



Published in final edited form as:

J Am Geriatr Soc. 2018 April ; 66(4): 687–692. doi:10.1111/jgs.15260.

Hospice quality of care in home vs. assisted living facility vs. nursing home settings

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Abstract

OBJECTIVES—To describe differences in perceived quality of hospice care for patients living in home, nursing home or assisted living facility settings through analysis of after-death surveys of family members.

DESIGN—Retrospective cohort study using hospice medical record data and Family Evaluation of Hospice Care (FEHC) survey data.

SETTING—Large, national hospice provider.

PARTICIPANTS—Patients who died while receiving routine hospice care and family caregivers who completed after-death quality of care surveys.

MEASUREMENTS—Survey results for 7,510 patients were analyzed using analysis of variance and chi-square tests. Logistic regression was used to assess relationship between location of care and overall service quality.

RESULTS—The overall survey response rate was 27%; 34.5% of families of assisted living hospice patients returned the survey vs 27.4% for home and 22.9% for nursing home patient ($p < .0001$). A majority, 84.3%, of respondents reported that the timing of hospice referral had occurred at “the right time.” Overall, 63.4% of respondents rated service quality as “excellent.” Hospice care in the nursing home was less likely to be perceived “excellent.” Differences in return rate by primary diagnoses were significant, although differences were not large.

CONCLUSION—There were significant differences in the characteristics of patients whose family members did and did not return surveys which has implications for increased use of after-

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COI STATEMENT: None to report.

AUTHOR CONTRIBUTIONS: Unroe, Callahan: Study concept and design. Unroe, Stump: Acquisition of data. Stump, Tu: Statistical analysis. Unroe, Effler, Stump: Literature search, interpretation of data, manuscript preparation. Callahan, Tu: Consulting on results interpretation. All authors: Review and editing of manuscript.

SPONSOR'S ROLE: None.

death surveys to evaluate hospice quality. Lower perceived quality of hospice care in nursing homes may be related to general dissatisfaction with receiving care in this setting. Survey results have the potential to set priorities for quality improvement, patient choice of provider, and potentially reimbursement. Underlying causes of differences of perceived quality in different settings of care should be examined.

Keywords

hospice; quality; nursing home; assisted living facility

Introduction

The use of hospice has expanded rapidly over recent decades, with almost 48% of Medicare decedents receiving hospice care in 2014.¹ Variations in delivery of hospice to patients with different diagnoses and in different settings has raised concerns about quality of care.^{2–6} The Affordable Care Act required the Centers for Medicare and Medicaid Services (CMS) to develop a plan to publicly report quality data for hospices using standardized measures across settings.⁷ Medicare now mandates that hospices send Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys to bereaved family members to rate the quality of care provided by the hospice;⁸ these after-death surveys of family members will be publicly reported starting in winter 2018⁹ as part of the Medicare Hospice Compare website.

Surveys of bereaved family members have been the most common approach to measuring the quality of hospice care. Prior to its replacement with the Medicare-mandated CAHPS survey, the Family Evaluation of Hospice Care (FEHC) survey was the most commonly used instrument.^{10,11} From 2009 to 2014 over four million FEHC surveys were distributed to families. An average of 1,469 hospices participated each year with an average annual response rate of 35.1% (NHPCO Staff, personal communication, January 2017). Low response rate, particularly for some populations, and other limitations of the FEHC survey are relevant as use of post-death surveys and public reporting expands. The results of the FEHC surveys have been used by hospices for internal quality improvement. In addition, research studies examining results of the FEHC have compared differences in reported caregiver satisfaction among hospice patients with different diagnoses, for example patients with heart failure as compared with cancer hospice diagnoses.^{12–13} While diagnosis alone did not seem to make a difference in caregiver satisfaction, the nursing home setting was associated with lower satisfaction for both heart failure and cancer.¹³ Similar studies evaluated family member satisfaction based on characteristics such as race or ethnicity. Family members of African American and Hispanic hospice patients reported more concerns about the quality of care in the areas of care coordination, honoring patient's wishes, and emotional/spiritual forms of support.^{14–15}

