

NHPCO Original Article

Timing of Referral to Hospice and Quality of Care: Length of Stay and Bereaved Family Members' Perceptions of the Timing of Hospice Referral

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Abstract

Previous research has noted that many persons are referred to hospice in the last days of life. The National Hospice and Palliative Care Organization collaborated with Brown Medical School to create the Family Evaluation of Hospice Care (FEHC) data repository. In 2005, 106,514 surveys from 631 hospices were submitted with complete data on the hospice length of stay and bereaved family member perceptions of the timing of hospice care. Of these surveys, 11.4% of family members believed that they were referred "too late" to hospice. This varied from 0 to 28.1% among the participating hospice programs with 30 or more surveys. Among those with hospice lengths of stay of less than a month, only 16.2% reported they were referred "too late." Although the bereaved family member perceptions of the quality of end-of-life care did not vary by length of stay for each of the FEHC domains, the perception of being referred "too late" was associated with more unmet needs, higher reported concerns, and lower satisfaction. Our results suggest that family members' perception of the timing of hospice referral—not the length of stay—is associated with the quality of hospice care. This perception varies substantially among the participating hospice programs. Future research is needed to understand this variation and how hospice programs are delivering high quality of care despite short length of stay. J Pain Symptom Manage 2007;34:120–125. © 2007 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Hospice, quality of end-of-life care, timing of referral

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Introduction

Hospice was developed to provide comprehensive services that allow dying persons to live their lives to the fullest. Originally, the concept of hospice was introduced as an ongoing program to ease suffering during the transition between life and death. Although many experts recommend a hospice stay of at least three months to provide adequate services,¹ the average length of stay is less than 60 days. In the United States, the median length of stay declined from 29 days in 1995 to 26 days in 2005, with 30% of those served by hospice dying in 7 days or less (www.nhpco.org). Short hospice stays are not desirable due to their impact on the dying persons' and the caregivers' quality of life and the quality of end-of-life care. Recent studies have shown lower satisfaction with hospice services was correlated with family members' reports of late referrals,² and shorter length of stay was associated with family members' reports of decreased number of services provided.³ Furthermore, although many patients prefer to die at home,⁴ patients with hospice enrollment less than 7 days are less likely to receive care at home.⁵

Over the past 10 years, the Brown Medical School Center for Gerontology and Health Care Research has collaborated with the National Hospice and Palliative Care Organization (NHPCO) to create an actionable tool to measure consumer perceptions of the quality of end-of-life care. The Family Evaluation of Hospice Care (FEHC) has been validated⁶ and used in the national study of dying in the United States.⁷ The survey is currently used as part of an ongoing NHPCO performance measurement program, with a web-based repository that allows hospice programs to submit their data and receive a 30-page quarterly report regarding their quality of end-of-life care.⁸ As of 2006, nearly 1000 hospices are submitting their data online. The FEHC data repository allows us to examine at a national level the relationship of length of stay, perceived timing of hospice referral, and quality of end-of-life care.

Methods

Development of Survey

Based on expert opinion, a structured review of existing guidelines, and consumer focus

groups, Teno and colleagues developed the FEHC.⁹ The original instrument was shortened and a mode test was conducted that found the survey could be self-administered, with similar results to telephone administration. The FEHC is based on a conceptual model of patient-focused, family-centered medical care. Under this model, a health care institution provides excellent end-of-life care when it: 1) provides the desired physical comfort and emotional support; 2) supports shared decision making; 3) treats the patient with respect; 4) attends to the needs of the family for emotional support and the needed information; and 5) coordinates care effectively. Detailed information on how to calculate the problem and modified domain score is available in the paper by Connor and colleagues.⁸ Although the analysis was done with full problem scores, we summarize the findings by reporting the percent of persons who report one or more concerns with the quality of care.

In this study, our goal was to examine the association of the perceptions of the quality of care with both hospice length of stay and bereaved family members' perceptions of the timing of hospice referral. For the latter, respondents were asked the following question, "In your opinion, was [PATIENT] referred to hospice too early, at the right time, or too late during the course of [HIS/HER] final illness?" Hospice length of stay was based on the bereaved family member report.

Data Collection

Brown Medical School's Center for Gerontology and Health Care Research, in collaboration with the NHPCO, developed a Web site for hospices to submit data for the repository used by this report. The Web site was piloted at Brown and then modified by the NHPCO. Participation in the FEHC survey is voluntary, although the NHPCO has encouraged all hospices nationwide to take part. Hospices or third-party vendors contact bereaved family members between one to three months after the patient's death to invite them to participate in the survey. The surveys are usually completed by paper and pencil and returned to the hospice program or a data vendor hired to compile the results. The response rate as calculated based on the one-year total number of surveys completed over the number mailed out is 45%.

