Sampler of Findings from the 1986 National Mortality Followback Survey on Risk Factors, Disability, and Health Care

ISADORE SEEMAN, MPH

Mr. Seeman was the Project Manager for the 1986 National Mortality Followback Survey of the National Center for Health Statistics, Public Health Service.

Tearsheet requests to Isadore Seeman, 9915 Dameron Dr., Silver Spring, MD 20902; tel. 301-681-5017.

Synopsis

The National Center for Health Statistics conducted a mortality followback survey of a national probability sample drawn from all deaths of U.S. adults in 1986 and an oversampling of deaths of persons with selected characteristics.

Responses were received from the next of kin or other close relatives of 16,598 adult decedents (88.6 percent). Data were collected through a mail questionnaire, followed by telephone or personal interviews with nonrespondents. Data were also collected from the hospitals and other health care facilities used by the decedent in the last year of life.

Illustrative results are presented on the four major subject areas studied: risk factors for premature death, disability and care in the last year of life, socioeconomic differentials, and the reliability of selected items reported on the death certificate. Researchers are encouraged to explore the data tape to pursue indepth epidemiologic studies.

The USE of the DEATH RECORD for inquiry into epidemiologic aspects of mortality has been an invaluable practice since John Graunt's pioneering work in England in the 1660s. There are, however, limits on this source of data to provide insight on the prevention of premature death and other aspects of mortality. Since the death certificate is primarily a legal and administrative document, it imposes the need for relative brevity and specific relevance to these purposes. Of the 28 items on the 1986 U.S. Standard Certificate of Death, 15 are useful for epidemiologic study.

The death certificate serves an additional epidemiologic purpose by pointing the way to further inquiry about the decedent and the death. The mortality followback survey uses the name and address of the informant on the death certificate as a lead to securing further information (1). Since this "informant" is the person who provided the personal information about the decedent contained on the death certificate, usually the decedent's next of kin or other close relative, the followback survey offers a valuable methodology to probe aspects of lifestyle, disability, health care, and socioeconomic circumstances of the decedent.

1986 National Mortality Followback Survey

The 1986 National Mortality Followback Survey (NMFS), the fifth such survey conducted by the National Center for Health Statistics (NCHS) (2-5), focused on four areas: (a) risk factors for premature death, (b) disability and health care in the last year of life, (c) socioeconomic differentials in mortality, and (d) the reliability of selected items reported on the death certificate (6). The 1986 survey was the first national mortality followback survey to collect such a wide range of data of epidemiologic interest, thus offering a fertile source for indepth studies. The four previous surveys dealt almost exclusively with the extent of hospitalization in the last year of life.

Methods

To assure the maximum response rate in the survey, four methodologic experiments were conducted in the pretest which covered 1,360 deaths. When no response was received after a first mailing of the questionnaire, a second copy was sent by certified mail to one-half of the nonrespondents,

'Out-of-pocket payments for health care in the last year of life were less than \$500 for 22.5 percent of the decedents, and out-of-pocket payments of \$10,000 or more were made by 2.5 percent.'

and by first-class mail to the other half. Substantive responses were received from 37.5 percent of the certified mailing and from 24.9 percent of the first-class mailing. This positive effect of the use of certified mail was eliminated, however, after the completion of telephone and personal interviews. For those sent the certified mailing the final response rate was 83.3 percent, and for those sent the first-class mail the rate was 87.6 percent (7). No certified mail was used in the main survey.

A split-sample test was done on the inclusion of "don't know" (DK) boxes to answer most of the questions on one-half of the pretest questionnaires; the other half had no such boxes. On the forms without the boxes, respondents were instructed to put a question mark in the answer space if they did not know the answer. This test had no significant effect on the total completion rate for the questionnaire, with 59.7 percent of those with DK boxes returned by mail, and 57.2 percent of those without DK boxes returned. On questionnaires containing DK boxes, however, the average percent of don't know responses was 7.1 percent, compared with 1.9 percent on questionnaires without DK boxes, a significantly lower rate of substantive response with the DK boxes (8). The questionnaire in the main survey contained no DK boxes.