Other studies have explored the differences in the clinical characteristics among hospice patients in different settings of hospice care.^{13–18} However, we identified limited prior research examining perceived quality of hospice care across settings. In field testing of the Hospice CAHPS survey, reported experiences of care were typically worse in the nursing

home versus home settings.¹⁹ The author theorized that such differences may be associated with different visit patterns in the nursing home setting. Our previous work explored differences in the mix of services provided to hospice patients in nursing home, assisted living facility and home settings.²⁰ Understanding differences in quality of care across settings has implications for ongoing policy discussions regarding reform of the hospice benefit and, specifically, how it might be structured or reimbursed based on setting of care. Understanding these differences might also help patients and families better interpret publicly reported data.

In this paper, we compare perceptions of hospice quality across settings of care using the FEHC survey for 7,510 hospice patients from a large, national hospice provider. Unlike previous studies that have examined FEHC results, we also present data describing the characteristics of patients for whom families did not complete after-death surveys, as well as those whose families did. Further, this is the first study to directly compare perceptions of quality of routine hospice care for patients in three different settings of care – at home, in nursing homes, or in assisted living facilities.

Methods

This study was approved by the Indiana University Purdue University-Indianapolis Institutional Review Board.

Sample

We obtained electronic medical record data from a national, for-profit provider of hospice services, operating multiple programs across 18 states. There were 69,363 patients who were at least 18 years of age and had been enrolled in hospice between Jan 1, 2009 and Dec 31, 2014 (72,839 hospice admissions). We chose to focus only on the patient's last hospice admission (N=69,363) if they had accrued multiple stays during this time frame. For the analysis, we first selected 32,679 patients receiving routine hospice care (47%). Patients receiving continuous or higher level of care, or respite level of care or those receiving care at an inpatient hospice or hospital setting were excluded (N=36,684). The distribution of these excluded non-routine patients included 6,212 continuous care (16.9%), 25,422 inpatient (69.3%), 677 respite (1.9%), 2,198 mixture of preceding three categories (6%) and 2,175 status undetermined (5.9%) patients. Three sites of care were of interest: patient homes, nursing homes (skilled, non-skilled and long-term nursing facilities) and assisted living facilities. We narrowed the sample to include patients having at least 95% of their hospice days at only one of these sites (N=32,605 patients). Furthermore, the patient had to be a decedent to have a FEHC survey administered to the family (N=27,714). 7,510 (27%) had a completed FEHC survey that was returned by a family member which served as the denominator for the analysis of survey results. 3,664 patients received hospice services at home (49%), 2,195 in nursing homes (29%) and 1,651 in assisted living facilities (22%).

Survey

The FEHC survey contains about 60 questions separated into five domains: (1) attending to family needs for support, (2) attending to family needs for information, (3) coordination of

care, (4) providing symptom management and emotional support, and (5) overall satisfaction. Overall perception of quality is assessed: "Overall, how would you rate the care the patient received while under the care of hospice?" Respondents are able to answer Excellent, Very Good, Good, Fair, or Poor. A full description of the survey design has been previously published.²¹ Combining scores on seventeen variables from the above domains, we also calculated the NHPCO composite score which measures overall hospice service quality. Scoring rules were obtained from NHPCO.²² Variables from the survey were recoded into problem scores or indicators (1=worst possible response vs. 0=otherwise). Missing values were recoded to 0 for up to three responses. If a caregiver provided more than 3 missing responses, the total composite score was not calculated. Responses of the total composite score ranged from 0 to 100 where 100=best possible hospice service quality.

The FEHC was distributed via a 3rd party vendor. It was mailed to the caregivers six weeks following the patient's death. Recipients can respond electronically or via mail; a preprinted envelope is provided for return. The vendor collected the responses and returned the data to the hospice in categorical summaries, along with the narrative comments. Excellent overall care quality rating was a metric closely tracked by the organization.

