Bereaved Family Members’ Evaluation of Hospice Care: What Factors Influence Overall Satisfaction with Services?

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Abstract

As patients near the end of life, bereaved family members provide an important source of evaluation of the care they receive. A study was conducted to identify which processes of care were associated with greater satisfaction with hospice services from the perspective of bereaved family members. A total of 116,974 surveys from 819 hospices in the United States were obtained via the 2005 Family Evaluation of Hospice Care, an online repository of surveys of bereaved family members’ perceptions of the quality of hospice care maintained by the National Hospice and Palliative Care Organization. Overall satisfaction was dichotomized as “excellent” vs. “other” (very good, good, fair, and poor). Using multivariate logistic regression, the association between overall satisfaction and the individual item problem scores that compose the Family Evaluation of Hospice Care were examined. Bereaved family members were more likely to rate overall satisfaction with hospice services as “excellent” if they were regularly informed about their loved one’s condition (adjusted odds ratio [AOR] = 3.76, 95% confidence interval [CI] = 3.61–3.91), they felt the hospice team provided the right amount of emotional support to them (AOR = 2.21, 95% CI = 2.07–2.38), they felt that the hospice team provided them with accurate information about the patient’s medical treatment (AOR = 2.16, 95% CI = 2.06–2.27), and they could identify one nurse as being in charge of their loved one’s care (AOR = 2.02, CI = 1.92–2.13). These four key processes of care appear to significantly influence an “excellent” rating of overall satisfaction with hospice care.

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Key Words

Hospice, end-of-life care, family members, satisfaction

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Introduction

Since its inception in the 1960s, the hospice movement has constantly evolved to meet the needs of terminally ill patients and their families. Research has consistently shown that hospice utilization has improved the quality of care patients receive at the end of life.1–6 This multidisciplinary approach to the treatment of patients who are nearing death consists not only of physicians and nurses, but of social workers, spiritual support staff, bereavement coordinators, and volunteers as well. Owing to the continuous evolution of the hospice program, systems must be put in place to guarantee that hospice agencies provide the best possible care—care that is consistent with the goals established by patients and their families.

As patients near the end of life, many are unable to provide information about the care they receive. Therefore, the perspectives of family members provide an important source of evaluation. Several studies have documented family members’ high satisfaction with the services that hospice agencies provide, particularly as compared to services provided in institutional settings.7–10 However, other studies have identified family members’ concerns with some aspects of hospice care, including the timing of hospice referral, communication with hospice staff, provision of emotional support, and provision of care for home hospice patients during off hours (i.e., nighttime).11–16 Understanding the determinants of family members’ overall satisfaction with hospice services may provide information that can help the hospice industry improve both the quality of care patients and families receive at the end of life as well as the family member’s overall satisfaction with this care.

Earlier studies that have examined the perceptions of bereaved family members regarding hospice care have provided valuable information, but are limited by qualitative study designs, small sample sizes, and data derived from single hospice agencies or geographic regions.7–9,12–14 Therefore, the National Data Repository of the Family Evaluation of Hospice Care (FEHC) provided a unique opportunity to examine which specific processes of care are associated with higher satisfaction with hospice services among over 800 hospices across the United States.

Methods

Study Population

The study population was generated from respondents to the FEHC survey. Respondents were contacted by hospice programs one to three months after their loved ones died and asked if they would like to participate in the FEHC survey. Given that the objective of our study was to determine what factors influence overall satisfaction with hospice services, all persons who agreed to participate and responded to the main outcome question, “Overall, how would you rate the care the patient received while under the care of hospice?,” were included in the analyses.

Data Sources

Eight hundred nineteen hospices from 50 states, the District of Columbia, and Puerto Rico used the FEHC survey instrument.17 These hospices represent 22% of all hospices nationwide. Hospice participation in the use of the FEHC was voluntary. All hospices with FEHC data were included in this study, even though in some cases response rates were low.

