The Recording of Demographic Information on Death Certificates: A National Survey of Funeral Directors

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SYNOPSIS

Objective. The authors sought to ascertain the methods used by funeral directors to determine the demographic information recorded on death certificates.

Methods. Standardized questionnaires were administered to funeral directors in five urban locations in the U.S. In addition, personnel on four Indian reservations were interviewed. Study sites were selected for diverse racial/ethnic populations and variability in recording practices; funeral homes were selected by stratified random sampling.

Results. Fifty-two percent of responding funeral directors reported receiving no formal training in death certification. Seventy-nine percent of respondents reported finding certain demographic items difficult to complete—26% first specified race as the problematic item, and 25% first specified education. The decedent's race was "sometimes" or "often" determined through personal knowledge of the family by 58% of respondents; 43% reported "sometimes" or "often" determining race by observation. Only three respondents reported that occupation was a problematic item.

Conclusions. The authors recommend that the importance of demographic data and the instructions for data collection be clarified for funeral directors, that standard data collection worksheets be developed, and that training videos be developed.

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INTRODUCTION

Data from vital records such as death certificates provide critical information for use in monitoring the health of the population, conducting research, implementing prevention programs, and formulating health policies. In the United States, state laws require that demographic information on death certificates be recorded by funeral directors, who are asked to report the decedent's characteristics on the basis of information from the next of kin. Despite the importance of this data source for public health, demography, and other fields, information collection practices actually used by funeral directors have not been studied.

Discrepancies between death certificates and other data sources with regard to the demographic characteristics of individuals may originate in recording practices. Several studies have shown inconsistencies for some racial and ethnic groups between death certificates and other sources.[1-7] For example, in an analysis of a sample of U.S. adults, "race"/ethnicity information on death certificates for most racial/ethnic populations was found to be generally consistent with the information reported by decedents before they died—the standard for death certificate reporting of race/ethnicity. However, many individuals who had identified themselves as American Indian were reported as white or black on death certificates.[4] In another study, a comparison of racial information on a sample of U.S. death certificates with information reported by next of kin indicated that certificates are highly consistent with next-of-kin reports determining racial identification for whites and blacks, but less so for Asians and Pacific Islanders and for American Indians.[3]

Similar problems of categorization apply to the determination of the occupation and industry of decedents. Despite the demonstrated utility of death certificate data in occupational epidemiology for exploring the etiology of specific diseases such as tuberculosis,[8] cancers,[9] and neurological diseases,[10] the quality of occupation and industry data reported on death certificates varies widely. Schade and Swanson cite numerous studies in which "misclassification or overreporting of occupation and industry data on the death certificates ranged from 30% to 50%," suggesting that the "utility of death certificate data for studies of occupationally induced diseases, especially those such as cancer, which require usual employment as the minimum level of accuracy," is limited.[11]

Evidence of inconsistency was found between death certificate and next of kin information on other variables as well, including age, in a study using 1986 data.[3] An educational attainment item was added to the U.S. Standard Certificate of Death in 1989 in response to the need for a simple measure of socioeconomic status.[12-14] Anecdotal reports to CDC's National Center for Health Statistics (NCHS) indicate that in some states funeral directors have difficulty in either eliciting or obtaining accurate responses for educational attainment.

The death registration system in the United States is decentralized; responsibility for registration is vested in the registration areas: the states, New York City, Washington, DC, and territories of the United States. NCHS has promoted the degree of uniformity necessary for national statistics by periodically issuing recommended standards, which take the form of recommended laws and regulations (Model State Vital Statistics Act and Regulations), definitions, and reporting forms (U.S. Standard Certificates and Reports). These standards are developed through a cooperative process that involves the federal government, the states, and groups such as associations of funeral directors, medical personnel, and researchers, who either complete the various records or use the data.

Information collected through state registration systems is obtained and compiled by NCHS to produce national vital statistics data through the Vital Statistics Cooperative Program.

As early as the 1600s, a few political jurisdictions or large cities began registering deaths, although most states did not enact laws mandating the registration of deaths until after 1900. By 1933, all states had achieved at least 90% registration completeness and were included in the national vital statistics data system. The registration system that developed in the United States after 1900 placed most of the responsibility for registration of deaths on funeral directors.

