

Is Care for the Dying Improving in the United States?

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Abstract

Background: Striking changes occurred in health care in the United States between 2000 and 2013, including growth of hospice and hospital-based palliative care teams, and changes in Medicare payment policies.

Objective: The aim of this study was to compare informants' reports and ratings of the quality of end-of-life care for decedents between 2000 and 2011–2013.

Methods: The study design comprised retrospective national surveys. Subjects were decedents age 65 years and older residing in the community from two time periods. Similar survey questions were asked at the two time periods. Bivariate and multivariate analyses were conducted, using appropriate survey weights to examine response differences between time periods, after adjusting for the decedent's age, race, pattern of functional decline, and the presence of a cancer diagnosis, as well as the respondent's relationship to the decedent.

Results: A total of 1208 informants were interviewed; 622 in 2000 and 586 in 2011–2013. Respondents from deaths in 2011–2013 were more likely to state that their loved ones experienced an unmet need for pain management (25.2% versus 15.5% in 2000, adjusted odds ratio [AOR] 1.9, 95% confidence interval [CI] 1.1–3.3). More respondents reported that religion and spirituality were addressed in the later time period (72.4% not addressed compared with 58.3%, AOR 1.4, 95% CI 1.1–1.9). High rates of unmet need for palliation of dyspnea and anxiety/depression remained. The overall rating of quality did not improve but decreased (with 56.7% stating care was excellent in 2000 and 47.0% in the later survey, AOR 0.70, 95% CI 0.52–0.95).

Conclusions: Substantial unmet needs in end-of-life care remain. Continued efforts are needed to improve the quality of end-of-life care.

Introduction

D YING IS A FUNDAMENTAL EXPERIENCE of the human condition. A recent Institute of Medicine (IOM) report¹ found major deficiencies in quality of end-of-life care and called for continued efforts to improve end-of-life care in the United States. Despite substantial investment in hospice and palliative care services, trends in utilization between 2000 and 2009 point to more intensive care unit (ICU) care in the last month of life, more late referrals to hospice care, and more repeat hospitalizations in the last 90 days of life.² To help frame the IOM report's conclusion and guide future policy, we used two national surveys that interviewed bereaved family members about their perceptions of the quality of end-of-life care between 2000 and 2011–2013. A 1990 IOM report³ defined quality of care as the “degree to which health services for individuals and populations increased the likelihood of *desired* health outcomes and are *consistent* with

professional knowledge.” Implicit in this definition and endorsed in the 2001 IOM report, *Crossing the Quality Chasm*,⁴ is that medical care be patient-centered, “providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patients' values guide clinical decisions.” Dying, unlike other time periods, requires that quality indicators go beyond a medical record review to include interviews with consumers. Consumer perceptions are important in the evaluation and improvement of end-of-life care.

Previously, we developed a conceptual model,⁶ designed a survey that examined the constructs from the conceptual model,⁷ and conducted a national mortality followback survey that explored bereaved family members' perceptions of the quality of end-of-life care for persons who died in 2000.⁸ As part of this study of decedents in 2000, we conducted 111 in-depth qualitative interviews.^{9–11} Key findings included superior ratings and reports of care quality with hospice care

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provided at home compared with other settings without hospice care,⁸ more reported concerns with the quality of care in geographic regions with higher ICU utilization,¹² and more frequent concerns and unmet needs with end-of-life care reported by bereaved family members who were African American.¹³ Questions based on this mortality followback survey were included in the National Health and Aging Trends Study (NHATS) during the Last Month of Life (LML) interview for decedents. The replication of these items provides a unique opportunity to examine the impact, from a population perspective, of the increase in hospice access and other historical changes by comparing bereaved family member surveys completed more than a decade apart. The first objective is to examine changes at the population level. A secondary goal is to examine associations between hospice service use and quality of care at the end of life.

Methods

Design overview

A retrospective interview with a bereaved family member or close friend of the decedent was conducted at two time periods. In 2000, we used a mortality followback approach that contacted the next of kin on the death certificate to find the person most knowledgeable about decision making and the decedent in the last months of life. We used a national sample of death certificates from persons who died in 2000. Our approach was outlined in a previous publication with a reported cooperation rate of 65%.⁸

NHATS¹⁴ is a prospective cohort study, which began in 2011. NHATS sampled 12,411 persons age 65 years and older living in the contiguous United States from the Medicare enrollment file; interviews were completed for 8245 persons (response rate 70.9%). In Rounds 2 and 3, NHATS included a module based on the previously described mortality followback survey to capture end-of-life care experiences for decedents. The response rate for the NHATS LML interview was 94.4% in Round 2 and 94.1% in Round 3.