Survey Design

The 2005 FEHC survey is a 61-item questionnaire designed to evaluate hospice services along several patient- and family-centered domains of care. This survey is used by hospices across the country, and bereaved family members of decedents who died while receiving hospice services are invited to complete the survey. The results of the survey are compiled and maintained in a repository by the National Hospice and Palliative Care Organization. The domains considered in the FEHC include: (1) attending to family needs for support, (2) attending to the family needs for information, (3) coordination of care, (4) provision of desired physical comfort and emotional support, and (5) overall satisfaction.18 With the exception of the overall satisfaction domain, which was not used in this analysis, each of these domains generates a problem score and comprises individual questions. For instance, the domain identified as attending to the family needs for support consists of questions about the amount of emotional and spiritual support provided to the family by the hospice agency. The domains and the component questions
that comprise them are listed in Table 1. Details about the survey design, domains, and problem scores can be found elsewhere.18

The main outcome of interest, overall rating of hospice services, was obtained from respondents by asking the following question: “Overall, how would you rate the care the patient received while under the care of hospice?” Responses to this question were initially recorded along a five-point scale of evaluation (“excellent,” “very good,” “good,” “fair,” and “poor”). For the purposes of our analysis, the main outcome was dichotomized as “excellent” vs. “other.” Some of the independent variables were initially recorded along a four-point response scale, whereas others required a “yes/no” response. For instance, for the question “How much emotional support did the hospice team provide to you prior to the patient’s death?,” the responses were “less than was wanted,” “the right amount,” “more attention than was wanted,” and “no answer.” For the purposes of our analysis, they were also dichotomized to include the desired response (the right amount) vs. the other responses (less/more than was wanted). Additionally, for questions with “yes” or “no” responses, such as “Would you have wanted more information about what to expect while the patient was dying?,” a dichotomized variable was created to represent the response. (See Table 1 for all of the component questions and responses used in our analysis.)

**Analysis**

All analyses were conducted using Stata SE (9.0, College Station, TX). A descriptive analysis of respondents and decedents was conducted using the Chi-squared ($\chi^2$) test. Imputation was performed for missing data by substituting the modal response. Measurement of the association of overall satisfaction was conducted by performing multivariable logistic regression analysis; the main outcome variable and the individual components of each domain (as described above) were included in the model. Given the large sample size, and the likelihood of the great majority of findings being significant at the 0.05 level, $P$-values were not included in this paper. The Huber White correction was used to account for clustering within hospices. Regression analyses were performed with and without imputation and no significant differences in the coefficients of the two models were detected.

**Results**

**Sample Characteristics—Decedents and Respondents**

Survey results were obtained from 819 hospices; these hospices represented each of the 50 United States and Puerto Rico. Of the 121,817 total respondents, 116,974 (96.0%) provided an answer to the main outcome measure. Table 2 presents the baseline characteristics for decedents and proxies. Over 50% of decedents were female, and most were 65 years of age or older (84.7%). Over 90% of decedents were non-Hispanic white and 3.1% were of Hispanic origin. The leading cause of death for decedents in the sample was cancer (52.1%). For the respondents, 72.6% were female and 93.9% were non-Hispanic white. The majority of respondents identified themselves as the spouse, partner, or child of the decedent, and almost half (49.1%) of the respondents were 45–64 years of age.

**Individual Component Scores**

Table 1 presents the results of the association of bereaved family member perceptions of the quality of care with their overall satisfaction in terms of individual components of problem scores.

**Attending to Family Needs for Support.** Family members were more likely to have higher overall satisfaction with care if they felt they had sufficient contact with the hospice team about their religious or spiritual beliefs (adjusted odds ratio [AOR]: 1.77, 95% confidence interval [CI]: 1.64–1.90), and if they believed that the hospice team provided them with the right amount of emotional support after the patient died (AOR: 1.72, 95% CI: 1.62–1.82). Additionally, family members were more than two times as likely to have higher levels of satisfaction with hospice if they were provided the right amount of emotional support prior to the patient’s death (AOR: 2.21, 95% CI: 2.07–2.38).

**Attending to Family Needs for Information.** Family members were more likely to have higher overall satisfaction with hospice if they were provided with adequate information about
what to expect while the patient was dying (AOR: 1.98, 95% CI: 1.91–2.07), information about the medications used to manage the patient’s pain (AOR: 1.52, 95% CI: 1.42–1.63), and information about what was being done for the patient’s dyspnea (AOR 1.75, 95% CI: 1.60–1.91). Additionally, family members were more than three times as likely to have higher overall ratings of satisfaction with hospice services if they were kept regularly informed about the patient’s condition (AOR: 3.76, 95% CI: 3.61–3.91).

**Coordination of Care.** Family members were more likely to have higher overall ratings of...
satisfaction with hospice if there was one nurse identified as being in charge of the patient’s overall care (AOR: 2.02, 95% CI: 1.92–2.13).

