

# Family Perspectives on End-of-Life Care at the Last Place of Care

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OVER THE PAST CENTURY, DYING has become increasingly institutionalized. In the early 1900s most people died at home, but by the middle of the 20th century the majority of deaths in industrialized nations occurred in health care institutions. With recent changes in health care, society is struggling with the role that governmental and nongovernmental regulatory structures should play in assuring that the health care system provides competent, coordinated, and compassionate care at life's end.<sup>1</sup>

Early efforts to define a "good death" were based on expert opinion.<sup>2-4</sup> Recent attempts have used focus groups and in-depth interviews to capture patient and family perspectives.<sup>5-7</sup> Several authors of the current study developed a conceptual model of quality of end-of-life care<sup>7</sup> with input from dying patients, their families, structured review of professional guidelines, and experts. This research indicates that high-quality end-of-life care results when health care professionals (1) ensure desired physical comfort and emotional support, (2) promote shared decision making, (3) treat the dying person with respect, (4) provide information and emotional support to family members, and (5) coordinate care across settings. Outcome

**Context** Over the past century, nursing homes and hospitals increasingly have become the site of death, yet no national studies have examined the adequacy or quality of end-of-life care in institutional settings compared with deaths at home.

**Objective** To evaluate the US dying experience at home and in institutional settings.

**Design, Setting, and Participants** Mortality follow-back survey of family members or other knowledgeable informants representing 1578 decedents, with a 2-stage probability sample used to estimate end-of-life care outcomes for 1.97 million deaths from chronic illness in the United States in 2000. Informants were asked via telephone about the patient's experience at the last place of care at which the patient spent more than 48 hours.

**Main Outcome Measures** Patient- and family-centered end-of-life care outcomes, including whether health care workers (1) provided the desired physical comfort and emotional support to the dying person, (2) supported shared decision making, (3) treated the dying person with respect, (4) attended to the emotional needs of the family, and (5) provided coordinated care.

**Results** For 1059 of 1578 decedents (67.1%), the last place of care was an institution. Of 519 (32.9%) patients dying at home represented by this sample, 198 (38.2%) did not receive nursing services; 65 (12.5%) had home nursing services, and 256 (49.3%) had home hospice services. About one quarter of all patients with pain or dyspnea did not receive adequate treatment, and one quarter reported concerns with physician communication. More than one third of respondents cared for by a home health agency, nursing home, or hospital reported insufficient emotional support for the patient and/or 1 or more concerns with family emotional support, compared with about one fifth of those receiving home hospice services. Nursing home residents were less likely than those cared for in a hospital or by home hospice services to always have been treated with respect at the end of life (68.2% vs 79.6% and 96.2%, respectively). Family members of patients receiving hospice services were more satisfied with overall quality of care: 70.7% rated care as "excellent" compared with less than 50% of those dying in an institutional setting or with home health services ( $P < .001$ ).

**Conclusions** Many people dying in institutions have unmet needs for symptom amelioration, physician communication, emotional support, and being treated with respect. Family members of decedents who received care at home with hospice services were more likely to report a favorable dying experience.

JAMA. 2004;291:88-93

www.jama.com

measures based on each of these domains have been developed and validated.<sup>8</sup> The goal of this study was to use these measures to provide national esti-

mates of the dying experience and to examine whether family members' perceptions of the quality of end-of-life care differed by the last place of care.

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## METHODS

We conducted a mortality follow-back survey of deaths in 2000. We contacted the informant listed on the death certificate, usually a close family member, to ask whether she or he knew how and where the decedent was treated in the last few weeks of life. If not, the informant was asked to identify another person who would know about the circumstances of the decedent's death and dying experience. Decedents dying as a result of trauma (eg, homicide, motor vehicle crashes) and decedents under the age of 18 were excluded. The majority (72%) of the interviews were conducted between 9 and 15 months after the patient died.