For nonrespondents to mail questionnaires, a test of the use of the telephone versus personal interview was conducted. No significant difference was found, with 76.8 percent of those telephoned responding and 75.4 percent of those visited in person responding. In the main survey, a telephone interview was attempted first for nonrespondents, and a personal interview was conducted only if the telephone attempt was not successful.

Since the questionnaire was quite lengthy, containing 193 response items, a shorter version with 135 items was also used in the pretest. After the mailing phase the short form yielded a significantly higher response, 61.2 percent, compared with 53.6 percent for the long form. This difference was eliminated, however, after completion of the telephone and personal interviews, both yielding an

85.0 percent response. The questionnaire in the main survey was a compromise, containing 158 response items.

For the main survey, a national probability sample of all death certificates of persons ages 25 and older who died in 1986 in the United States was drawn (9). To provide an adequate sample for analysis of subgroups, and to meet the needs of co-sponsoring Federal health agencies with special interests, there was oversampling of deaths of persons younger than age 45, blacks, American Indians, and persons dying of ischemic heart disease, asthma, and selected cancer sites. A total of 18,733 death certificates was selected, nearly 1 percent of all deaths of U.S. adults. Because of respondent consent requirements set by the State, deaths of Oregon residents were not surveyed.

A 24-page questionnaire was mailed to the informant named on the death certificate approximately 6 months after the death. A second mailing was made to nonrespondents 4 weeks later. The U.S. Bureau of the Census which conducted the data collection for NCHS then attempted an interview by telephone or in person for those who failed to respond to the mailings. A short questionnaire was also sent to all health care facilities in which the decedent stayed at least overnight during the last year of life. Information from these facilities was sought on admission and discharge dates, diagnoses, and procedures performed. The facilities were identified on the death certificate, the informant questionnaire, and from other facilities used.

The response rate for informants was 88.6 percent, and the estimated response from facilities was 79.9 percent. To gauge the reliability of informant responses to selected questions, a telephone reinterview was conducted with the same respondent for about 5 percent of the records 2 or more weeks after the initial response.

This paper offers highlights of the survey findings to entice epidemiologists and researchers to explore the data in greater depth.

Results

Since all of the personal information not obtained from the death certificate was secured by proxy response, it is important to examine the relationship of the informant to the decedent. The informant was a close relative of the decedent on 81.3 percent of the questionnaires: a spouse on 35.9 percent, an offspring on 33.5 percent, a sibling on 7.8 percent, and a parent on 4.1 percent. For 16.4 percent of the replies, the informant was

more distantly related or was a friend or neighbor, and on 1.7 percent, a staff person in a nursing home where the decedent resided provided the information. Further, 71.1 percent of the respondents had lived with the decedent as an adult for 10 years or more, and 57.9 percent for 20 years or more. Thus the information came largely from a reliable source.

The literature on proxy response for the kinds of information sought suggests that such information is generally reliable and that the most significant factor is the relationship of the informant to the decedent (10-12). Spouses and offspring are best able to respond to questions dealing with the decedent's adult life. Siblings can deal best with matters occurring during the decedent's childhood. Distant relatives and friends are the poorest proxy respondents. Further, the best responses result from questions that are broadly defined. The greater the detail sought, the less reliable the response.

Of major significance in analyzing the findings of the survey is an appreciation of the age distribution of the decedents, adjusted by weighting to be a representative sample of the nearly 2 million adults who died in the United States in 1986. Decedents younger than age 25 who were excluded from the survey constituted only 4.5 percent of all deaths in the United States (13). Of the decedents surveyed, 49.9 percent died at ages 75 or older and 21.3 percent at ages 85 or older. For the living adult U.S. population in 1986, 7.9 percent were ages 75 or older, and 1.9 percent were ages 85 or older (14). Clearly we are dealing with an aged population, and the findings must be viewed in this perspective. White persons constituted 87.6 percent of the decedents, black persons 11.5 percent, and other races 1.0 percent. Women accounted for 48.2 percent of the deaths, and men for 51.8 percent.