Table 1
Characteristics of Decedents
(n = 106,514 Surveys)

Characteristics	Decedents n = 106,514 (%)	Perceived Appropriate Timing of Referral n = 92,899 (%)	Perceived Late Referral n = 12,182 (%)
Age 85 years and older at time of patient's death	49.1	32.6	47.1
Sex			
Male	41.3	41.4	41.7
Primary illness leading to hospice admission			
Cancers—all types	42.7	43.0	39.9
Heart & circulatory disease	9.9	9.8	10.2
Lung & breathing disease	7.6	7.5	8.4
Kidney disease	2.2	2.2	2.3
Liver disease	1.6	1.6	1.5
Stroke	3.9	4.03	3.3
Dementia & Alzheimer's disease	7.8	7.7	7.8
AIDS & other infectious diseases	0.2	0.2	0.2
Frailty & decline due to old age	5.7	5.7	5.6
Other illness	4.2	4.04	5.2
Highest grade or level of school completed			
8th grade or less	8.9	9.01	8.1
Race			
American Indian or Alaskan Native	0.7	0.6	0.8
Asian or Pacific Islander	0.7	0.7	0.7
Black or African American	3.3	3.4	2.6
White	82.9	83.0	82.5
Another race or multiracial	1.6	1.2	1.4
Length of time patient received hospice services			
2 days or less	10.0	8.2	24.7
3–7 days	21.7	20.4	32.5
8–14 days	15.08	15.0	15.9
15–29 days	11.5	11.9	9.7
1–3 months	25.7	27.3	14.1
4–6 months	8.2	9.0	2.0
7–9 months	3.0	3.3	0.6
10–12 months	1.9	2.0	0.3
>1 year	2.8	3.0	0.3

Analytic Approach

For this study, we report the descriptive results and examine the association of length of stay, bereaved family member of the timing of hospice referral, and the perception of quality of end-of-life care with each of the

domains of the FEHC. Because of the large number of cases, even minor differences achieve statistical significance; we set a threshold of 5% difference as being clinically relevant. For those hospices contributing 30 or more surveys to the repository, we reported the variation in bereaved family members' report that referral to hospice was "too late."

Results

Perception of Timeliness of Hospice Referral

Eighty-seven percent reported that the patient was referred at the right time, whereas 11.4% felt that hospice services were initiated "too late." Only 1.4% ($n = 1433$) reported that the patient was referred at a time too early for hospice services (Table 1). There were no statistically significant differences in perception of appropriate vs. late referrals when patients were grouped by age at time of death, sex, primary illness leading to hospice admission, education, race, or ethnicity.

Length of Stay, Perception of Being Referred "Too Late," and Perceived Quality of End-of-Life Care

Fig. 1 depicts the association between length of stay and the quality-of-care domains in the FEHC. For each domain and overall satisfaction, there is essentially a flat line, indicating the lack of an association between hospice lengths of stay and bereaved family members' perceptions of the quality of care. In contrast, bereaved family members who believed their relative was referred "too late" reported more unmet needs, higher reported number of concerns, and lower satisfaction with the quality of end-of-life care than those who indicated referral was made at the "right time" (Table 2). More family members who felt that the referral was "too late" reported unmet needs of the patient for management of pain (9.7 vs. 5.0%), dyspnea (10.0 vs. 4.1%), and emotional support (18.2 vs. 8.1%). Similarly, family members reported having greater unmet needs for their own emotional support (18.8 vs. 10.0%). More family members also felt that they were less informed about what to expect (41.4 vs. 25.2%) and about management of symptoms (17.9 vs. 9.0%). Furthermore, family members who perceived a late