Furthermore, family members were more likely to have higher overall ratings of satisfaction if the hospice team appeared to be knowledgeable enough about the patient’s medical history to provide the best possible care (AOR: 1.93, 95% CI: 1.80–2.08) and were more than two times as likely to be satisfied with services if the hospice team provided accurate information about the patient’s medical treatment (AOR: 2.16, 95% CI: 2.06–2.27).

 Provision of Desired Physical Comfort and Emotional Support. Respondents were more likely to have higher overall ratings of satisfaction with hospice services if they felt the patient received the right amount of pain control (AOR: 1.73, 95% CI: 1.61–1.86), relief of dyspnea (AOR: 1.52, 95% CI: 1.38–1.68), and emotional support (AOR: 1.73, 95% CI: 1.61–1.86).

Discussion

Dame Cicely Saunders stated that “the family is seen as the unit of care as it finds its own potential, searches for meaning and makes the achievements possible at the end of life.”19 Using a national database of over 800 hospices and more than 100,000 bereaved family members, our study determined that the family, the basic unit of care to which Saunders refers, values the services that hospice provides—particularly when certain patient- and family-centered goals are achieved. Family members were almost four times as likely to have reported higher evaluations of the care received if they were regularly informed about their loved one’s condition. They were more than two times as likely to report higher evaluations of hospice care if they felt they received the right amount of emotional support prior to the patient’s death. Additionally, they were twice as likely to report higher levels of satisfaction with hospice services if they felt the hospice team provided them with accurate information and knew enough about the patient’s medical history to provide the best possible care.

Several studies have identified components of hospice services that are of concern to bereaved family members.11–16 Our study expands on this growing body of literature about bereaved family members’ concerns about hospice care by using a validated, widely disseminated instrument to not only identify “problem areas,” but to also identify specific processes of care that appear to positively influence overall satisfaction with services. Therefore, hospices may want to target these identified processes in their quality improvement efforts to improve next-of-kin satisfaction with care.

Bereaved family members in our study were almost four times as likely to rate their satisfaction with services as excellent if they were kept informed about their loved one’s condition. This preparedness for death has been shown throughout the literature to improve caregiver well-being and bereavement outcomes for
grieving family members. For instance, studies have shown that caregivers who are not prepared for death often experience more psychiatric morbidity. Additionally, caregivers have noted the significant benefits of receiving comprehensive information to prepare them for the future and have expressed appreciation for the support provided by specialist palliative care services. Our study reiterates that providing bereaved family members with information about their loved one’s condition may influence their overall satisfaction with hospice services; as a consequence, complications of the grieving process, such as depression and anxiety, may be reduced.

The FEHC survey is an important tool in evaluating the services that hospices throughout the country provide. Respondents whose loved ones received services from hospices in each of the United States voluntarily submitted information about the quality of care they and their loved one received. This information is important because it serves as a tool that individual hospice organizations can use to improve upon the services that they provide, and the information gathered can be used to establish interventions that pinpoint processes of care that are in need of improvement.

Important limitations should be noted in interpreting the findings of this study. Submission of the FEHC is voluntary, though the National Hospice and Palliative Care Organization continues to encourage participation from hospices throughout the country. Therefore, compared to nonparticipating programs, participating programs may have more interest in improving the quality of care they provide. Additionally, family members are asked to participate in the survey within one to three months of the patient’s death. Some would argue that recall bias comes into play when respondents are contacted during the bereavement period; however, studies have shown that retrospective assessments by bereaved family members may be valid for some items of service provision and that proxies can reliably report on the quality of services and on observable symptoms. Despite these proposed limitations, our study sample consisted of over 100,000 respondents from a number of hospice programs, thereby increasing its external validity.

**Conclusion**

We found bereaved family members were more likely to have higher satisfaction with hospice services if certain key processes of care were achieved. These processes of care involved regular and accurate communication about the patient’s medical condition by the hospice team, provision of adequate amounts of emotional support by hospice staff, and the family’s belief that hospice staff was knowledgeable enough about the patient’s medical history to provide the best possible care. These processes, along with several others were noted to be of concern to family members whose loved ones died while receiving hospice services. By using evaluation tools such as the FEHC, hospice agencies around the country can continue to provide the best possible care to dying patients and their families, and interventions can be created to focus on processes of care that are of greater concern to families of hospice patients.

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