Risk factors for premature death. The use of tobacco was an important area explored. In this decedent population, 55.6 percent were reported to have smoked at least 100 cigarettes in his or her lifetime. Among regular smokers, 70.8 percent smoked for 20 years or more. Heavy smoking, defined as 25 cigarettes or more per day, was reported for 31.0 percent of the decedents.

The thrust of the findings of other studies on the effects of smoking on longevity is confirmed in this survey. For example, among white men age 25, those who never smoked could expect to live 8 years longer than men who were heavy smokers (15). For white women age 25, the difference in life

expectancy was even greater—16 years or 37 percent longer for nonsmokers. Among white women age 25, 45 percent of heavy smokers could expect to die before age 70, compared with 15 percent for nonsmokers.

Alcohol use was examined. Heavier drinking, defined as 2 or more drinks of alcoholic beverages per day every day, was reported for 25.2 percent of the men and 7.6 percent of the women. (All of the cited comparisons by sex, race, and age are significant at the 0.05 level.) When death rates by age are examined, the data show a clear dose-response relationship as alcohol consumption increases. Among male decedents who were heavier drinkers, 42.3 percent of the deaths occurred before age 65, and among male abstainers 22.4 percent of the deaths occurred of the deaths of heavier drinkers occurred before age 65, compared with 13.2 percent for abstainers.

What was observed with regard to exercise? Only 16.9 percent of the decedents were reported to have engaged in regular aerobic exercise. Adherence to physician advice was measured: when a physician had prescribed medication for high blood pressure, 9.8 percent of the decedents were reported to have taken the medication irregularly or hardly at all.

Disability. Nearly half of all adult decedents were reported to have required help or special equipment in performing one or more of five routine activities of daily living in the last year of life. Help with bathing was required by 55.1 percent, help in walking by 49.9 percent, with dressing by 48.5 percent, and with use of the toilet by 48.3 percent. Help with eating was required by 34.4 percent of the decedents. Consistently, more women than men required help. For example, 64.0 percent of the women needed help with bathing compared with 46.9 percent of the men. A difference was observed even when increased longevity for women is taken into account. At ages 85 and older, 82.1 percent of women needed help in bathing compared with 69.2 percent of men. A spouse helped at home most often (43.6 percent), and a daughter next most often (35.3 percent).

Health care in the last year of life. An overnight stay or longer in a hospital or nursing home in the last year of life was experienced by 81.1 percent of the decedents; 85.7 percent of the women and 76.8 percent of the men. A hospital stay in the last year was reported for 75.8 percent of the decedents, and a nursing home stay for 27.6 percent. Widowed

'National data rarely available from other sources were secured on lifetime use of a nursing home, use of hospice care, the execution of a living will, family income in relation to mortality, the interval between cessation of work and death, and other issues.'

persons were admitted to a nursing home more frequently than those with any other marital status. They constituted 57.3 percent of such admissions, 74.5 percent for widowed persons ages 85 and older. Home hospice care was received by 8.7 percent of the decedents; a residential hospice was used by less than one-half of 1 percent. The services of a visiting nurse in the home were received by 29.0 percent of the decedents, and homemaker service, by 9.5 percent.

The literature contains little information about lifetime use of a nursing home (17). Informants in this survey reported that 28.8 percent of the decedents had ever used a nursing home; 37.7 percent of women and 20.6 percent of men. For decedents ages 85 or older, 60.4 percent had ever used a nursing home. Less than 1 year was spent in a nursing home by 49.2 percent of the decedents, and 5 years or more by 16.3 percent.

During the last year of life, 12.1 percent of the decedents had no visits with a physician, 34.6 percent saw a physician between 2 and 9 times, and 16.4 percent saw a physician 25 times or more.