A 2-stage probability sample<sup>9,10</sup> (designed to select states, then individuals within states) was used to generate national estimates of the dying experience. Detailed information on the sampling and calculation of the weights is available at <http://www.chcr.brown.edu/dying/factsondying/sample.htm>. Based on 1998 US mortality data, 2 strata were created: 8 states accounting for nearly one half of the deaths in the United States were selected with certainty, and 17 of the 42 remaining states were randomly selected (because South Dakota law precludes release of death certificate data, it was not part of the frame). Wisconsin and New Mexico refused to participate, citing privacy concerns, and Georgia delayed data transfer too long for the data to be useable. Deaths in the 22 identified states accounted for 70.4% of all annual deaths in the United States. Restrictions placed by the New York City branch of the state vital statistics made inclusion untenable. The study design and informed consent procedures were reviewed by institutional review boards at Brown University, the University of Massachusetts, and within each participating state.

With this strategy we sampled 3275 death certificates. For 549 (16.7%), an informant could not be located. Of the remaining 2727 cases, 1578 (57.9%) resulted in completed interviews, 3 were ineligible, 66 had no informant listed

on the death certificate, 688 listed that informants refused to participate, 40 contacts reached households in which English was not spoken, and 12 informants were too ill to be interviewed. At the end of the field period, 335 cases were still active. Our assumption that an eligible respondent could have been found for about half the cases remaining in the field resulted in a conservative cooperation rate of 65%. To calculate national estimates, data were weighted to account for the sampling design and differential nonresponse among states. A total of 1578 interviews represent 1.97 million deaths in the year 2000.

In comparing the available demographic information on death certificates resulting in interviews and those without interviews, there were no differences by sex ( $P = .32$ ), but respondents representing decedents 64 years and younger were less likely to be interviewed (completion rate: 39.3% vs 50.6%;  $P < .001$ ), as were Hispanic and African American respondents (35.6% vs 49.4%;  $P < .001$ ).

Respondents were asked about quality of care at the last place the patient spent at least 48 hours. The main outcome measures were based on a conceptual model of patient-focused, family-centered medical care.<sup>7</sup> The first domain (ie, providing the desired level of physical comfort and emotional support)<sup>8</sup> was measured by unmet needs regarding pain, shortness of breath, or emotional distress. We calculated the rate of unmet needs for each symptom. A need was defined as unmet when the respondent reported that the patient did not receive any or not enough help with that symptom. The second domain (ie, promoting shared decision making) was considered unmet when the respondent reported that the patient had no contact with physicians but desired such contact, or when the informant expressed concerns with physician communication about shared decision making. We inquired whether the dying person was treated with respect by asking the respondent,

"While [the patient] was at [the last place of care], how often was [he or she] treated with respect by those who were taking care of him/her—always, usually, sometimes, or never?" We report the rate of family respondents indicating that patients were not always treated with respect. We summarized each of the 3 remaining domains (ie, attending to family needs for information and emotional support, and coordinating care) as a count of the number of reported quality-of-care concerns as perceived by the informant. For these analyses, we compared those who expressed "no concern" with those who expressed "1 or more concerns." The actual survey tool, calculation of scores, and information on the psychometrics of the measures are available at <http://www.chcr.brown.edu/dying/measure.htm>.

All analyses were performed using SUDAAN version 8.0 (RTI International, Research Triangle Park, NC) to account for the complex sampling design. We used the  $\chi^2$  test to examine associations between reported perceptions of care and site of care. In the case of ordered responses, the Mantel-Haenszel  $\chi^2$  test was used. Multivariate logistic regression analyses were conducted to examine whether the association of last place of care and reported perceptions of care persisted after adjusting for the decedent's age, years of education, sex, race, the underlying cause of death, respondent perceptions of whether death was unexpected, and whether the decedent had difficulty rising from a chair or bed 90 days prior to death.

