Awareness of Hospice Services: Results of a National Survey

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Synopsis

The Supplement on Aging to the 1984 National Health Interview Survey contained questions about hospices and the hospice concept. Respondents were asked about their familiarity with and perceived access to hospice services. Nearly 53 percent of respondents aged 55 and older were unfamiliar with the hospice concept. Of those familiar with hospice, only approximately one-half (48.5 percent) reported that it is available if needed. Age was strongly, linearly related to familiarity with hospice; those over 85 were less likely to know of it (76.6 percent). Female respondents were more knowledgeable than men at all ages. Prior history of cancer and higher education levels were also associated with knowledge of hospice.

AWARENESS OF THE AVAILABILITY of a service is an obvious prerequisite to its use. Lack of knowledge of the availability of health services is considered an access barrier which is potentially as influential as consumers' attitudes, geographic location, and financial limitations (*1,2*). In an era of rapid changes in the organization of health services, consumers' lack of understanding of the structure of health care may be a barrier to the use and expansion of services shown to be cost-effective (*3,4*).

During the last 15 years, the hospice concept has evolved from a social movement into a unique service benefit covered under Medicare and other third-party payors (*5,6*). Several studies suggest that the hospice may be a less costly, less institutional alternative to conventional care for terminal cancer patients; to date, no study shows hospice to be more costly than conventional care (*6,7*).

The growth of the U.S. hospice movement has been remarkable. Since the first hospice began receiving patients in 1974, the number of hospices in the United States has grown exponentially. In 1986, there were 1,418 hospices registered in the listing of providers compiled annually by the National Hospice Organization, with at least one in every State (*8*). Media attention on the hospice concept has been substantial. The proportion of the potentially eligible population (based on the number of cancer deaths in a geographic area) served by hospices reached 30 percent as early as 1981 in selected counties (*9*). More recently, estimates of eligible patients served by hospice have exceeded 40 percent in areas in Kentucky (*10*).

Another approach to assessing the potential influence of the hospice concept on the medical care system is to determine the general public's familiarity with hospice services, particularly older persons and those with cancer who might eventually use the service. This study reports the results of analyses of data from several questions about respondents' awareness of hospice in the Supplement on Aging (SOA) to the 1984 National Health Interview Survey (NHIS).

Methods

The National Health Interview Survey has been conducted since 1957 by the National Center for Health Statistics (NCHS). Each year a nationally representative sample of households participates in personal interviews, answering questions on basic health, demographics, and other selected health topics of current interest. A complete description of the NHIS design and procedures has been published (*11,12*).

In 1984, the NHIS sample included approximately 41,000 households; basic health and demographic information was obtained on about 105,000 persons living in those households. The special

health topic that year was health of the elderly. The questionnaire was referred to as the Supplement on Aging. It was designed to collect information on all persons 65 years of age or older and a randomly selected 50 percent of persons 55–64 living in NHIS sample households. SOA interviews were completed for 16,148 persons—96 percent of eligible persons.

When weighted to adjust for the sample design and nonresponse, the sample can be used to make reliable estimates to the total United States, civilian, noninstitutionalized, community-dwelling population aged 55 and over. The statistics in tables 1 and 2 represent weighted estimates for that population and include the estimated sampling error (standard error) for each statistic. Sampling errors were estimated using a pseudo-replication technique for typical statistics. A regression curve was fitted to those estimates, and the formula for that curve was used to compute the standard errors shown in this paper (*13*).

Two questions on hospice were included in the SOA:

1. "Are you familiar with the term 'HOSPICE,' that is, a service for the terminally ill?"
2. (IF YES) "Is there a hospice or an in-home hospice service in the (metropolitan area/county) that you could use if you needed one?"

The analyses we present exclude cases with missing data and those interviews conducted with proxy respondents. It is reasonable to assume that respondents unable to answer such questions (requesting a proxy) would be less aware of new health services options like hospices or would at least not be in a position to choose them independently. For the under 85 years subgroup, the potential bias arising from missing data cannot be large because the level of missing data is relatively low, ranging from 9 to 12 percent. However, for the 85 and older age group, the bias could be significant because data are missing for more than 40 percent.