Disorientation and memory problems in the last year of life were experienced by decedents; 8.0 percent had trouble knowing where he or she was all or most of the time; this was true for 10.8 percent of the women and 5.4 percent of the men. Trouble all or most of the time remembering the year was experienced by 9.7 percent, and 10.4 percent had trouble some of the time recognizing family members.

Informants reported that 44.9 percent of the decedents had high blood pressure, 43.9 percent of white decedents and 52.8 percent of black decedents. A heart attack was reported for 29.2 percent of the decedents, a stroke for 25.5 percent, Alzheimer's disease for 11.2 percent, and a mental health problem for 11.5 percent. Cancer was reported by the informant as the cause of death for 25.7 percent of the decedents.

A living will was reported to have been executed by 8.9 percent of the decedents.

Medicare was the source of payment for most of the last year's health care bill, as reported by 39.7 percent of the informants. Medicaid was the primary source for 7.2 percent, private health insurance for 15.1 percent, and the family for 10.9 percent. Of all adult decedents, 72.9 percent were eligible for Medicare; 92.3 percent of those ages 65 or older were eligible. Out-of-pocket payments for health care in the last year of life were less than \$500 for 22.5 percent of the decedents, and out-of-pocket payments of \$10,000 or more were made by 2.5 percent.

Socioeconomic circumstances. Issues surrounding the appropriate age for pension payments are being debated. The decedent was reported to be still employed at death for 13.1 percent of the sample. Normal retirement accounted for termination of employment for 46.9 percent of the decedents who had stopped work before death, and ill health or disability accounted for the retirement of 28.4 percent. Decedents had stopped work 25 years or more before death, according to 16.2 percent of the informants, for 20 years or more for 26.3 percent, and for 10 years or more for 53.7 percent.

At the time of death, 44.9 percent of the decedents were married, 35.4 percent were widowed, 7.7 percent were divorced, and 8.1 percent had never been married. Among women, 55.4 percent were widows; among men, 16.7 percent were widowers. For those dying at ages 85 and older, 69.8 percent were widowed—82.6 percent of the women and 44.4 percent of the men. Widowhood for 20 years or more was experienced by 32.4 percent of the women and 11.5 percent of the men. The decedent was reported to have been married for 20 years or more by 78.4 percent of the informants, for 40 years or more by 50.8 percent, and for less than 10 years by only 4.9 percent.

Living alone at the time of death were 27.2 percent of the decedents, 39.5 percent of the women and 19.1 percent of the men. Decedents lived in 2-person families according to 38.5 percent of the respondents.

Informants reported that 32.5 percent of the decedents had not gone beyond elementary school, that 42.1 percent had completed high school, that 17.7 percent had some college education, and for 7.6 percent the extent of schooling was unknown. It must be remembered that these older persons were attending school when education was less valued and less possible for many persons. A survey of the adult population living in 1986 showed 13.6 percent had not gone beyond elemen-

tary school, 53.6 percent had completed high school, and 33.8 percent had some college education (18).

The family income in the full year before death was reported to be under \$5,000 for 17.2 percent of the decedents, between \$5,000 and \$14,999 for 33.7 percent of the decedents, between \$15,000 and \$24,999 for 14.1 percent, and \$25,000 and more for 14.8 percent. No data on income were provided for 20.2 percent of those responding. Informants reported that there were no decedent family assets at the time of death in 16.3 percent of the decedent families. Family assets were at the low end, between \$1 and \$24,999 for 29.5 percent of the decedents, in the mid-range of \$25,000 to \$249,999 for 32.7 percent, and at the upper range of \$250,000 and more for 4.5 percent. No information on assets was obtained for 33.3 percent of the sample.

Comparability of reported items. The demographic items reported on both the death certificate and the survey questionnaire were examined for comparability. The exact age agreed on 77.5 percent of the records, but there was agreement within 1 year of age on 92.7 percent of the records. The age given on the questionnaire tended to be 1 year older than on the death certificate. The agreement on race was 97.9 percent, on marital status 95.0 percent, and on veteran status 96.7 percent.