## RESULTS

### Characteristics of Decedents and Respondents

TABLE 1 describes decedents by their last place of care, defined as where they spent 48 hours prior to death. The site of death and last place of care were the same for 92.1% of cases. For the majority (68.9%), the last place of care was an institutional setting, either a hospital or nursing home. Home was the last place of care for 31.1%; of those, 36.1%

died without any nursing services, 12.4% had home nursing services, and 51.5% had home hospice services. Older women and those currently unmar-

ried were more likely to reside in a nursing home. Persons who died with home hospice services were more likely to have had cancer, while those who died

at home without formal services were more likely to have died from heart disease. Thirty-seven percent of those persons who died at home without for-

**Table 1.** Characteristics of Decedents by Last Place of Care\*

Characteristic	1993 Comparison Data†	Last Place of Care, % (95% CI)†					
		Total	Home Without Nursing Services	Home With Home Care Nursing Services	Home With Hospice Services	Nursing Home	Hospital
Sample size, No.							
Actual	10 122	1578	198	65	256	487	572
Weighted	1 980 388	1 966 705	221 071	76 231	315 165	600 802	753 436
Age, mean (95% CI), y	73.9	74.8 (73.5-76.1)	71.4 (69.0-73.6)	79.2 (74.9-83.5)	72.9 (70.8-75.0)	83.8 (82.1-85.5)	74.8 (73.5-76.1)
Women	50.1	53.4 (50.2-56.6)	42.7 (34.1-51.2)	56.3 (40.8-71.8)	49.7 (42.2-57.1)	67.0 (60.8-73.1)	47.0 (42.6-51.4)
Race/ethnicity							
White, non-Hispanic	83.2	86.8 (82.8-90.8)	88.4 (81.7-95.0)	78.3 (65.6-91.0)	81.3 (71.8-90.8)	92.5 (89.4-95.7)	84.8 (79.7-89.9)
Black, non-Hispanic	11.6	7.8 (5.0-10.5)	7.8 (2.0-13.7)	12.8 (3.6-21.9)	7.4 (3.0-11.7)	5.1 (2.3-7.9)	9.6 (5.3-13.8)
Hispanic	3.2	4.8 (2.5-7.2)	3.8 (1.2-6.5)	8.9 (0.0-18.5)	10.0 (3.2-16.7)	1.8 (0.6-3.1)	5.1 (1.6-8.5)
Education less than high school degree	46.7	36.5 (31.8-41.2)	29.7 (19.2-40.2)	34.0 (18.2-49.9)	30.6 (23.9-37.2)	41.9 (35.9-47.9)	36.8 (30.0-43.7)
Married	42.5	40.7 (37.0-44.3)	46.0 (38.8-53.2)	32.4 (17.6-47.3)	54.7 (45.1-64.4)	22.4 (17.6-27.3)	48.4 (42.7-54.0)
Cause of death							
Cancer	25.8	28.0 (25.4-30.6)	7.9 (1.7-14.1)	29.2 (12.8-45.5)	68.3 (61.0-75.6)	15.9 (12.8-19.0)	26.6 (22.2-31.0)
Heart disease	36.2	41.9 (39.2-44.7)	77.2 (68.5-85.8)	40.7 (27.5-54.0)	11.5 (7.1-16.0)	47.1 (42.4-51.8)	40.3 (35.9-44.7)
Stroke syndrome	7.6	9.4 (7.7-11.0)	7.3 (2.4-12.3)	5.5 (0.0-12.0)	0.6 (0.0-1.2)	14.0 (10.4-17.7)	10.4 (7.8-12.9)
Dementia		6.0 (4.6-7.5)	1.0 (0.0-2.5)	1.0 (0.0-2.8)	3.2 (0.0-6.9)	16.0 (12.3-19.8)	1.3 (0.3-2.3)
Difficulty rising from bed/chair in last year of life	NA	65.3 (62.6-67.9)	37.1 (28.3-45.9)	65.8 (51.1-80.5)	70.8 (64.6-76.9)	80.4 (77.0-83.8)	59.1 (53.6-64.6)
Written advance directives	NA	70.7 (67.5-73.9)	55.6 (47.4-63.9)	70.8 (52.6-89.1)	81.6 (75.5-87.6)	80.8 (77.2-84.4)	62.5 (57.3-67.8)

Abbreviations: CI, confidence interval; NA, not available.

\* $P < .001$  for comparison of all characteristics except education less than high school degree ( $P = .33$ ).

†All percentages are weighted. "Last place of care" indicates the last location where the decedent spent more than 48 hours prior to death. For 125 out of the 1578 cases, the site of death was not the last place of care. Of these 125 cases, 96 were persons who were transferred to a hospital emergency department or who died soon after hospital admission.