By law, funeral directors are responsible for completing and filing death certificates. In most states, the funeral director who first assumes custody of the body is responsible, while in other states, responsibility lies with the funeral director handling the body's disposition. The funeral director obtains personal information from the best source available (usually next of kin) and obtains cause-of-death information from the attending physician, medical examiner, or coroner. The funeral director then files the death certificate with the appropriate registration authority in the state where the death occurred. The federal government and many states provide handbooks for funeral directors on completing death certificates.[15,16] Certificates filed by funeral directors are reviewed by local and state registrars, who may query blank or inappropriate responses on certificates. In national mortality statistics, information on "race," marital status, and His-

panic origin is missing for ≤0.4% of deaths; occupation is missing for 1.5%; industry is missing for 1.4%; and information on education is missing for 4.4% (NCHS, Division of Vital Statistics, unpublished data; 1997). Although deaths of American Indians on reservations are also reported on state death certificate forms, the reservations are legally autonomous and reporting processes on reservations can differ, affecting the completeness of death information on American Indians.

Little has been written about the process by which demographic information is obtained by the estimated 35,000 licensed funeral directors in the United States on more than 2.3 million U.S. decedents per year.[17] This study assessed the methods used by funeral directors to complete death certificates. More specifically, we analyzed the processes for obtaining and recording demographic information, the training in procedures for collecting demographic information received by the funeral directors, and potential obstacles to the collection of required information.

METHODS

The study was conducted in two phases. We began in 1993 by holding focus groups with funeral directors in three locations—Birmingham, San Francisco, and Albuquerque—to develop a survey questionnaire and to assess the feasibility of collecting information using a telephone survey. Second, using information from the focus groups, we designed a questionnaire for a survey of funeral directors. Based on the focus groups, we decided that valid information could be better collected through in-person interviews than through telephone interviews.

To standardize observations of the demographic data collection process, we described a series of fictitious decedents and asked funeral directors to assume that the interviewer was the fictitious decedent's next of kin and to role-play collecting demographic information on the decedent. However, because we did not collect detailed, contextual information on what the funeral director was thinking and why, we could not fully interpret these data and thus do not include them in this analysis.

We selected five urban sites for study interviews on the basis of varied ethnic distributions, known differences in the use of information on occupation and industry that may result in differences in data collection, a mixture of urban and rural populations, and travel costs. Five sites were selected: Albuquerque, Seattle, Philadelphia, the Washington, DC, area (including parts of Virginia and Maryland), and the Memphis area (including parts of Mississippi and Arkansas).

For each study site, we randomly drew a sampling frame from a funeral home list purchased from American Business Lists (Omaha, Nebraska), supplemented by funeral director association lists and telephone directories. To assure representation of minority populations, lists were stratified by race/ethnicity when possible, using surnames to identify probable Asian and Hispanic funeral homes. A list approximately 50% greater than the desired size was compiled to allow for funeral homes no longer in business and homes for which interviews could not be arranged. The selected funeral homes were sent a letter explaining the project and inviting participation. Approximately two weeks later, prospective participants were telephoned and asked to schedule an interview. Because the process of vital record reporting can differ on American Indian reservations in terms of personnel and procedures, additional interviews were conducted in four American Indian settings using a different questionnaire, with personnel involved in the process of reporting to clarify the process in these settings; these results are reported here separately from other interview findings.

The Klemm Analysis Group, Inc. (Washington, DC) developed the sampling frame and conducted the interviews using a standardized questionnaire. Klemm maintained the confidentiality of study subjects by removing personal identifiers from electronic files for analysis.

In addition to summarizing how demographic data were typically obtained and processed by the funeral directors who were interviewed, we also examined the association between several funeral home characteristics and the processing of demographic information.

RESULTS

A total of 98 funeral directors, each from a different funeral home, were interviewed with a standard questionnaire in the fall of 1995; 75% were men and 25% women. According to self-report, 58% were white, 40% black, and 2% Hispanic; none of the funeral directors in our sample was Asian. Most of those interviewed (85%) reported being owners or managers of the funeral homes where they were interviewed. Respondents reported a median of 20 years of experience in completing death certificates (range 1–50). Most (89%) funeral homes visited were located in urban settings.

The participating funeral directors reported having held a median of 125 funeral services during the prior year, with a range of 0 to 1,200; they reported

completing a median of 150 death certificates in the prior year, with a range of 4 to 1,700. A median of two full-time employees was responsible for completing death certificates; in only 14% of funeral homes were part-time employees responsible for completing death certificates.

Forty-eight percent of respondents reported having received formal training in the completion of death certificates; the remaining 52% reported having no training, or learning on the job. Among those with formal training, 61% acquired their training at mortuary school, and an additional 9% at embalming school; 22% attended a state program or seminar. Handbooks of procedures for completing death certificates were reported to be available in 69% of funeral homes; 93% of these handbooks were from state or other government agencies. About half of the funeral directors (54%) reported receiving training intended to review or update their knowledge of certification procedures; 48% of those receiving this training reported not having received initial formal training.