Discussion

The mortality followback survey offers a unique methodology for epidemiologic and sociological inquiry into factors associated with mortality. Nine Federal agencies co-sponsored the 1986 NMFS with NCHS, probing issues of particular relevance to their missions as well as general concerns. The sixth NMFS is planned by NCHS for 1993.

The 1986 survey, with a scope greatly expanded beyond the four earlier surveys, provides baseline data for many aspects of mortality. National data rarely available from other sources were secured on lifetime use of a nursing home, use of hospice care, the execution of a living will, family income in relation to mortality, the interval between cessation of work and death, and other issues.

The availability of a fertile volume of data on the demographic, socioeconomic, and health care characteristics of decedents along with cause of death offers a valuable opportunity for epidemiologic study (19). Some examples of studies completed or being pursued with the use of 1986 NMFS data are a study of the experience of decedents with medical device implants, AIDS deaths (20), deaths from diseases of the heart (21), deaths from alcohol-related causes, a followup of the 1960 Kitigawa and Hauser study of socioeconomic differentials in mortality, and the use of hospice care.

Researchers are encouraged to examine the data from this survey and conduct indepth studies of aspects related to their special interests. A public use data tape is available from the National Technical Information Service (22).

References.....

- Sirken, M. G., and Dunn, H. L.: Expanding and improving vital statistics. Public Health Rep 73: 537-540 (1958).
- National Center for Health Statistics: Hospitalization in the last year of life, United States 1961. Vital Health Stat [22] No. 1. Department of Health, Education, and Welfare, Washington, DC, September 1965.
- National Center for Health Statistics: Socioeconomic characteristics of deceased persons, United States 1962-63.
 Vital Health Stat [22] No. 9. Department of Health, Education, and Welfare, Washington, DC, February 1969.
- National Center for Health Statistics: Health insurance coverage of adults who died in 1964 or 1965: United States. Vital Health Stat [22] No.10. Department of Health, Education, and Welfare, Washington, DC, October 1969.
- Enstrom, J. E., and Godley, F. H.: Cancer mortality among a representative sample of nonsmokers in the United States during 1966-68. JNCI 65: 1175-1183, November 1980.
- Seeman, I., Poe, G. S., and McLaughlin, J. K.: Design of the 1986 National Mortality Followback Survey: considerations on collecting data on decedents. Public Health Rep 104: 183-188, March-April 1989.
- Poe, G. S., et al.: Certified versus first-class mail in a mixed-mode survey of next-of-kin respondents. J Official Statistics 6: 157-164 (1990).
- Poe, G. S., et al.: Effects on level and quality of response of the inclusion of "don't know" boxes in factual questions in a mail questionnaire. Public Opinion Q 52: 212-222 (1988).
- National Center for Health Statistics: Development, methods, and response characteristics: 1986 National Mortality Followback Survey. Vital Health Stat [2]. In press.
- Lerchen, M. L., and Samet, J. M.: An assessment of the validity of questionnaire responses provided by a surviving spouse. Am J Epidemiol 123: 481-489 (1986).
- McLaughlin, J. K., Dietz, M. S., Mehl, E. S., and Blot, W. J.: Reliability of surrogate information on cigarette smoking by type of informant. Am J Epidemiol 126: 144-146 (1987).
- Rogot, E., and Reid, D. D.: The validity of data from next-of-kin in studies of mortality among migrants. Int J Epidemiol 4: 51-54 (1975).
- National Center for Health Statistics: Advance report of final mortality statistics. Monthly Vital Statistics Rep [37] No. 6 (supp), September 1988.
- 14. U.S. Bureau of the Census: United States population