Setting and participants

To create similar analytic samples across the two studies, we restricted our analyses to decedents who were living in the community prior to death, excluding those living in residential care settings and nursing homes. This exclusion allowed us to create two national samples of decedents with surveys completed by bereaved family members or close friends, rather than facility staff caregivers of decedents. Additionally, we required decedents to be 65 years and older with Medicare insurance.

Measures

Both studies used validated measures of respondents' perceptions of the quality of care in terms of decision making, pain and symptom management, emotional support, and an overall rating of the quality of care.⁷ These questions are part of a National Quality Forum-endorsed quality measure that examines whether end-of-life care is patient- and family-centered. The survey items are based on a conceptual model that presupposes high-quality end-of-life care occurs when: 1) the dying patient receives his or her desired level of symptom management; 2) decisions are made with enough

input from, and are consistent with, the patient's values and goals; 3) the patient is treated with respect; 4) care is coordinated; and 5) the dying patient and the family receive their desired spiritual and emotional support.

Questions about symptoms asked whether the decedent received his or her desired amount of help with the following symptoms: pain, dyspnea, and anxiety or feelings of sadness. For each decedent who experienced a given symptom, the respondent was asked whether the decedent had the right amount of help treating that symptom. An additional question asked whether health care providers or professional staff spoke with the decedent about his or her religious and spiritual beliefs. If this discussion occurred, the respondent was asked whether the decedent had enough contact. An unmet need was defined as either having no discussion or not having enough contact. To examine shared decision making, we used two questions: whether during the last month of life a decision was made that the decedent would not have wanted, and whether there was a decision made without enough input from the decedent and/or family. Two additional questions assessed the extent to which the decedent was treated with respect and whether the respondent was kept informed about the decedent's condition; these items used 4-point response categories from "always" to "never." We dichotomized answers into "always" versus all other categories indicating an opportunity to improve. Additionally, an item on overall rating of the quality of care asked the respondent to report on the care the decedent received using a 5-point scale of "excellent" to "poor."

The majority of questions in both surveys related specifically to the last month of life. However, the 2000 survey question wording focused on the last *place* of care for the following variables: symptom management, whether the family was informed, and overall rating of the quality of care. For these variables, the NHATS specified answers to the last *month* of life. The majority (76.0%) of decedents in 2000 were either at home exclusively or at home plus one other setting of care in the last month of life.

In its third round, NHATS asked about use of hospice care in the last month of life across various settings (e.g., home, hospital, nursing home, free-standing hospice). This allowed us to examine the association of receipt of hospice care in the last month of life with respondents' overall ratings of quality of care.

Statistical analyses

We first characterized the extent to which the social and demographic characteristics of decedents and respondents differed between the two surveys. Bivariate and multivariate analyses were conducted to compare differences between the two surveys after adjusting for decedent age, race and ethnicity, presence of a cancer diagnosis, respondent relationship to decedent, and pattern of functional decline as indicated by not getting out of bed. A multivariate logistic regression model was estimated for each outcome measure. Because of difference in the time frame of questions on symptoms, whether the family member was informed about the patient's condition, and the overall rating of the quality of care, we conducted a sensitivity analyses of persons who died at home and spent the last 30 days at home in both time periods. All analyses were conducted in Stata statistical

TABLE 1. CONTRASTING DECEDENT AND BEREAVED RESPONDENTS IN 2000 COMPARED WITH 2011–2013

Characteristic	2000 (n=622)	2011–13 (n=586)	P value
Weighted N	794,341	2,257,759	
<i>Decedent characteristic</i>			
Sex (% male)	28.5	28.2	0.94
Age 85 and older	13.4	16.4	0.17
Race and Ethnicity			
White	85.0	81.0	0.22
Black	6.9	8.7	0.46
Hispanic	6.1	6.5	0.29
Other	2.3	3.9	0.23
<i>Respondent characteristic</i>			
Spouse	35.6	31.8	0.28
Child	44.1	53.0	0.02
Other relative	18.4	9.0	0.0001
Other relation	1.9	6.1	0.0005

software version 13.0 (StataCorp., College Station, TX) using appropriate nonresponse adjusted survey weights.¹⁵

Results

A total of 1208 informants were interviewed, including 622 respondents from 2000 (representing 794,341 deaths) and 586 respondents from 2011–2013 (representing 2,257,759 deaths; Table 1). Decedents did not differ in age, gender, or race (Table 1). Respondents in NHATS were more likely to be a child or daughter/son-in-law of the decedent (53.0% versus 44.1%, $p=0.02$) or an “other” relation (6.1% versus 1.9%, $p=0.0005$) compared with the earlier survey.