In both table 1 and table 2, the category familiar with hospice and available in area represents those persons who answered "yes" to both hospice questions. Respondents who answered "yes" to the first question and "no" or "don't know" to the second question are in the category familiar but not available or unknown availability. Those who answered "no" to the first question are in the category unfamiliar. Therefore, a "yes" or "no" response to the second question reflects only the respondent's perception and not necessarily the actual availability of hospice services. It was not possible to link respondents' residential location (for example, county) with information about the location of hospices nationwide since SOA data are only tabulated according to four national geographic regions and urban and rural status. Consequently, it is not possible to ascertain the validity of respondents' perceptions of the availability of hospice services.

Results

Table 1 presents the three categories of response to the two questions about hospice awareness by age, sex, education, and residence status in a standard metropolitan statistical area (SMSA) and geographic region. Nearly 77 percent of respondents ages 85 and older were not familiar with hospice, while only 47.9 percent of respondents between 55 and 64 years of age were unaware of hospice; of the younger group, 26 percent were familiar with hospice and aware of the availability of a hospice in the area, while only 9.7 percent of the oldest respondents were similarly informed about hospice. With each succeeding decade of age there is a clear, substantial reduction in the level of awareness. A robust trend in this direction also exists for the response category "Familiar with hospice but not available or unknown availability." Older respondents predictably were also less likely to be knowledgeable about hospice and its availability: about one-fourth of the youngest respondents knew if a hospice was available, compared with less than one-tenth among the oldest respondents.

A strong linear relationship exists between level of education and knowledge of hospice as well, with the better educated being more familiar with hospice services. However, even among the most highly educated group, only 43 percent were familiar with the term and confident of its availability, and nearly 17 percent were unfamiliar with the term.

The global SMSA–non-SMSA comparison in table 1 suggests that, although persons living in the urban SMSA environment were more likely to be familiar with the term hospice and knowledgeable about the availability of hospice services in their area than was true for rural, non-SMSA respondents, urban respondents were also more likely to be unfamiliar with the concept. This seeming contradiction results from the increased proportion of non-SMSA respondents who, although familiar with the term, perceive a lack of access to hospice.

Table 1. Hospice knowledge by age, sex, education, geographic region, and SMSA residence status of respondents, Supplement on Aging, National Health Interview Survey, 1984

Characteristics	Number (thousands)	Familiar with hospice and available in area		Familiar, but not available or unknown availability		Unfamiliar with hospice	
		Percent	SE	Percent	SE	Percent	SE
Sex and age							
Male:							
All persons 55 and over	18,378	20.6	±.7	22.4	±.7	57.9	±.9
55–64 years	8,878	23.2	±1.3	23.2	±1.3	53.6	±1.5
65–74 years	6,369	20.2	±1.0	23.9	±1.1	55.9	±1.2
75–84 years	2,718	14.7	±1.4	18.4	±1.5	67.0	±1.8
85 years and older	413	9.6	±2.9	9.2	±2.8	81.2	±3.8
Female:							
All persons 55 and older	25,490	24.7	±.7	26.0	±.7	49.2	±.8
55–64 years	11,199	28.2	±1.2	28.4	±1.2	43.4	±1.3
65–74 years	8,682	25.2	±.9	26.9	±1.0	48.0	±1.1
75–84 years	4,666	18.7	±1.1	20.8	±1.2	60.5	±1.4
85 years and older	943	9.8	±1.9	15.7	±2.4	74.5	±2.8
Education							
None	279	3.4	±2.2	0.0	±.0	96.6	±2.2
1–8 years	9,236	8.3	±.6	10.6	±.6	81.1	±.8
9–11 years	6,141	14.4	±.9	23.1	±1.1	62.5	±1.2
High school graduate	11,848	28.5	±.8	29.8	±.8	41.7	±.9
1–3 years college	3,928	35.3	±1.5	35.7	±1.5	29.0	±1.4
College graduate	2,076	39.4	±2.1	37.2	±2.1	23.4	±1.9
Post college	1,505	43.0	±2.5	40.4	±2.5	16.6	±1.9
Geographic region							
All Northeast	10,410	22.4	±.8	27.2	±.9	50.4	±1.0
Northeast SMSA	3,022	16.5	±1.4	22.1	±1.5	61.4	±1.8
Northeast non-SMSA	7,388	24.9	±1.0	29.2	±1.1	45.9	±1.2
All North Central	10,888	28.0	±.8	24.2	±.8	47.7	±.9
North Central SMSA	2,899	30.5	±1.7	19.7	±1.5	49.8	±1.9
North Central non-SMSA	7,989	27.7	±1.0	25.8	±1.0	46.5	±1.1
All South	14,009	18.0	±.6	20.8	±.7	61.2	±.8
South SMSA	3,510	25.2	±1.5	17.8	±1.3	57.1	±1.7
South non-SMSA	10,499	15.8	±.7	22.1	±.8	62.1	±1.0
All West	7,627	25.9	±1.0	28.2	±1.0	45.9	±1.1
West SMSA	2,243	29.6	±1.9	24.3	±1.8	46.0	±2.1
West non-SMSA	5,384	24.3	±1.2	29.9	±1.3	45.8	±1.4