‡Comparison data from the 1993 US Mortality Follow-back survey.<sup>11</sup>

**Table 2.** Characteristics of Survey Respondents by Decedents' Last Place of Care\*

Characteristic	Last Place of Care, % (95% CI)†					
	Total	Home Without Nursing Services	Home With Home Care Nursing Services	Home With Hospice Services	Nursing Home	Hospital
Sample size, No.						
Actual	1578	198	65	256	487	572
Weighted	1 966 705	221 071	76 231	315 165	600 802	753 436
Women	71.0 (68.2-73.7)	67.8 (57.5-78.1)	78.1 (65.4-90.8)	69.0 (61.3-76.8)	70.5 (65.9-75.0)	72.4 (67.4-77.3)
Less than high school degree	10.4 (7.8-12.9)	12.7 (7.9-17.5)	12.4 (1.0-23.7)	11.0 (5.6-16.3)	9.8 (6.0-13.7)	9.7 (6.4-13.0)
Relationship to decedent						
Spouse	30.1 (26.7-33.4)	34.9 (26.5-43.4)	25.9 (12.0-39.7)	42.3 (32.5-52.0)	14.6 (11.3-17.9)	36.3 (30.3-42.2)
Child	40.5 (37.0-44.1)	32.0 (24.3-39.7)	50.3 (34.3-66.2)	39.2 (29.0-49.4)	48.3 (43.8-52.8)	36.4 (30.9-42.0)
Friend/other	3.2 (2.3-4.2)	2.3 (0.0-4.5)	4.2 (0.0-10.7)	1.4 (0.0-2.9)	5.3 (3.1-7.6)	2.6 (1.3-3.8)
Contact with patient all 7 days in last week of life	72.1 (68.7-75.4)	67.4 (59.8-75.1)	73.3 (58.2-88.3)	91.2 (86.7-95.8)	57.4 (51.1-63.7)	76.2 (71.8-80.6)
Dying was "extremely" unexpected	22.6 (19.7-25.4)	65.0 (58.0-72.1)	33.6 (17.8-49.5)	7.1 (2.1-12.0)	12.0 (8.2-15.7)	23.8 (19.6-28.1)

Abbreviation: CI, confidence interval.

\* $P < .001$  for comparison of all characteristics except sex ( $P = .74$ ).

†All percentages are weighted.

mal services were functionally impaired, defined as having difficulty rising from a bed or chair. A written advance directive (either a living will or a durable power of attorney for health care) was reported for 70.7% of decedents. Characteristics of respondents are shown in TABLE 2. Most were family members who were in close contact with the dying person; 72.1% either saw or spoke with the patient for all 7 days prior to death.

### Family Perceptions of the Quality of End-of-Life Care

Family perceptions of quality of care differed by the last place of care in

which the decedent received formal services. TABLE 3 shows the unadjusted and adjusted results for the last place of care where the decedent received formal services. Nearly one fourth of all respondents reported that the patient did not receive any or enough help with pain (24.2%) or dyspnea (22.4%). Family members of persons whose last place of care was a nursing home or home with home health nursing services had a higher rate of reported unmet needs for pain (nursing home: adjusted odds ratio [OR], 1.6; 95% confidence interval [CI], 1.0-2.2; home with nursing services: adjusted OR, 1.6; 95% CI, 1.1-2.0) compared with those persons with

home hospice services. Unmet needs for dyspnea did not differ by setting of care. Overall, half of family members reported that the patient did not receive enough emotional support. Recipients of home hospice care had lower rates of unmet needs (34.6%) compared with the other settings of care. About 1 in 4 families reported concerns with physician communication regarding medical decision making, although there was no difference by setting of care. Families reported more concerns with whether the patient was always treated with respect when the last place of care was a nursing home (adjusted OR, 2.6; 95% CI, 2.3-2.9),