Analysis

Patient demographic, hospice use characteristics, and care location (home, nursing home and assisted living) were described by survey response status (returned and completed, yes vs. no). Continuous and categorical characteristics were compared using analysis of variance (ANOVA) and chi-square tests, respectively. Comparisons were made first between the responders and non-responders, then across care locations. For location of care, an overall omnibus chi-square test was used to assess overall difference across all three sites. We then performed all pairwise comparisons using chi-square tests to evaluate the differences between home and nursing home, home and assisted living, and nursing home and assisted living. We reported the content of the survey by care location. The overall service quality assessment and a composite score were compared across the three care locations, by using chi-square and ANOVA tests. Individual survey items were compared similarly, as previously described. To control for the inflation of the overall Type I error rate from multiple comparisons, we used reported p-values adjusted by the false discovery rate (FDR) method.²⁴ Adjusted p-values less than 0.001 were considered statistically significant. In addition, logistic regression was used to assess the relationship between location of care and overall service quality controlling for potential confounding factors. Covariates included patient age, hospice length of stay, gender, race, marital status, primary hospice diagnosis, region and relationship of caregiver to patient. Odds ratios (OR) with p-values less than 0.001 were considered statistically significant. All statistical analyses were performed using SAS software for Windows.

Results

Of the 27,714 decedents who received routine hospice care, surveys were returned for 7,510 (27%) (Table 1). There were significant differences in the characteristics of patients whose family members did and did not return surveys. Of patients receiving care in an assisted

living facility, 34.5% returned a survey compared to 27.4% receiving care at home and 22.9% in a nursing home ($p < .0001$). Patients with long lengths of stay (> 6 months) represent 8.8% of the total sample but comprise 11% of the returned surveys. Fewer surveys were returned for non-white patients; 9.3% of returned surveys reported on care for black patients, even though black patients represented 15.2% of the population ($p < .0001$).

Survey respondents were more likely to be female and white (Table 2). There were some significant variations between respondents based on setting of care. A majority of respondents were children of the patients in nursing home (58.6%) and assisted living facility (66.8%) settings compared to a higher percentage of partner/spouses (42.6%) for patients at home.

A majority, 84.3%, of respondents reported that the timing of hospice referral had occurred at “the right time.” Only 1.4% of respondents felt that hospice referral had been “too early” and 9% reported that it was “too late.” Respondents for nursing home patients were more likely not to answer this question and less likely than assisted living facility or patients at home to report that timing had been at the right time (79.1%) ($p < .0001$).

There were no differences in the composite NQF quality score among the three sites of hospice care ($p = .4874$) (Supplemental Table 3). Several differences among sites of care, including in rating of overall care quality, were seen on individual questions. Nearly 90% of all respondents rated hospice care as either excellent or very good. For hospice patients who had received care at home, 67.8% of family members reported that hospice care was excellent vs. 64.3% for assisted living facility and 55.1% for nursing home patients ($p < .0001$). The correlation between the composite quality score and the 5-category measure of overall service quality was 0.65.

Families also answered questions about communication with hospice providers, including whether they received relevant clinical information about the patient’s care. Families of nursing home patients were more likely than patients at home or in assisted living facilities to report that they did not receive information on pain medications used or treatments for breathing problems ($p < .0001$). Families also reported whether they had wanted more information and, importantly, there were marginal, but not statistically significant differences among sites in desire for more information ($p = .0064$ and $p = .0649$). This likely reflects the increased role of formal direct caregivers, rather than family caregivers, in the nursing home setting. In the home setting, family caregivers are more likely to have a hands on role in providing care and may thus have more direct interaction with hospice providers compared with settings where more formal care is provided. Family caregivers of patients who died at home were more likely to report that they were not confident in doing what was needed to care for patients – 27.9% vs. 16% for patients in assisted living facilities and 12.4% for patients in nursing homes ($p < .0001$). Notably, family members of hospice patients in nursing homes were less likely to feel that death occurred in the setting of the patient’s choice – 81.7% vs. 93.5% for patients in assisted living and 98.8% for patients care for at home ($p < .0001$) (**full survey results in Supplemental Table 2**).