SE = Standard error, SMSA = Standard Metropolitan Statistical Area.

Overall, of those who answered that they were familiar with hospice, SMSA residents were more likely to feel that they have access to hospice services (45 percent versus 53 percent) than were non-SMSA residents.

Examining this relationship within each geographic region revealed an interesting interaction. The Northeast was the only area where SMSA residents were less likely than the nonurban respondents to be both familiar with hospice services and aware of hospice availability. The opposite pattern is found in the North Central, Southern, and Western Regions with respect to the familiar and available category, with awareness being higher in SMSA locations. In each of these geographic areas, for those respondents familiar with hospice, perceived lack of access to services was lower among SMSA respondents. While a slightly higher percent of SMSA residents were unfamiliar with hospice in the North Central and Western Regions, this was not true in the South. In that area, a lower proportion were familiar with hospice, overall, and the SMSA–non-SMSA differential is clear; those persons living in non-SMSA locations were less likely to be aware of hospice services or to feel that hospice is accessible to them. Whether these perceptions about the availability of hospice are true cannot, unfortunately, be addressed with these data.

Further analyses shown in table 2 examined the knowledge of persons who have ever had cancer with those who have not, by age category. Current

Table 2. Hospice knowledge and cancer history of respondents, Supplement on Aging, National Health Interview Survey, 1984

Cancer history and age group	Number (thousands)	Familiar with hospice and available in area		Familiar, but not available or unknown availability		Unfamiliar with hospice	
		Percent	SE	Percent	SE	Percent	SE
Had cancer	4,129	24.6	±1.6	28.3	±1.7	47.1	±1.9
55–64 years	1,379	24.4	±3.2	34.4	±3.6	41.2	±3.7
65–74 years	1,620	28.0	±2.2	26.6	±2.2	45.3	±2.5
75–84 years	978	22.0	±2.7	25.5	±2.8	52.6	±3.2
85 years and older	152	5.4	±3.7	9.8	±4.8	84.7	±5.8
Never had cancer	39,593	22.9	±.5	24.2	±.5	52.9	±.6
55–64 years	18,634	26.2	±.9	25.6	±.9	48.2	±1.0
65–74 years	13,392	22.4	±.7	25.5	±.8	52.1	±.9
75–84 years	6,372	16.5	±.9	19.1	±1.0	64.3	±1.2
85 years and older	1,195	10.2	±1.8	13.9	±2.0	75.9	±2.5

SE = Standard error, SMSA = Standard Metropolitan Statistical Area.

or previous experience with cancer was indicated by respondents' answer to the question, "Please tell me if you have ever had cancer of any kind?" Generally, a history of cancer was associated with only a slightly greater likelihood that the respondent would be familiar with hospice (52.9 percent verus 47.1 percent). Among those with cancer experience, knowledge of hospice was greater than that of noncancer respondents among the 75–84-year-olds (22 percent versus 16.5 percent) but not for those older than 85 (5.4 percent versus 10.2 percent).