**Table 3.** Patient- and Family-Centered Outcomes at the Last Place of Care\*

Last Place of Care†									
Outcome	Total, Unadjusted % (95% CI)	Home With Home Care Nursing Services		Home With Hospice Care		Nursing Home		Hospital	
		Unadjusted %	Adjusted OR (95% CI)‡	Unadjusted %	Adjusted OR (95% CI)‡	Unadjusted %	Adjusted OR (95% CI)‡	Unadjusted %	Adjusted OR (95% CI)‡
Provided Desired Physical Comfort and Emotional Support to Patient									
Patient did not receive any or enough help with									
Pain	24.2 (21.2-27.3)	42.6	1.6 (1.1-2.0)	18.3	Reference	31.8	1.6 (1.0-2.2)	19.3	1.2 (0.3-1.9)
Dyspnea	22.4 (18.7-26.0)	38.0	1.4 (0.5-2.2)	25.6	Reference	23.7	1.0 (0.6-1.7)	18.9	0.7 (0.3-1.2)
Emotional support	50.2 (44.4-56.0)	70.0	2.7 (1.7-3.1)	34.6	Reference	56.2	1.3 (1.1-1.5)	51.7	1.3 (1.0-1.6)
Supported Shared Decision Making									
Respondent wanted but did not have contact with physician	30.1 (24.1-36.1)	22.5	1.6 (0.5-3.3)	14.0	Reference	31.3	2.0 (1.4-2.5)	51.3	1.8 (1.5-1.9)
Respondents with contact had concern(s) about physician communication	23.9 (20.1-26.4)	26.6	1.1 (0.4-2.1)	17.6	Reference	17.7	1.2 (0.5-2.1)	27.0	1.3 (0.8-1.9)
Treated Patient With Respect									
Not always treating patient with respect	21.1 (18.3-23.9)	15.5	2.9 (1.5-4.3)	3.8	Reference	31.8	2.6 (2.3-2.9)	20.4	3.0 (2.2-3.8)
Attended to Needs of the Family									
Concern(s) about emotional support	34.6 (31.5-37.8)	45.4	1.6 (1.0-1.9)	21.1	Reference	36.4	1.6 (1.3-1.9)	38.4	1.5 (1.3-1.8)
Concern(s) about information regarding what to expect while patient was dying	29.2 (22.3- 36.1)	31.5	0.9 (0.4-1.8)	29.2	Reference	44.3	1.5 (1.2-1.7)	50.0	1.4 (1.1-1.6)
Coordinated Care									
Staff did not know enough about patient's medical history to provide best care	15.2 (12.7-17.7)	7.5	0.7 (0.2-2.3)	7.9	Reference	19.6	2.0 (1.2-2.9)	15.4	1.5 (0.9-2.4)
Overall Assessment of Quality of Care									
Excellent	49.4 (45.9-52.9)	46.5	0.4 (0.2-0.8)	70.7	Reference	41.6	0.4 (0.3-0.6)	46.8	0.6 (0.3-0.7)

Abbreviations: CI, confidence interval; OR, odds ratio.

\*Results are presented only for the 1380 decedents who had contact with health care institutions. Questions regarding the quality of care were not asked of the 198 persons who died at home without nursing services.

†All percentages are weighted.

‡Adjusted OR from a multivariate logistic regression model adjusting for age, sex, underlying cause of death, education, race/ethnicity, respondents' perception of whether the death was expected, and whether the patient had difficulty rising from a chair 3 months prior to death. In addition, ORs are adjusted to approximate the relative risk according to the method of Zhang and Yu.<sup>12</sup>

hospital (adjusted OR, 3.0; 95% CI, 2.2-3.8), or home with home health services (adjusted OR, 2.9; 95% CI, 1.5-4.3), compared with persons who died at home with hospice services. Similarly, in contrast to other settings of care, family members of those dying at home with hospice services reported fewer concerns with the amount of emotional support provided to them. Overall satisfaction was better for those who received home hospice services: 70.7% rated care as "excellent" vs less than 50% for the other settings of care ( $P < .001$ ).

## COMMENT

No national study has adequately characterized the US experience of dying.<sup>13</sup> Key findings of our study are that bereaved family members reported high rates of unmet needs for symptom management, concerns with physician communication about medical decision making, a lack of emotional support for themselves, and a belief that their dying family member was not always treated with respect. A higher rate of concerns with the quality of end-of-life care was reported for persons whose last place of care was a nursing home or hospital. Increasingly, nursing homes are replacing hospitals as the last place of care.<sup>14</sup> With the "baby boom generation" starting to reach retirement, there is an urgent need for improving the end-of-life care in the United States.