Only 5% of funeral directors reported recording demographic information from next of kin directly on death certificates. Most used their own worksheets or worksheets from other sources. One-third of funeral directors (33 of 98) reported that they transcribed data onto certificates themselves; 45% used assistants for transcription, and 18% used other personnel.

When asked what they did when informants did not know the answer to a question about the decedent, 25% of funeral directors reported recording the item as unknown or leaving it blank; 10% looked up administrative records themselves to assess the missing item; and 36% reported that they asked informants to research the issue or provided them with a form to fill out. An additional 26% of funeral directors reported that they asked other relatives for the missing information. When these informants were also unable to answer the question, 89% of funeral directors who asked other relatives recorded "unknown" or "unavailable" on the certificate.

Asked if they ever determined race by knowledge of the decedent's family instead of by asking the informant, 58% of respondents said they did so either "sometimes" or "often"; 42% said they "seldom" or "never" did so. Asked if they ever determined "race" by observation of the decedent, 43% of respondents said they did so "sometimes" or "often"; 57% said they "seldom" or "never" did so.

Asked if they ever determined Hispanic origin by knowledge of the decedent's family, 44% of respondents said they did so either "sometimes" or "often"; 56% said they "seldom" or "never" did so. Asked if they ever determined Hispanic origin from the decedent's name, 26% of respondents said they did so either "sometimes" or "often"; 71% said they "seldom" or "never" did so.

Asked, "Are there any demographic items in the death certificate that cause particular problems when you ask them?" 79% of respondents answered yes. Of these respondents, 20 of 77 (26%) first mentioned race as an item with which they sometimes had a problem; 10 of 77 (25%) first specified education. Among those who first mentioned problems with the race item, the principal reasons given for the difficulty by 12 of 19 (63%) were "inadequate criteria for judgment/unclear" and "people wonder why it is necessary" (21%). Among those who first reported problems with the education item, the principal reasons given for the difficulty were "people wonder why it is necessary" (7 of 19, or 37%), "people are embarrassed by it" (21%), and often "unknown" (21%). Among other items seen as causing problems were names of decedents' parents (12%), address (8%), Hispanic origin (6%), and age (5%). Reporting of occupation was said to be a problem by only three respondents, two of whom found the criteria for the category unclear.

Overall, among those reporting problems with specific death certificate items, 26% (20 of 77) claimed that the problem was lack of clear criteria for determining a category; another 26% claimed that the difficulty was that next of kin did not understand why the information was necessary; 16% reported that the information was not known to informants; 9% reported that next of kin did not know what was meant by legal address. Poor records for elderly decedents was also mentioned as a reason for difficulty with an item (8%), and embarrassment on the part of informants was also noted (7%). Although specifically asked in the interview, none of the funeral directors thought that a problem was his or her own lack of understanding of the item.

We tested 22 potential associations for significance with the two-tailed Fisher exact test (see Table). Self-reported "race"/ethnicity of the funeral director was associated with problems with the race and education items; white respondents were more likely than black respondents to report problems with each of these items. We found no other statistically significant associations among those tested.

To explore whether reporting differed for American Indians in the study areas, we interviewed health officials on two reservations near Seattle and on two pueblos near Albuquerque. The Seattle respondents were directors of local Indian Health Service offices; they reported that funeral proceedings for most tribal

Table. Associations among selected study variables

Association of	*With*	*Significance*
finding race to be a problem	• number of certificates completed annually,	NS
	• training of the funeral directors,	NS
	• race of the funeral director	<0.003
finding education to be a problem	• number of certificates completed annually,	NS
	• training of the funeral directors,	NS
	• race of the funeral director	<0.05
lack of criteria as a reason for problems	• number of certificates completed annually,	NS
	• years of experience,	NS
	• presence of a data collection manual	NS
problem with any certificate item	• presence of a data collection manual	NS
race determined by knowledge of family (rather than from next of kin)	• number of certificates completed annually,	NS
	• training of the funeral directors,	NS
	• race of the funeral director	NS
race determined by observation (rather than from next of kin)	• number of certificates completed annually,	NS
	• training of the funeral directors,	NS
	• race of the funeral director	NS
Hispanic origin determined by knowledge of the family (rather than from next of kin)	• number of certificates completed annually,	NS
	• training of the funeral directors,	NS
	• race of the funeral director	NS
Hispanic origin determined by name (rather than from next of kin)	• number of certificates completed annually,	NS
	• training of the funeral directors,	NS
	• race of the funeral director	NS

NS = not significant (two-tailed Fisher's exact test)

members were handled by non-Indian funeral homes serving the general public. This practice was confirmed by non-Indian funeral directors in the Seattle area, who indicated that they handled most local tribal deaths and followed the standard certification procedures even if burial took place on tribal land. Albuquerque respondents were tribal enrollment technicians responsible for tribal records. These technicians reported that death certificates for tribal members whose deaths occurred on reservations were the responsibility of the technicians and that funeral directors were rarely involved in Indian funeral proceedings or death certification.