Table 2 presents the unadjusted and adjusted differences in informants’ reports of the quality of care. In both surveys, similar proportions reported that decedents experienced pain in the last month of life, but more informants reported an unmet need for pain management in 2011–2013 (25.2%) than in 2000 (15.5%, AOR 1.9, 95% CI 1.1–3.3). More decedents were reported to have experienced anxiety or sadness while dying in 2011–2013 than in 2000. In contrast, families re-

ported that health care providers were more likely to discuss religious or spiritual concerns in 2011–2013 than in 2000, yet 58.3% still either did not discuss or wanted more discussion about these concerns. Similarly, persistent opportunities to improve treatment of dyspnea, anxiety/depression, and treating the patient with respect remained (Table 2).

At both time periods, there persisted important opportunities to improve decision making. More than 10% of informants stated that a decision was made without enough input from the decedent or family member. For deaths in 2011–2013, 11% of informants reported that a decision about medical treatment was made that the decedent would not have wanted. Of the 11.9% that died in an ICU in 2011–2013, 20.9% stated their family member got care that they did not want. More respondents in 2000 rated the care the decedent received as excellent compared with the more recent survey (56.7% in 2000 and 47.0% in 2011–2013, AOR 0.70, 95% CI 0.52–0.95).

Because questions that asked about symptoms, whether the family was always kept informed, and overall rating of care asked about the last place of care in 2000 and last month of life in NHATS, we conducted a sensitivity analysis that examined those decedents who spent the entire last month at home and died at home. Table 3 reports the same pattern of declining ratings of the quality of care between the two time periods, increasing ratings of unmet needs for pain management, and improving ratings of discussions of spiritual and/or religious beliefs. One difference from the full sample is that among those who died at home there was an increase between 2000 and 2011–2013 in the percentage of respondents who stated the decedent was not always treated with respect, and that increase reached conventional statistical significance.

Finally, for decedents found in Round 3 of NHATS, we examined the respondent rating of overall quality of care by whether hospice was involved in the care of the decedent in the last month of life. We found that the percentage of respondents stating that care was excellent was higher among those receiving hospice in the last month of life: 60.9% stated care was excellent when hospice was involved compared with 46.7% stating the care was excellent when hospice was not involved (AOR 2.2, 95% CI 1.3–4.0).

TABLE 2. CONTRASTING INFORMANT PERCEPTIONS OF THE QUALITY OF CARE IN 2000 COMPARED WITH 2011–2013

Informant report	2000 (n=622)	2011–13 (n=586)	AOR (95% CI) ^a
Weighted N	794,341	2,257,759	
Experienced pain	67.7	67.0	1.1 (0.8–1.5)
Unmet need for pain management	15.5	25.2	1.9 (1.1–3.3)
Experienced anxiety and/or depression	46.5	55.8	1.7 (1.2–2.3)
Unmet need for anxiety/sadness	48.9	49.8	1.0 (0.7–1.6)
Dyspnea	55.1	56.2	1.0 (0.8–1.4)
Unmet need for dyspnea	23.6	21.4	1.1 (0.7–1.8)
Not always treated with respect	12.7	15.2	1.2 (0.8–1.8)
Religious/spiritual concerns	79.2	58.3	1.4 (1.1–1.9)
Decision made without enough input from the decedent or family	11.7	13.8	1.2 (0.8–1.8)
Decision made that the decedent would not have wanted	10.0	11.0	1.0 (0.6–1.6)
Family not always kept informed	21.2	20.2	0.9 (0.6–1.4)
Overall care was excellent	56.7	47.0	0.70 (0.52–0.95)

^aAdjusted for decedent age, race and ethnicity, presence of a cancer diagnoses, respondents’ relationship to decedent, and pattern of functional decline as indicated by not getting out of bed.

TABLE 3. SENSITIVITY ANALYSES: PERSON DIED AT HOME

<i>Informant report</i>	2000 (n = 223)	2011–13 (n = 119)	P value
Experienced pain	72.0	65.0	0.37
Unmet need for pain management	18.0	27.0	0.31
Experienced anxiety and/or depression	43.0	62.0	$p \leq 0.05$
Unmet need for anxiety and/or sadness	45.7	45.7	0.99
Experienced dyspnea	48.6	48.0	0.91
Unmet need for dyspnea	25.9	25.5	0.95
Not always treated with respect	4.3	11.6	0.05
Religious/spiritual concerns	60.6	48.4	0.09
Family not always kept informed	13.5	10.5	0.56
Overall care was excellent	69.4	54.9	0.54

Discussion

Based on deaths in 2000, the first national study that characterized the dying experience in the United States concluded, “With the baby boom generation starting to reach retirement, there is an urgent need for improving end-of-life care in the United States.”⁸ Our results comparing perceptions of bereaved family members or close friends on the quality of care of community-dwelling decedents from two time periods help frame the interpretation of the IOM report on end-of-life care in the United States and provide evidence of the urgency to improve. Indeed, our finding that the overall rating of the quality of care as “excellent” has decreased from 56.7% to 47.0% suggests bereaved family members’ perceptions of quality of end-of-life care have not improved but rather may have worsened over the last decade.