Our finding that bereaved family members of patients with home hospice services (in contrast to the other settings of care) reported higher satisfaction, fewer concerns with care, and fewer unmet needs is consistent with smaller and less generalizable studies that have examined the effect of hospice or palliative-care services.<sup>15</sup> However, there are important opportunities to improve hospice care, with more than 1 in 4 respondents reporting unmet needs in the management of dyspnea and in the emotional support provided. An overly simplistic reaction would be to place blame with the nursing home or hospital indus-

try. Yet, in the past decade, each has been faced with substantial limitations in federal funding and with challenges in care management. For example, nursing homes are now caring for sicker patients despite shortages of nursing staff and high rates of staff turnover.<sup>16</sup> These factors influence not only the quality of end-of-life care but also the incidence of decubitus ulcers, inadequacy of feeding assistance, and potentially preventable hospitalizations.<sup>17</sup> Most likely, these perceptions of bereaved family members are the result of a complex set of interactions that include our death-denying culture and existing financial incentives that reinforce invasive treatment approaches to medical care.

Important limitations should be acknowledged in the interpretation of these results. Because of the difficulty in prognosticating death and defining who should be counted in the denominator, we used a mortality follow-back approach that easily defines the denominator and uses death certificates to contact next-of-kin.<sup>18,19</sup> Family members both acted as a proxy for the decedents and reported their own perceptions of the quality of end-of-life care based on their own interactions with clinicians. They may have inaccurately perceived patients' unmet needs for symptom management; however, a recent synthesis of literature suggests that families are able to accurately report on many quality-of-care domains.<sup>11</sup> In addition, we interviewed only 65% of the persons who could be located. Younger persons, African Americans, and Hispanics were somewhat less likely to participate in this survey. Nonetheless, as reported in Table 1, our sample is comparable to the 1993 US National Mortality Follow-back Survey.<sup>20</sup> Finally, interpretation of the results of last place of care and quality of end-of-life care must take into account the nonexperimental design. While we adjusted for leading cause of death, age, and other characteristics, location of death is to some extent self-selected.

Despite these limitations, this is the largest study to date using a mor-

tal follow-back approach and new survey methods to examine family perceptions of the quality of end-of-life care. Such national information on the quality of end-of-life care in the United States has been sorely lacking. Bereaved family members voiced significant concerns with the quality of end-of-life care, regardless of whether care was provided in a nursing home or hospital. Only bereaved family members whose loved one received home hospice services reported higher satisfaction and fewer unmet needs. However, simply increasing access to hospice services may not adequately improve end-of-life care in the United States, given that qualification for Medicare Hospice Benefit requires that 2 physicians certify a 6-month prognosis, and accurately prognosticating life expectancy for persons dying of diseases other than cancer is difficult.<sup>21</sup> Rather, our results call for a public health approach that uses sustained and multifaceted interventions to improve end-of-life care in the United States.<sup>1</sup>

**Author Contributions:** Dr Teno, as principal investigator of this study, had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analyses.

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**Statistical expertise:** Teno.

**Obtained funding:** Teno.

**Administrative, technical, or material support:** Teno, Clarridge, Wetle, Mor.

**Study supervision:** Teno, Clarridge, Mor.

**Funding/Support:** Funding for this research was provided by grant 037188 from The Robert Wood Johnson Foundation.

**Role of Sponsor:** The Robert Wood Johnson Foundation did not have any role in the design, conduct, interpretation, review, approval, or control of this article.

**Disclaimer:** The opinions and findings in this manuscript are those of the authors and do not necessarily represent the views of Robert Wood Johnson Foundation.

**Acknowledgment:** We thank the survey staff at the Center for Survey Research for their tireless efforts in conducting this study. We especially thank Jack Fowler, PhD, and Tony Roman, MS, for help with the sampling design and calculations of sampling weights.

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Whatever else may be shaken, there are some facts established beyond warring; for virtue is better than vice, truth is better than falsehood, kindness than brutality. These, like love, never fail.

—Quintin Hogg (1845-1903)