DISCUSSION

The health status of minority racial and ethnic populations and populations of poor socioeconomic position are prominent foci of the national public health agenda. The second goal of *Healthy People 2010* is to eliminate disparities in health across different segments of the population, including "racial"/ethnic groups.[18] Achieving this goal through public health surveillance, analysis, and program planning and implementation requires the valid and consistent classification of individuals into "racial" and ethnic categories.

We found that funeral directors identified problems with several demographic items on death certificates. For example, although few funeral directors noted problems in the reporting of occupation, 26% of those reporting problems noted problems in the reporting of "race," and another 26% noted problems reporting education. Among respondents who noted problems, the principal reasons given were lack of understanding of the need for the item (26%), unclear criteria for determination of the entries (26%),

lack of knowledge on the part of informants (16%), poor records for the elderly (8%), and embarrassment on the part of informants (7%). While our study population was a diverse sample of the U.S. funeral directors, it was not a statistically random sample; thus, specific study results might not represent funeral directors' perspectives or practices in general.

We must note that the lack of problems perceived by funeral directors (e.g., no perceived problem but poor data for the occupation/industry item as identified by independent review) need not correspond to demographic accuracy of the information recorded; for example, although funeral directors did not report a problem in recording occupation and industry, in fact the information they record often does not follow the rules and is inaccurate. Likewise, perceived problems need not correspond to lack of accuracy. Rather than accuracy, the perceptions of funeral directors suggest reasons why they have difficulty obtaining some of the information on death certificates. Our preliminary analysis of these difficulties might provide directions for improving the process.

Our preliminary examination of four American Indian settings suggests substantial variability in the collection of demographic information for this population. In Seattle, information on American Indians living on reservations appears to be most often recorded by non-Indian funeral directors. In contrast, in the Albuquerque area, demographic information on decedents is apparently most often collected by tribal enrollment specialists. This variability in collection procedures needs to be further examined to determine possible effects on reporting of mortality data for the American Indian population.

We propose several measures that might help funeral directors obtain more accurate demographic information on death certificates. These measures should be developed and implemented in collaboration with national organizations of funeral directors. Several states are currently moving toward the use of electronic death registration systems to collect and file death certificates, and the development of these electronic systems will provide unique opportunities to include features to assist funeral directors in the completion of items on the death certificate.

Common reasons funeral directors gave for difficulties with specific demographic items on death certificates were the lack of clear criteria and failure on the part of the next of kin to understand the need for the item. We recommend that the instructions for completing all items be reviewed and improved so that funeral directors will have better guidance. We also recommend that the importance of death certificate information and the rationale for collecting specific items be more clearly indicated to funeral directors so they have a better understanding of the reasons the information is needed and can better explain these reasons to their informants. Changes should be tested and incorporated into available handbooks.

No standard worksheets are currently available for collecting demographic information for death certificates. We recommend that a standard worksheet be developed for the initial recording of demographic information and that this form include succinct written instructions for the completion of each item. At a minimum, we recommend that standard definitions and instructions for the completion of each item be developed and provided to all funeral directors.

Computer software currently used by funeral directors to complete death certificates and electronic death registration software that is being developed should incorporate succinct instructions and prompts on the criteria for completing specific items.

We know of no standard approach to training funeral directors in methods of completing death certificates. We recommend that states develop training programs for funeral directors to promote improvement in the quality of demographic information. Among the tools that should be considered is the use of training videos. A basic video would serve as the foundation for training, but videos would have to be modified to take into account differences among states in certificate items and registration procedures.

Finally, funeral directors should be provided feedback on uses of the data they collect. Feedback might include mortality reports or columns written for periodicals read by funeral directors. Presentations at state and national conventions of funeral directors might also be explored as a means of providing feedback.