In a logistic regression model (Supplemental Table 1), family members of patients who had received hospice care in nursing homes or assisted living facilities compared to patients who lived at home were significantly less likely to report receiving excellent care (OR=0.48, $p<.0001$ and OR=0.67, $p<.0001$, respectively; Supplemental Table 1). In addition, family members of patients who lived in the South (OR=0.82, $p=.0006$; vs. Midwest) were significantly less likely to rate hospice care as excellent.

Discussion

Quality measurement in hospice has been challenging and has struggled to keep pace with the rapid expansion of hospice services.^{24–25} Now that after-death surveys are mandatory and will be publicly reported, it is important to understand the sample of family members who respond to the survey as well as differences in perceived quality among various sub-populations of hospice patients. In this analysis of 7,510 surveys of family members, overall perceptions of the quality of care provided to their loved one were high – about 95% of all respondents felt that care was good, very good, or excellent. The experience over several years of the widely used FEHC survey is instructive for interpretation of the similar CAHPS survey. These analyses raise several points which merit further discussion, including representativeness of after-death surveys and how variations in perceived quality may reflect the overall experience of people at the end of life in these different care settings.

While survey results provide insight into the perspective of family members of people who have died with hospice services, a majority of families did not complete this survey. There are differences in completion rates based on length of stay – thus the survey approach may be less helpful for measuring the quality of care for patients with shorter stays. Further, non-white patient families were less likely to complete the survey. This is particularly concerning given reported racial differences in experiences and quality of care near the end of life care.^{26–29} Some differences in respondents for patients care for in different settings are expected and are due to differences in the patient populations – patients who are cared for in assisted living tend to be older and are more likely to have a son or daughter caregiver vs. a spouse. Improvements in survey data collection or analysis strategies that account for response differences could help improve the representativeness of the mandated survey results. Other strategies, beyond after-death surveys, may be needed to obtain the perspectives of under-represented hospice patients and families. Data on the family experience of hospice care should be considered alongside other measures of hospice quality to present a fuller picture.

Importantly, the calculated composite score did not reveal differences among settings. Some responses to individual items on the survey, however, revealed variation in the perceptions of family members of patients cared for in different settings. Quality of communication is a key construct measured on the survey. Families of nursing home patients reported receiving less information about aspects of clinical care, but did not report higher dissatisfaction with the amount of information compared to families of patients in other settings. Patients who live in nursing homes receive care from nursing aides and nurses in the facility – families may provide additional support at the bedside but are not involved in dispensing medications and other aspects of supporting medical care that they may be at home. The nursing home staff must work directly with hospice staff to implement plans of care. The level of access to

formal caregivers provided in assisted living settings varies and thus families may be more involved in direct care for patients in that setting vs. a nursing home. In the home setting, patients receiving routine hospice care often rely on family caregivers who will play a more direct role in hands on care. It is thus not surprising that family caregivers at home, who would bear primary responsibility for delivering care, may express less confidence in knowing what they needed to do vs. when they are able to rely on formal caregiving staff.

Families were less likely to rate their hospice care in the nursing home as “excellent” and also more likely to report that patients did not die in the setting of their choice. Concerns about quality of nursing home care and patient’s unhappiness with being in that setting, which serves as a safety net for people who do not have adequate support at home, may be reflected in these responses and thus not be a true measure of perceptions of the quality of the hospice care provided. Also, the challenges of integrating hospice care into the nursing home setting have been described.^{30–31} Issues with coordination of care plans or communication between hospice and nursing home staff can occur and could contribute to lower perceptions of quality of care. Families may struggle to distinguish between care provided by hospice staff and nursing home or assisted living facility staff, presenting a challenge to measuring quality of care provided in these settings.

Identifying appropriate timing for hospice referral remains a challenge for clinical providers and is a concern for policymakers. Assisted living and nursing home patients are more likely to have longer lengths of stay, compared to patients in home settings. Most families who responded to the FEHC survey, however, felt that hospice was provided at the “right” time and few reported that hospice had become involved too early.

