How Often Is End-of-Life Care in the United States Inconsistent with Patients' Goals of Care?

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Abstract

Background: Despite its importance, little is known about the prevalence of, and factors associated with, end-of-life care that is consistent with patients' wishes.

Objective: To document the proportion of bereaved respondents who reported care inconsistent with patients' wishes and characterize the predictors of end-of-life care associated with inconsistent care.

Design: Retrospective analysis of nationally representative survey data of persons aged >65 years.

Settings/Subjects: Bereaved family members responding to the last month of life component of the National Health and Aging Trends Study.

Methods/Measurements: Bereaved family members assessed treatment decisions and their consistency with patients' wishes, unmet needs, and quality of care. We examined differences between patients receiving inconsistent versus consistent care.

Results: A total of 1212 family members were interviewed, representing (when weighted) 4.8 million decedents. Thirteen percent stated that care was inconsistent with decedent's wishes. Consistent care was unassociated with patient's sex, age, or race/ethnicity. Death at home was more likely to represent consistent care, and death in the hospital or nursing home was more likely to represent inconsistent care ($p=0.052$). Respondents reporting inconsistent care were more likely to rate the quality of care as fair or poor (19.1% vs. 4.8%, $p<0.001$), reported more unmet needs for pain management (30.5% vs. 19.4%, $p=0.037$), and reported more concerns with communication (29.8% vs. 17.0%, $p=0.003$).

Conclusions: One in eight respondents stated care in the last months of life was inconsistent with patients' wishes; such care was associated with worse ratings of care, pain management, and communication with clinicians.

Keywords: communication; end-of-life care; goals of care; palliative care

Introduction

THE INSTITUTE OF Medicine's (IOM) report on approaching death has recommended that a patient-centered and family-oriented approach to end-of-life care that honors individual preferences be a national priority.¹ In this report, the IOM called for a transformation in how we care for the dying in this country, emphasizing the need for improved communication about end-of-life preferences between clinicians and patients.

Concerns remain about how well we are matching medical care to individual values and preferences, yet we know very little about the care received at the end of life in this country or how best to measure receipt of unwanted care. Using data from the National Health and Aging Trends Study (NHATS), we documented the proportion of bereaved respondents who reported care that was inconsistent with patient's wishes, and characterized the sociodemographics, site of death, and quality of end-of-life care in the last months of life associated with inconsistent care.

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Accepted June 5, 2017.

Methods

Design overview

Data were from the NHATS,² a prospective nationally representative survey of Medicare beneficiaries aged 65 and older. This study began in 2011 and focuses on functioning in late life, including end-of-life experiences. Data are initially collected from participants and, after death, from informants knowledgeable about participants' experiences in the month before death. Information on the NHATS sample and response rate has been previously reported.³ Response rates from the rounds of administration used in this study were 94.4% for Round 2 (2012), 94.1% for Round 3 (2013), 94.8% for Round 4 (2014), and 95.8% for Round 5 (2015).⁴

We used data from the NHATS last month of life interview that includes validated measures of perceptions of quality of care in terms of symptom management, emotional support, communication and decision making, and overall ratings of care. The questions were developed based on a National Quality Forum-endorsed quality measure that assesses whether end-of-life care is patient and family centered.⁵

Measures

Participant data. Age, gender, race, and ethnicity were collected at participant baseline interviews. For survey participants unable to report, a proxy respondent provided this information.

Family member data. We restricted our sample to responses from informants who were family members or close friends, excluding those completed by nonfamilial guardians and facility staff caregivers whose perceptions may be less accurate. If persons living in facilities such as nursing homes had a family informant, they were included.

Consistent versus inconsistent care. To determine whether care was consistent with patients' wishes in the last month of life, informants were asked whether any decisions were made about treatments that the patient would not have wanted. Specifically, informants were asked, "During the last month of {SP}'s life, was there any decision made about care or treatment that {he/she} would not have wanted?"

Symptoms. For perceptions of symptom management, respondents were asked whether the decedent had pain, dyspnea, anxiety, or feelings of sadness. If present, they were asked how much help the decedent received with the symptom ("less than was needed," "more than was needed," or "about the right amount"). A dichotomized variable for unmet needs for each symptom was created and defined as either having unmet needs or not.

Communication and decision making. Informants were asked whether decisions were made without enough input from the patient or family (yes/no). Quality of communication and care questions included how often the patient was treated with respect and how often the family was informed about the care plan. Response options for both questions were "always," "usually," "sometimes," or "never." Responses were dichotomized into "always" versus "other."

Overall quality of end-of-life care. Respondents were asked to rate the overall quality of care in the last month using the following 5-point scale: "excellent," "very good," "good," "fair," and "poor."

Statistical analysis

All analyses were conducted using appropriate survey weights.⁶ Bivariate analyses were conducted using Pearson's chi-square test to compare decedent characteristics and perceptions of informant respondents who reported care was consistent versus inconsistent with their loved one's wishes. In sensitivity analyses, we ran multivariate logistic regression models adjusting for round of NHATS data collection (2, 3, 4, or 5), age ≥ 85 years, functional trajectory, black race, Hispanic ethnicity, whether the patient had cancer, and family member's relationship to the decedent (spouse or child). A two-sided alpha level of ≤ 0.05 was considered statistically significant. Data were analyzed using STATA, version 14.0 (StataCorp., College Station, TX) statistical software.