Between 2000 and 2013, there have been striking changes in U.S. health care including growth in Medicare Advantage, changes in payment policies, and efforts to improve access to hospice and palliative care services. The utilization of hospice services increased by more than 200% between 2000 and 2009² and there was a similar growth in hospital-based palliative care teams.¹⁶ During this same time period, there was a 23% increase in ICU utilization, a 48% increase in the rate of health care transitions, and a 36% increase in health care transitions in the last 72 hours of life.² Our research is not a test of the effectiveness of expansion of access to hospice and palliative care services, but it provides evidence of the need to improve the quality of end-of-life care based on examining differences in consumer perception of the quality of end-of-life care at two time periods. There was substantial improvement in discussions of spiritual and/or religious concerns; however, more than one in two bereaved family members of patients who died between 2011 and 2013 still stated that such discussions did not occur or were inadequate. Persistent opportunities to improve other aspects of end-of-life care remain; for instance, 21.4% of respondents stated there was need for improved management of dyspnea and 15.2% stated the dying patient was not always treated with respect.

With the aging of the U.S. population, persons are now dying of multiple comorbid illnesses, and medical decisions involve weighing continued aggressive care in an attempt to

prolong life if possible against the patient’s quality of life. Of concern, respondents noted that decisions were made that the decedent would not have wanted in 11.0% of deaths in 2011–2013. This increased to 20.9% when the death occurred in an ICU. One in five family members stated they were not always kept informed regarding the patient’s medical condition and 13.8% stated decisions were made without enough input from the decedent or family. Our findings that respondents report end-of-life care that was inconsistent with a decedent’s wishes and that there is a persistent rate of unmet care needs support the 2014 IOM report’s call for continued effort to improve the quality of care for seriously ill and dying persons.

Our research question is not whether hospice or palliative care services improve the quality of care for individual patients and families. Rather, our research examines changes from a population perspective on how the United States is experiencing end-of-life care in the last month of life. We report that if hospice was involved in the care of the dying patient in the last month of life, the respondent was 2.2 times more likely to say the care was excellent. Our results are consistent with the analysis of the Health and Retirement Study (HRS) between 1998 and 2010 that reported that proxy reports of moderate or severe pain at the end of life increased for all decedents by 20.9%.¹⁷

Future research is needed to understand the reasons for the observed findings. One potential reason may be how older adults in the United States are using hospice and palliative care services.^{18–20} Between 2000 and 2009, there has been a striking increase in the number of short hospice stays.² Palliative care services remain underdeveloped in the outpatient setting.²¹ Key to improving end-of-life care is timely communication and advance care planning.²² The current financial incentives under Medicare reward procedures and ICU utilization, but do not incentivize these in-depth discussions.^{23,24} Our findings support the 2014 IOM report that calls for improved advance care planning, a major restructuring of our health financing, increase in transparency, and more accountability of health care providers.¹

Important limitations of this study should be acknowledged. First, we relied on bereaved family member interviews asking respondents to either act as a proxy for the decedent or to answer based on their interactions with health care providers. There are concerns with the accuracy of a surrogate acting as proxy and his or her ability to recall events from a relative’s last month of life. Our research examines reports of unmet needs of pain and other symptom management. It is possible that with the increasing public attention to end-of-life care, respondents may now have higher expectations or be more willing to acknowledge a given symptom. However, the strengths of the retrospective approach are that it allows similar time periods to be compared and avoids the missing data bias of seriously ill patients, who are often unable to be interviewed in the last weeks of life. A second limitation of our study is that the surveys being compared were similar with the exception that the 2000 survey framed some questions by the last *place* of care rather than the last *month* of care. The majority of persons at the two time periods were only in one location in the last month of life, but this remains an important limitation in comparing surveys from these two time periods. We conducted a sensitivity analyses among those who died at home and spent the last month at home and found similar

patterns over time that suggest important opportunities to improve the quality of care. Third, we examined only those residing in community settings because of different interview protocols for persons in residential care settings. Thus, our results are not generalizable to those residing in institutional settings, such as nursing homes.

Striking changes in health care have occurred in the past decade. Although there were improvements, our report found that respondents rated the quality of end-of-life care lower overall. Notably, adequate pain control was less likely to be achieved in 2011–2013 relative to 2000, as reported by decedents' families. Additionally, in spite of the increasing attention focused on advance care planning and shared decision making, about one in seven stated their family member received medical treatment that they would not have wanted. Our results suggest there is a persisting urgent need to improve end-of-life care.

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Author Disclosure Statement

No competing financial interests exist.

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