There were limitations to these analyses. While this sample of hospice patients was large and geographically diverse, it is derived from one provider whose practices may differ from other hospice providers, which may limit generalizability. Further, we limited our sample to patients who received routine hospice care and who lived in one setting near the end of life to more clearly differentiate perceived quality between patients cared for at home vs. assisted living facilities vs. nursing homes. Patients who transition across care settings near the end of life may be more vulnerable to disruptions in care that affect quality.

These findings highlight considerations for policymakers, hospices, and patients and their families. Medicare continues to drive towards increased transparency for consumers through public reporting. Survey results have the potential to set priorities for quality improvement, patient choice of provider, and potentially reimbursement. Survey methodology will need to take into account variations in patient population sub-groups and response rates. Further, potential underlying causes of differences of perceived quality for patients in different settings of care should be examined. Daily care is generally provided by staff in nursing home or assisted living facilities, which may distance family members from day to day treatment discussions. Hospice providers may need to tailor communication strategies based on patient setting.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

Supported by National Institute on Aging (K23AG048323) & American Federation for Aging Research (AFAR).

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IMPACT STATEMENT

We certify that this work is novel.

The potential impact of this research on clinical care & health policy includes the following: interpretation of quality measurement for patients receiving hospice in different setting of care.

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Table 1

Patient demographic characteristics by FEHC survey status (N=27,714 patients receiving routine hospice care between 2009 and 2014 and whose hospice discharge status was death)

Characteristic	FEHC Survey Status			P-value*
	Overall N=27,714	Survey Not Present N=20,204	Survey Present N=7,510	
Age, mean (SD); median; range	80.1 (13.1); 83; 19–110	79.5 (13.4); 83; 19–110	82.0 (12.0); 85; 19–108	<.0001
Length of hospice episode (days), mean (SD); median; range	59.7 (116.8); 17; 1–2117	56.1 (111.6); 16; 1–2117	69.3 (129.1); 20; 1–1615	<.0001
1–6, No. (%)	6972 (25.2)	5380 (26.6)	1592 (21.2)	<.0001
7–14, No. (%)	5689 (20.5)	4195 (20.8)	1494 (19.9)	
15–30, No. (%)	4905 (17.7)	3567 (17.7)	1338 (17.8)	
31–60, No. (%)	3738 (13.5)	2621 (13.0)	1117 (14.9)	
61–90, No. (%)	1679 (6.1)	1186 (5.9)	493 (6.6)	
91–180, No. (%)	2281 (8.2)	1629 (8.1)	652 (8.7)	
>180, No. (%)	2450 (8.8)	1626 (8.1)	824 (11.0)	
Male sex, No. (%)	10996 (39.7)	8075 (40.0)	2921 (38.9)	.1048
Race, No. (%)				<.0001
White	21169 (76.4)	14713 (72.8)	6456 (86.0)	
Black	4222 (15.2)	3525 (17.5)	697 (9.3)	
Asian	538 (1.9)	447 (2.2)	91 (1.2)	
Hispanic	1191 (4.3)	1051 (5.2)	140 (1.9)	
Other	594 (2.1)	468 (2.3)	126 (1.7)	
Married, No. (%)	8416 (30.4)	5767 (28.5)	2649 (35.3)	<.0001
Primary hospice diagnosis, No. (%)				<.0001
Cancer	9534 (34.4)	7139 (35.3)	2395 (31.9)	
Dementia	5702 (20.6)	4027 (19.9)	1675 (22.3)	
Cardiovascular disease	3064 (11.1)	2203 (10.9)	861 (11.5)	
Cerebrovascular disease	2403 (8.7)	1796 (8.9)	607 (8.1)	
Pulmonary disease	1558 (5.6)	1132 (5.6)	426 (5.7)	
Debility	2202 (8.0)	1488 (7.4)	715 (9.5)	
End stage renal disease	692 (2.5)	542 (2.7)	150 (2.0)	
Other	2559 (9.2)	1877 (9.3)	682 (9.1)	
Hospice region in U.S., No. (%)				<.0001
Northeast	3208 (11.6)	2254 (11.2)	954 (12.7)	
Midwest	12834 (46.3)	9055 (44.8)	3779 (50.3)	
South	9041 (32.6)	6835 (33.8)	2206 (29.4)	
West	2631 (9.5)	2060 (10.2)	571 (7.6)	
Location, No. (%)				<.0001