Results

Decedent characteristics

Five hundred and three respondents completed the last month of life interview in Round 2 (2012), 523 in Round 3 (2013), 404 in Round 4 (2014), and 296 in Round 5 (2015). Among these interviews, 1212 (70.2%) were completed by either a family member or a close friend of the decedent, representing a weighted sample of 4.8 million decedents. About 44% of decedents were male and 21% were more than the age of 85 years. Most decedents were white (80%), and 53% of proxy informants were a child of the decedent. For site of death, 37% died at home and 23% died in a hospital (Table 1).

Family member perceptions

Among family members, 87.4% reported care consistent with decedents' wishes. Decedent demographic characteristics, informant's relationship to the decedent, and transitions in care settings in the last three days did not vary significantly between groups receiving consistent versus inconsistent care (Table 1). Death at home was more prevalent among decedents receiving goal-concordant care (38.1% vs. 27.9%), whereas death in the hospital was more prevalent among decedents receiving inconsistent care (30.3% vs. 21.6%). Similarly, death in a nursing home was more prevalent among decedents receiving inconsistent care (22.9% vs. 17.8%; $p = 0.052$).

When care was inconsistent with the decedent's wishes, informants were more likely to have concerns about the quality of care in the last month of life (Table 2). Decedents receiving inconsistent care were more likely than those receiving goal-concordant care to have unmet needs including (1) among all decedents, informants reported more unmet needs for pain management (27.3% vs. 15.2%; $p = 0.005$) and (2) among decedents experiencing pain in the last month of life, informants reported more unmet needs for pain management (30.5% vs. 19.4%; $p = 0.037$). Informants of patients receiving inconsistent care were also more likely to have reported that they were not always kept apprised of the care

TABLE 1. DECEDENT CHARACTERISTICS ACCORDING TO WHETHER CARE WAS CONSISTENT OR INCONSISTENT WITH DECEDENTS' GOALS OF CARE (WEIGHTED PERCENTAGES)

	<i>All</i>	<i>Care consistent with decedent goals</i>	<i>Care inconsistent with decedent goals</i>	<i>p^a</i>
<i>N</i>	1, 212	1068 (87.4%)	144 (12.6%)	
Weighted <i>N</i>	4, 796, 354	4, 191, 054	605, 300	
Male	44.3%	43.0%	53.3%	0.069
Age 85 and older	21.0%	21.2%	19.2%	0.555
Race and ethnicity				0.308
White (%)	79.9	79.4	82.9	
Black/African American (%)	9.7	10.0	7.9	
Hispanic (%)	2.3	2.6	0.3	
Other (%)	6.8	6.5	9.0	
Unknown (%)	1.4	0	1.6	
Cancer diagnosis	12.8%	12.9%	12.1%	0.833
Late transition ^b	17.1%	16.5%	21.5%	0.168
Site of death ^c				0.052
Home (%)	36.9	38.1	27.9	
Hospital ^d (%)	22.7	21.6	30.3	
Nursing home (%)	18.5	17.8	22.9	
Other ^e (%)	22.0	22.4	18.9	
Proxy informant				
Spouse	27.8%	26.3%	38.2%	0.130
Child (%)	53.1	54.0	47.0	
Other family member (%)	9.4	9.5	8.6	
Other relation (%)	9.7	10.2	6.1	

^aPearson's chi-square test.

^bDefined as a transition to another location within the last three days of life.

^c*N* for site of death = 1196.

^dIncluding intensive care unit.

^e"Other" includes palliative care unit, hospice inpatient unit, hospice residence and other.

plan (29.8% vs. 17.0%; $p=0.003$), that decisions were made without enough input from the decedent or family (26.0% vs. 6.8%; $p<0.001$), and that the patient was not always treated with respect (23.0% vs. 12.1%; $p=0.003$).

Overall ratings of care were lower among bereaved respondents who reported care was inconsistent versus consistent with decedent preferences, with the main differences seen in ratings of overall care as fair (12.6% vs. 2.5%) or poor (6.5% vs. 2.3%, $p<0.001$) (Table 2).

Results from adjusted analyses were similar and are displayed in Table 2.

Discussion

One in eight bereaved family members report that care in the last month of life was not consistent with the decedent's wishes. Despite national efforts to improve advance care planning, our data suggest that too often decisions do not respect the patient's wishes and are made without enough input from the dying patients or their family. These results support the IOM's call to improve communication between clinicians, patients, and families to better match care to patients' values and preferences and provide insight into measurement of goal-concordant care.¹

The finding that decedents whose care was inconsistent with their preferences (according to informants) were more likely to die in the hospital setting (including intensive care unit [ICU]) supports this approach to measuring goal-concordant care. Trends in utilization for Medicare benefi-

ciaries between 2000 and 2009 have demonstrated increasing ICU use in the last 30 days of life and hospital readmissions in the last 90 days of life,⁷ despite evidence suggesting that quality of life, physical discomfort, and psychological well-being are rated lower for patients who die in the hospital or ICU compared with patients who die at home.⁸ Informants' reports of failures to meet patients' symptom needs for those receiving inconsistent care provide additional support for the presence of a demonstrable gap between the care patients want and the care they receive. This is a problem that has been documented before⁹ and remains unaddressed all these years later if/when care is inconsistent.