Discussion

As the 1984 NHIS reveals, nationwide nearly 53 percent of respondents aged 55 and older were unfamiliar with hospice. Of those familiar with hospice, only 48.5 percent reported that such services were available if needed.

Age was strongly, linearly related to familiarity with hospice; those over 85 were least likely to know of it. Female respondents were more knowledgeable than males at all ages, supporting the notion that women are more familiar with health care options than men. Respondents reporting that they currently or previously had cancer were only somewhat more familiar with hospice than were those without a history of cancer (40 percent versus 35 percent). Given the association between hospice and cancer, this differential was smaller in magnitude than anticipated. Finally, we found that respondents residing outside of SMSAs were more likely to be familiar with hospice than their metropolitan counterparts, due in part to the large proportion of nonmetropolitan respondents in the Northeast familiar with hospice. Additionally, non-SMSA respondents who were aware of hospice were less likely be aware of their availability than were metropolitan respondents who knew of hospice.

Our finding that the oldest old were least likely to be familiar with hospice is consistent with other reports in the gerontological literature, in which researchers noted that older age is associated with reduced knowledge of available services (*14,15*). In interpreting these results it is important to recall those requiring a proxy interview and the institutionalized were not included in these analyses. Only the relatively healthy, independent "old old" are represented.

The population of patients using hospice services has historically not been the "old old." A review of numerous studies and hospice program descriptions has shown that the average age of the hospice patient is just over 65, with less than one-quarter being older than 75 (*6,16*). The nursing home population, characterized as the oldest old with limited family supports, do not use hospice. These data suggest that younger elders with a terminal condition will continue to be more likely to exercise the hospice option, while the widowed, old old will continue to be served by nursing homes.

Access barriers, and not awareness of the availability of hospice services in the area, per se, appear to be the deciding factor in determining non-SMSA responses. Based on a review of table 1, non-SMSA respondents who were familiar with hospice were less likely to have access to knowledge about a hospice in their area. The nonmetropolitan regions actually had lower reported rates of unfamiliarity with hospice, with the South being the one significant exception. In that region, metropolitan areas seem to be characterized by both higher

familiarity and access rates, as well as low unfamiliarity. The strikingly different pattern evident in the Northeast is one of low familiarity and perceived availability in urban areas. The greatest SMSA–non-SMSA differential was observed in the Northeast as well, where only 48.9 percent of non-SMSA respondents were unfamiliar with hospice, compared with 61.4 percent of metropolitan residents.

Although the basis for regional variations is difficult to determine, differences may be related to the national maldistribution of hospices. Of the estimated 1,400 hospices operating in the United States, a disproportionate number are in the Northeast and California (*8*), and most are located in urban or suburban areas. However, in the Northeast, and particularly in New England, a higher number of hospices operate in rural settings. Historically, the majority of hospices in the Northeast are strongly home care-oriented and emphasize community organization and education. This pattern of location may explain the low level of familiarity with hospice services among urban dwellers in the Northeast. Similarly, the metropolitan-nonmetropolitan differential in the South may be due to the concentration of hospices in SMSA centers within that region.

Perhaps the finding of greatest interest is that respondents reporting cancer were only somewhat more likely to be familiar with hospice than were those without such experience. Over the past decade, considerable public and media attention has been devoted to the hospice movement and discussion of death and dying. That this message apparently has not reached its intended target may be surprising, but it is consistent with the research of mass media health promotion campaigns; they apparently have had little impact on the public's awareness of a particular issue (*17,18*).

If persons with cancer experience (who might ultimately need hospice services) are relatively unaware of such services, how do they learn of them? Recent research on the process of decision-making in using hospice services provides some insight. In a study of hospices, medical care providers, and terminal cancer patients and their families in Kentucky, Bonham and his colleagues found that providers nearly always introduced the idea of using hospice services (*10*). This study suggests that, as in many areas of health care, demand is induced by the supply of service, particularly when the provider acts as the principal determinant of service use (*19*). From this perspective, patients do not become familiar with hospice until the professional community feels that it is needed. Until that time, familiarity with the service may be like other general knowledge factors—highly related to educational background and exposure to the specific issue.