Just after completion of the study reported here, the Panel to Evaluate the U.S. Standard Certificates[19] finished its work in making recommendations for revisions to the U.S. Standard Certificate of Death. As part of its evaluation process, the Panel considered the development of a standard worksheet for funeral directors. Because funeral directors need a large amount of detailed information for business purposes that goes well beyond the requirements for the death certificate, many funeral directors have already developed their own worksheets to incorporate all of their needs into one form. Therefore, the Panel believed that it was not practical to expect funeral directors to use a worksheet designed only to obtain information needed for the death certificate. Instead, the Panel recommended that standard definitions and instructions for the completion of each item be developed and pro-

vided to all funeral directors as an attachment to the death certificate. This Panel also recommended that training programs be developed for funeral directors to promote improvements in the quality of the demographic information.

In summary, demographic characteristics such as sex, age, "race," education, industry, and occupation are essential elements for understanding the incidence, spread, and mortality associated with diseases and injuries. Funeral directors are the principal providers of this information in the United States. Using findings from our study, we have developed several recommendations to enhance procedures for recording demographic information and thereby improve the vital statistics system.

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REFERENCES

1. Hahn R, Mulinare J, Teutsch S. Inconsistencies in coding of race and ethnicity between birth and death in US infants: a new look at infant mortality, 1983 through 1985. JAMA 1992;267:259-63.
2. Hahn R. The state of federal health statistics on racial and ethnic groups. JAMA 1992;267:268-71.
3. Poe GS, Powell-Griner E, McLaughlin JK, Placek PJ, Thompson GB, Robinson K. Comparability of the death certificate and the 1986 National Mortality Followback Survey. Vital Health Stat 2 1993;(118):1-53.
4. Hahn RA, Truman BI, Barker ND. Identifying ancestry: the reliability of ancestral identification in the United States by self, proxy, interviewer, and funeral director. Epidemiology 1996;7:75-80.
5. Rosenberg HM, Maurer JD, Sorlie PD, Johnson NJ, MacDorman MF, Hoyert DL, et al. Quality of death rates by race and Hispanic-origin: a summary of current research, 1999. Vital Health Stat 2 1999;(128):1-13.
6. Sorlie PD, Rogot E, Johnson NJ. Validity of demographic characteristics on the death certificate. Epidemiology 1992;3:181-4.
7. National Center for Health Statistics. Vital statistics of the United States, 1992. Vol II, mortality part A. Washington: Public Health Service; 1996.
8. Chen GX, Burnett CA, Cameron L, Alterman T, Lalich N, Tanaka S, Althouse RB. Tuberculosis mortality and silica exposure: a case-control study based on a national mortality database for the years 1983–1992. Int J Occup Environ Health 1997;3:163-70.
9. Kang SK, Burnett CA, Freund E, Walker J, Lalich N, Sestito J. Gastrointestinal cancer mortality of workers in occupations with high asbestos exposures. Am J Ind Med 1997;31:713-8.
10. Schulte PA, Burnett CA, Boeniger MF, Johnson J. Neurodegenerative diseases: occupational occurrence and potential risk factors, 1982 through 1991. Am J Public Health 1996;86:1281-8.
11. Schade WJ, Swanson GM. Comparison of death certificate occupation and industry data with lifetime occupational histories obtained by interview: variations in the accuracy of death certificate entries. Am J Ind Med 1988;14:121-36.
12. Kitagawa EM, Hauser PM. Differential mortality in the United States: a study in socioeconomic epidemiology. Cambridge: Harvard University Press; 1973.
13. Rogot E, Sorlie PD, Johnson W, Schmidt DK. A mortality study of 1.3 million persons by demographic, social, and economic factors: 1979–1985 follow-up. Bethesda (MD): National Institutes of Health; 1992.
14. Tolson GC, Barnes JM, Gay GA, Kowaleski JL. The 1989 revision of the U.S. Standard Certificates and Reports. Vital Health Stat 4 1991;(28):1-34.
15. National Center for Health Statistics. Funeral directors' handbook on death registration and fetal death reporting. Hyattsville (MD): Department of Health and Human Services (US), Public Health Service; 1987. Available from: URL: http://www.cdc.gov/nchs/data/misc/hb_fun.pdf
16. National Center for Health Statistics. Guidelines for reporting occupation and industry on death certificates. Hyattsville (MD): Department of Health and Human Services (US), Public Health Service; 1988. Available from: URL: http://www.cdc.gov/nchs/data/misc/hb_occup.pdf
17. National Funeral Directors Association [cited 1999]. Available from: URL: http://www/nfda.org
18. Department of Health and Human Services (US). Healthy People 2010. Conference ed. Washington: Department of Health and Human Services (US); 2000.
19. National Center for Health Statistics. Report of the Panel to Evaluate the U.S. Standard Certificates. 2000. Available from: URL: http://www.cdc.gov/nchs/about/major/dvs/vital_certs_rev/panelreport_occ.pdf