- estimates, by age, sex, and race: 1980 to 1987. Current Population Reports, Series P-25, No. 1022, March 1988.
- Rogers, R. G., and Powell-Griner, E.: Life expectancies of cigarette smokers and nonsmokers in the United States. Soc Sci Med 32: 1151-1159 (1991).
- Stinson, F. S., et al.: Alcohol consumption in a 1986 sample of deaths. Alcohol Health and Research World 14: 154-162 (1990).
- Kemper, P., and Murtaugh, C. M.: Lifetime use of nursing home care. New Engl J Med 324: 595-600, Feb. 28, 1991.
- U.S. Bureau of the Census: Educational attainment in the United States: March 1987 and 1986. Current Population

- Reports, Series P-20, No. 428, August 1988.
- Seeman, I.: The National Mortality Followback Survey, summary for the United States. Vital Health Stat [20] No. 19. National Center for Health Statistics, Hyattsville, MD, October 1992.
- National Center for Health Statistics: Characteristics of persons dying from AIDS. Advance Data from Vital and Health Statistics, No. 173, July 1989.
- National Center for Health Statistics: Characteristics of persons dying from diseases of the heart. Advance Data from Vital and Health Statistics, No. 172, July 1989.
- 1986 National Mortality Followback Survey public use data tape. National Technical Information Service, No. PB 90-501800. 5285 Port Royal Rd., Springfield, VA 22161.

Vitamin Supplement Use and Its Correlates Among Elderly Japanese Men Residing on Oahu, HI

IKUKO KATO, MD ABRAHAM M.Y. NOMURA, MD GRANT N. STEMMERMANN, MD PO-HUANG CHYOU, PhD

Dr. Kato was visiting scientist at the Japan-Hawaii Cancer Study in Hawaii, and later a Senior Researcher, Division of Epidemiology, Aichi Cancer Center Research Institute, Nagoya, Japan. She is now in the Director's Office, International Agency for Research on Cancer, Lyon, France. Dr. Nomura is Director, Dr. Stemmermann is Pathologist, and Dr. Chyou is Biostatistician of the Japan-Hawaii Cancer Study, Kuakini Medical Center, Honolulu.

This work was supported in part by grant RO1-CA-33644 from the National Cancer Institute, National Institutes of Health, Bethesda, MD.

Tearsheet requests to Dr. Nomura, Japan-Hawaii Cancer Study, Kuakini Medical Center, 347 N. Kuakini St., Honolulu, HI 96817, telephone 808-521-5071.

Synopsis

Use of vitamin supplements and the association with personal characteristics were investigated

among 4,654 American men of Japanese ancestry in Hawaii. A total of 58 percent of the subjects who were ages 68 to 90 took vitamin supplements. Among supplement users, multivitamins were most commonly used (77 percent), followed by vitamin C (53 percent), E (43 percent), and A (10 percent).

Ninety-two percent of users took at least seven pills per week when all types of pills were combined. Vitamin supplement users were more educated, more physically active, more likely to be married, and less obese than nonusers. They also slept less, smoked less, and drank less alcohol and caffeine. They took more analgesics and stomach medication and had fewer days of hospitalization in the previous 10 years compared with nonusers.

Except for physical activity, use of stomach medicines, and hospitalization, the other characteristics were also positively correlated with the amount of vitamin pill intake. These findings indicate that vitamin supplement users have different health patterns compared with nonusers.

ALTHOUGH REPORTS indicate that several kinds of vitamins may be protective against malignant neoplasms and coronary heart disease (1), other studies have produced equivocal findings (2-6). In spite of the uncertainty about the beneficial effects of vitamins against these diseases, large numbers of people are already using vitamin supplements. This use was observed in a number of nutritional surveys conducted in various populations (7-29),

including specific occupational groups (30,31). Therefore, it is important to record vitamin intake from supplements in evaluating the relation between nutritional intake and disease.

Vitamin supplement users may differ from nonusers not only in the total amounts of vitamin intake, but also in other health behavior and practices, which are likely to affect their risk for disease. More information is needed on the charac-