Exercise After Giving Birth

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Synopsis

The aim of this study was to identify factors that may influence a pregnant woman's decision to exercise after giving birth. A sample of 98 pregnant women were asked to complete a questionnaire investigating attitudes, social norms, perceived barriers to exercise, and intention regarding exercising after giving birth. Also determined were age, education level, exercise habits, number of months elapsed since onset of present pregnancy, and number of children.

The regressions of intentions to exercise on all variables yielded R^2 of 0.52 for nulliparous and 0.60 for pluriparous pregnant women. Important differences in variables that explained intentions were found between both groups of women, with perceived barriers to exercise being a key predictor that was, in turn, influenced by previous experience with pregnancy.

It is suggested that the experience of the postnatal period modifies the interrelation between the variables explaining intentions regarding exercise after giving birth. Consequently, the programs should take into account the impact that the birth of a first child will have on the perceived barriers to exercise.