Our study has some limitations. First, NHATS is limited to individuals 65 years and older and thus findings may not be generalizable to younger populations, and we also limited our analysis to informants who were family and close friends, so nursing facility residents are not well represented. Second, subjective measures reported by family informants may not accurately reflect decedents' perceptions of care. This, however, is a limitation with all proxy informant surveys for decedents and even if the proxy misperceived the events, that is their perception and such a perception can cause them distress. Third, the last month of life interview reflects care in the last month of life and not necessarily at the last site before death, although often they are the same.⁷ Lastly, data from NHATS are cross-sectional, thus limiting our ability to imply causality.

Although the primary goal of palliative and end-of-life care interventions is to close the gap between care desired and

TABLE 2. FAMILY MEMBER PERCEPTIONS OF QUALITY OF CARE ACCORDING TO WHETHER CARE WAS CONSISTENT OR INCONSISTENT WITH DECEDENTS' GOALS OF CARE (WEIGHTED PERCENTAGES)

	<i>Care consistent with decedent goals</i>	<i>Care inconsistent with decedent goals</i>	<i>p^a</i>	<i>Adjusted odds ratio^b</i>	<i>95% CI</i>	<i>Adjusted p-value</i>
<i>N</i>	1068 (87.4%)	144 (12.6%)				
Weighted <i>N</i>	4, 191, 054	605, 300				
Concerns with quality of care in the last month of life						
Reported pain	70.9%	86.3%	<0.001	0.33	0.19–0.59	<0.001
Unmet need for pain management among those reporting pain	19.4%	30.5%	0.037	0.56	0.32–1.01	0.054
Unmet need for pain management among all decedents	15.2%	27.3%	0.005	0.46	0.27–0.77	0.004
Reported dyspnea	57.6%	65.8%	0.075	0.70	0.47–1.04	0.075
Unmet need for dyspnea management among those reporting dyspnea	17.6%	25.7%	0.200	0.64	0.30–1.35	0.234
Unmet need for dyspnea management among all decedents	11.1%	19.0%	0.039	0.54	0.30–0.99	0.046
Reported sadness/anxiety symptoms	59.4%	76.9%	<0.001	0.41	0.27–0.62	<0.001
Unmet need for addressing sadness/anxiety among those reporting symptoms	43.3%	56.5%	0.070	0.59	0.32–1.09	0.09
Unmet need for addressing sadness/anxiety among all decedents	27.4%	45.2%	<0.001	0.45	0.28–0.72	0.001
Family not always kept informed of care plan	17.0%	29.8%	0.003	0.48	0.30–0.77	0.003
Patient not always treated with respect	12.1%	23.0%	0.003	0.44	0.26–0.74	0.003
Decision made without enough input from the decedent or family	6.8%	26.0%	<0.001	0.20	0.12–0.35	<0.001
Ratings of care			<0.001			
Excellent	49.1%	40.0%		1.48 ^c	0.92–2.37	0.105
Very good	32.6%	22.0%				
Good	12.1%	17.8%				
Fair	2.5%	12.6%				
Poor	2.3%	6.5%				
Other ^d	1.4%	1.1%				

^aPearson's chi-square test.

^bMultivariate logistic regression models adjusted for round of NHATS data collection (2, 3, 4, or 5), age ≥85, functional trajectory, black race, Hispanic ethnicity, whether the patient had cancer and family member's relationship to the decedent (spouse or child).

^cFor multivariate logistic regression model, ratings of care dichotomized to excellent (0 or 1).

^dOther = does not apply, no care in last month of life, refused, do not know.

CI, confidence interval; NHATS, National Health and Aging Trends Study.

care received, evidence suggests that these interventions can also simultaneously reduce intensity of care¹⁰ and unwanted ICU utilization.¹¹ Measurement of goal-concordant care may provide valuable insights into ways to improve the quality and value of care. As hospitals and payers operate under increasing pressure to improve quality while reducing costs, these findings have important implications for the medical care system. In the United States, critical care costs alone are estimated to exceed \$82 billion annually, accounting for 13% of inpatient hospital costs^{12,13} and greater than one quarter of Medicare expenditures for the elderly are spent on end-of-life care. How much of these costs are attributable to care that was not wanted is unknown and is worthy of future investigation.

Acknowledgments

This project was supported by the National Institute of General Medical Sciences (5T32GM086270) and the Agency for Healthcare Research and Quality (K12HS022982). The

content is solely the responsibility of the authors and does not necessarily represent the official views of the Agency for Healthcare Research and Quality.

Author Disclosure Statement

No competing financial interests exist.

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