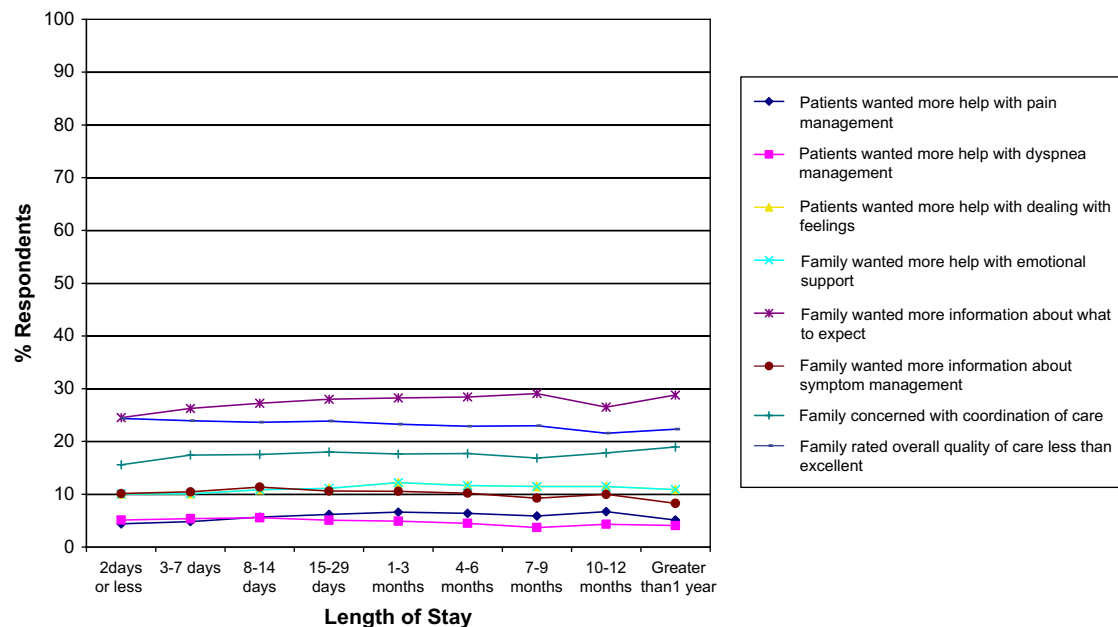


Fig. 1. Length of stay and reported hospice outcomes.

referral were more dissatisfied with the coordination of care (23.7 vs. 16.4%) and the overall quality of care (33.5 vs. 21.9%). This trend of unmet needs and greater dissatisfaction with care among those who reported referral that was “too late” was also found with reports of hospice staff not always treating the patient with respect, although the difference was less marked (5.4 vs. 2.8%).

Geographic and Hospice Variation of Perceptions of Late Referrals

Bereaved family member perceptions of being referred “too late” varied by both state and hospice program. Fig. 2 shows variation of perceptions of late referrals by a state-by-state basis, ranging from 7.8% in Vermont to 15.0% in South Carolina. Among the 521 hospices with 30 or more surveys, the variation of the

Table 2
Bereaved Family Members’ Perceptions of Timing of Referral and Quality of Care

	“At the Right Time” n = 92,899 (%)	“Too Late” n = 12,182* (%)
<i>Provide desired physical comfort and emotional support</i>		
Patient did not receive appropriate amount of help with		
Pain	5.03	9.66
Dyspnea	4.14	9.96
Dealing with feelings	8.14	18.18
<i>Treat dying person with respect</i>		
Not always treating patient with respect	2.77	5.43
<i>Attend to the needs of the family: one or more concerns with</i>		
Emotional support	9.96	18.77
Being informed about what to expect	25.18	41.37
Being informed about symptoms	9.03	17.77
<i>Coordination of care</i>		
One or more concerns	16.41	23.73
<i>Overall quality of care</i>		
Response less than excellent	21.86	33.48