What do our findings say about the future demand for hospice? Clearly, familiarity with a service is not a guarantee that it will be used when needed. Nonetheless, familiarity is a necessary prerequisite to individual choice of services. When our findings are viewed in the context of the decision-making process, they suggest that the patient's or family's knowledge may not be as important as other factors in determining future demand for hospice. The low level of familiarity with hospice we observed, coupled with the substantial use of hospice services by the terminally ill, suggests that the major determinants of future hospice use may be more strongly related to providers' knowledge and awareness, the proliferation of hospices, reimbursement policy, and professional attitudes about the appropriate use of hospice as a resource for dying patients, rather than to the general public's awareness of hospice.

References

1. Harle, Z., Noelker, L., and Blake, B.: Comprehensive services for the aged: theoretical and empirical perspectives. Gerontologist 25:644–649 (1985).
2. Wan, T. T. H., and Arling, G: Differential use of health services among disabled elderly. Res Aging 5:411–431 (1983).
3. Aday, L. A., Fleming, G. V., and Anderson, R. M.: Access to medical care in the U.S.: who has it? who doesn't? Pluribus, Chicago, 1984.
4. Ermann, D., and Gabel, J.: The changing face of American health care: multihospital systems, emergency centers, and surgery centers. Med Care 23: 401–420 (1985).
5. Greer, D. S., and Mor, V.: How Medicare is altering the hospice movement. Hastings Center Rep 15: 5–10 (1985).
6. Mor, V.: Hospice care systems: structure, process, costs, and outcome. Springer Publishing Company, New York, 1987.
7. Mor, V., and Kidder, D.: Cost savings in hospice: final results of the National Hospice Study. Health Services Res 20: 407–422 (1985).
8. The 1986 guide to the nation's hospices. National Hospice Organization, Arlington, VA, 1986.
9. Mor, V., and Hiris, J.: Determinants of site of death among hospice cancer patients. J Health Soc Behav 24: 375–385 (1983).
10. Bonham, G. S., Gochman, D. S., Burgess, L., and Fream, A. M.: The hospice decision: multiple determinants. Final report, University of Louisville, KY, 1986.
11. Fitti, J. E., and Kovar, M. G.: The supplement on aging to the 1984 National Health Interview Survey. Vital Health Stat [1] No. 21. National Center for Health Statistics, U.S. Government Printing Office, Washington, DC. In press.

12. Kovar, M. G., and Poe, G. S.: National Health Interview Survey design, 1973–84, and procedures, 1975–83. Vital Health Stat [1] No. 18. National Center for Health Statistics. DHHS Publication No. (PHS) 85-1320, U.S. Government Printing Office, Washington, DC, 1986.
13. Moss, A. J., and Parsons, V. L.: Current estimates from the National Health Interview Survey, United States, 1985. Vital Health Stat [10] No. 160. National Center for Health Statistics, DHHS Publication No. (PHS) 86-1588, U.S. Government Printing Office, Washington, DC, September 1986.
14. Silverstein, N.: Informing the elderly about public services: the relationship between sources of knowledge and service utilization. Gerontologist 24: 37–40 (1984).
15. Krout, J.: Knowledge and use of services by the elderly: a critical review of literature. Int J Aging Hum Dev 17:153–175 (1983).
16. Mor, V.: Hospice and the elderly: insights from the national hospice study. *In* Aging: the universal human experience, edited by G. L. Maddox, and E. W. Busse. Springer Publishing Company, New York City, 1987, pp. 479–493.
17. Masterson-Allen, S., Mor, V., and Lance, M. P.: Physician screening practices and colorectal cancer screening prevalence among the Rhode Island population. RI Med J 70: 217–221 (1987).
18. Rogers, E. M.: Mass media and interpersonal communication. *In* Handbook of communication, edited by I. Pool, et al. Rand McNally, Chicago, IL, 1973.
19. Pauly, M.: Economic aspects of consumer use. *In* Health care consumers, professionals, and organization, J. B. McKinley, editor. Massachusetts Institute of Technology, Cambridge, MA, 1981, pp. 56–87.

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-