Characteristic	FEHC Survey Status			P-value*
	Overall N=27,714	Survey Not Present N=20,204	Survey Present N=7,510	
Home	13352 (48.2)	9688 (48.0)	3664 (48.8)	
Nursing home	9578 (34.6)	7383 (36.5)	2195 (29.2)	
Assisted living	4784 (17.3)	3133 (15.5)	1651 (22.0)	

* Chi-square used for categorical variables; analysis of variance (ANOVA) used for continuous variables; p-values adjusted for multiple testing using false discovery rate method.

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Table 2

Caregiver characteristics by location (N=7,510)

Characteristic	Location				P-value*
	Overall N=7,510	Patient home N=3,664	Nursing home N=2,195	Assisted living N=1,651	
Gender, No. (%)					
Male	1490 (19.8)	659 (18.0)	454 (20.7)	377 (22.8)	.0418
Female	3881 (51.7)	1894 (51.7)	1104 (50.3)	883 (53.5)	<.0001
Information not provided	2139 (28.5)	1111 (30.3)	637 (29.0)	391 (23.7)	
Race, No. (%)					
White	4719 (62.8)	2164 (59.1)	1340 (61.0)	1215 (73.6)	.1835
Black	455 (6.1)	267 (7.3)	164 (7.5)	24 (1.4)	<.0001
Other race	145 (1.9)	94 (2.6)	41 (1.9)	10 (0.6)	
Information not provided	2191 (29.2)	1139 (31.1)	650 (29.6)	402 (24.4)	
Highest grade of education, No. (%)					
High school or less	1616 (21.5)	929 (25.4)	453 (20.6)	234 (14.2)	<.0001
Some college	1467 (19.5)	701 (19.1)	440 (20.0)	326 (19.7)	
4-yr college graduate	886 (11.8)	370 (10.1)	250 (11.4)	266 (16.1)	
Greater than 4-yr college degree	1363 (18.2)	538 (14.7)	403 (18.4)	422 (25.6)	
Information not provided	2178 (29.0)	1126 (30.7)	649 (29.6)	403 (24.4)	
Relation to patient, No. (%)					
Partner/Spouse	2029 (27.0)	1560 (42.6)	301 (13.7)	168 (10.2)	<.0001
Child	3840 (51.1)	1451 (39.6)	1286 (58.6)	1103 (66.8)	
Parent/Sibling/Other relative	1010 (13.5)	402 (11.0)	373 (17.0)	235 (14.2)	
Friend/Other	334 (4.4)	132 (3.6)	111 (5.1)	91 (5.5)	
Information not provided	297 (4.0)	119 (3.2)	124 (5.6)	54 (3.3)	
Timing of hospice referral, No. (%)					
Too late	679 (9.0)	306 (8.3)	238 (10.8)	135 (8.2)	.1207
The right time	6328 (84.3)	3176 (86.7)	1736 (79.1)	1416 (85.8)	<.0001

Characteristic	Location					P-value*
	Overall N=7,510	Patient home N=3,664	Nursing home N=2,195	Assisted living N=1,651	Omnibus test	
Too early	102 (1.4)	33 (0.9)	42 (1.9)	27 (1.6)		Patient home vs nursing home
Information not provided	401 (5.3)	149 (4.1)	179 (8.2)	73 (4.4)		Patient home vs assisted living
						Nursing home vs assisted living

* Chi-square used for categorical variables; p-values adjusted for multiple testing using false discovery rate method.