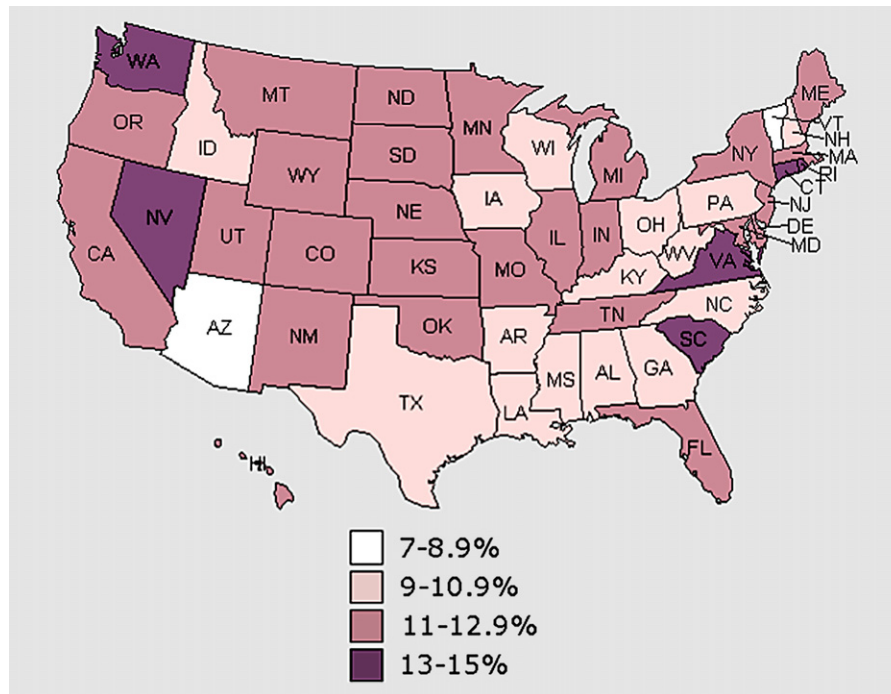


Fig. 2. Depicted is the state variation in bereaved family member response that their dying relative was referred "too late." Among the 819 participating hospices, 12,182 (11.4%) bereaved family members believe their loved one was referred "too late" to hospice services. This varied from 7.8% (VT) to 15.0% (SC).

perception of being referred "too late" ranged from 0 to 28.1% (mean 11.5%, 25th percentile 9.2, 75th percentile 14.0%).

Discussion

Slightly less than one in five bereaved family members with a hospice length of stay of less than one month stated that their family member was referred "too late" to hospice services. Unfortunately, this result raises more questions than it answers. Why aren't more bereaved family members reporting they were referred "too late" despite a short length of stay? It would appear that families need to be educated about the importance of a longer hospice length of stay. However, in some cases, an earlier hospice referral may not be possible. Waldrop et al.¹⁰ used open-ended interviews with 59 bereaved caregivers of hospice patients who died with short lengths of stay and found that 44% were diagnosed too late and 17% refused hospice services at an earlier time point. Schockett and colleagues² found that about one in four cases referred "too late" to hospice may not be easily changed to access hospice at

an earlier point in time, in that 13% of dying persons refused an earlier hospice referral and 10% were diagnosed at a late point in their illness. Based on these two studies, the rate of short stays that *could not* have been referred earlier to hospice varied between 23% and 61%. These two small studies suggest that it might not be possible for some dying persons to have been referred at an earlier time point.

Our data suggest that the perception of being referred "too late," rather than length of stay, is associated with greater unmet needs, more concerns, and lower satisfaction. One could hypothesize that hospice programs have become very adept at "rallying the troops" to provide excellent end-of-life care for those persons with short lengths of stay. The perception of being referred "too late" is not easily predicted by the existing sociodemographic data available in this data set. This perception of being referred "too late" varied between 0% and 28% among hospice programs with 30 or more surveys completed in 2005.

The striking variation in the perception of being referred "too late" calls for research to

understand whether hospices are using different organizational interventions to improve access to hospice services. For example, many hospices are now adopting "open access" policies to allow dying patients to receive potentially "life-prolonging treatment." This intervention potentially could improve access to hospice services, reducing bereaved family members' perceptions that their dying relatives or friends were referred "too late" to hospice services. Future research is needed to characterize this variation by hospice program in regard to whether there are different processes of care, consumer education efforts, and/or different hospice policies that lead to improved perceptions of the quality of care.

When interpreting these results, certain limitations of this study should be kept in mind. Data were collected from family members of deceased hospice patients using self-administered surveys. Respondents may have inaccurately perceived patients' unmet needs for emotional support and pain management. A recent review of studies on the reliability of information provided by proxies found that they were more reliable regarding observable symptoms and quality of services than subjective features of the patient experience.¹¹ However, it is unlikely that this discrepancy would be different among this study's comparison groups. Also, the response rate is 45%, thus adding a concern of possible selection bias.

In conclusion, the majority of respondents believed they were referred to hospice "at the right time," despite a reported short length of stay. Short hospice lengths of stay were not associated with perceptions of poor quality end-of-life care. Rather, the family members' perception that they were referred "too late" to hospice was associated with lower satisfaction, more unmet needs, and higher reported concerns. This perception of late referral varied by state and by hospice program. An important opportunity exists to educate the public about the benefits of longer hospice lengths of stay. Future research should seek to understand whether there are differences in state policies and regulations that may be contributing to late hospice referrals. Additionally, research is needed to understand whether hospices with lower rates of persons

being referred "too late" are using innovative programs to better meet the needs of dying patients and their families.

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