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Does Hospice Improve Quality of Care for Persons Dying from Dementia?

Joan M. Teno, MD, MS[*], **Pedro L. Gozalo, PhD**[*], **Ian C. Lee**[*], **Sylvia Kuo, PhD**[*], **Carol Spence, PhD**[†], **Stephen R. Connor, PhD**[‡], and **David J. Casarett, MD, MA**[§]

[*]Department of Community Health, Warren Alpert School of Medicine, Brown University, Providence, Rhode Island [†]National Hospice and Palliative Care Organization, Alexandria, Virginia [‡]Worldwide Palliative Care Alliance, London, United Kingdom [§]Division of Geriatrics, School of Medicine, Department ofMedicine, University of Pennsylvania, Philadelphia, Pennsylvania

Abstract

OBJECTIVES—To examine the effectiveness of hospice services for persons dying from dementia from the perspective of bereaved family members.

DESIGN—Mortality follow-back survey.

SETTING—Death certificates were drawn from five states (AL, FL, TX, MA, and MN).

PARTICIPANTS—Bereaved family members listed as the next of kin on death certificates when dementia was listed as the cause of death.

MEASUREMENTS—Ratings of the quality of end-of-life care, perceptions of unmet needs, and opportunities to improve end-of-life care. Two questions were also asked about the peacefulness of dying and quality of dying.

RESULTS—Of 538 respondents, 260 (48.3%) received hospice services. Family members of decedents who received hospice services reported fewer unmet needs and concerns with quality of care (adjusted odds ratio (AOR) = 0.49, 95% confidence interval (CI) = 0.33–0.74) and a higher rating of the quality of care (AOR = 2.0, 95% CI = 1.53–2.72). They also noted better quality of dying than those without hospice services.

CONCLUSION—Bereaved family members of people with dementia who received hospice reported higher perceptions of the quality of care and quality of dying.

Address correspondence to Joan M. Teno, 121 South Main Street, Providence, RI 02912. Joan_Teno@brown.edu.

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SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article:

Appendix S1. Questions used in the problem score and quality of rating score (copyrighted Joan Teno, MD, MS, Brown University, used with permission).

Keywords

hospice; quality of care; dying

Nursing homes are the final place of care for frail, older persons dying of chronic progressive illnesses such as dementia. The majority of people with dementia die in nursing homes.[1] Persons dying from dementia follow a disease trajectory consisting of progressive functional decline with the development of difficulty eating and recurrent infections that eventually result in death.[2] Persons with dementia residing in nursing homes increasingly receive hospice services, although a recent focus of the Medicare Payment Advisory Commission (MedPAC) and the Department of Health and Human Services Office of the Inspector General has been the significant growth in Medicare expenditures under the hospice benefit, from $2.9 billion in 2000 to more than $10 billion in 2007.[3] This increase in spending has largely been attributed to an increase in hospice length of stay and in the number of admissions of people receiving hospice services with noncancer diagnoses, such as dementia.

Multiple studies have reported significant concerns with end-of-life care in nursing homes. Persistent severe pain is an important concern in the nursing home setting.[4,5] Family members of those who died in a nursing home reported higher rates of unmet needs, more concerns with care, and lower ratings of satisfaction with the quality of care than those of persons who died at home with hospice care.[6] Residents with dementia often undergo burdensome treatments in the last months of life.[2,7] Because the goals of hospice care are effective symptom management and maximization of quality of life, hospice services should be of significant benefit to nursing home residents, yet little research has examined the effectiveness of hospice services for persons dying of dementia,[8] and the findings of studies that have been performed are inconsistent. Nursing home residents enrolled in hospice were found to be less likely to be hospitalized in the last 30 days of life[9] and more likely to receive regular assessment and treatment of pain[10] and have lower rates of having physical restraints, intravenous or parenteral feeding, and feeding tubes.[11] In contrast, two small studies did not find differences in unmet needs, family member ratings of the quality of care, or pain management in those receiving and not receiving hospice services.[12,13]

Given the public policy focus on Medicare payment for hospice services for people with dementia and the lack of research examining the quality of hospice care for persons with dementia, the current study undertook a secondary analysis of a survey of family members of people who died from dementia that asked about family members’ perceptions of the quality of end-of-life care with and without hospice services.

METHODS

This secondary analysis of the association between the receipt of hospice services and family member perceptions of the quality of care is based on a mortality follow-back survey. The goals of the original study were to examine the decision-making and outcomes of feeding tubes.[14] A mortality follow-back survey was conducted by contacting the persons listed as the next of kin on death certificates on which the leading cause of death was dementia. All surveys were administered over the telephone. The next of kin listed on the death certificate was asked whether they were the person who knew best about the decedent in the last months of life and whether they participated or would have participated in decision-making with a healthcare provider.

The mortality follow-back study was conducted between 2007 and 2009 in five states (AL, FL, TX, MA, and MN) with approximately one-third of the interviews conducted in each year. States were sampled based on the prevalence of feeding tube use; the inclusion of different geographic regions; variety in minority representation; and no state restriction in access to death certificates for research purposes. Based on our previous work,[7] states were purposely sampled based on the prevalence of feeding tubes in nursing homes. Two states were selected for lower (MN and MA) and three states for higher feeding tube prevalence (AL, FL, TX).

One thousand one hundred eleven death certificates that listed dementia as the leading cause of death were randomly sampled. Of those contacted, 64 were excluded: 14 based on a screening question that found that the decedent did not need assistance in eating and 50 because the decedents did not have a knowledgeable next of kin or that person did not speak English or Spanish. Two hundred seventy-seven persons could not be located. Of the 770 family members who were located, 545 (70.8%) participated in the survey.

The survey used the core items of the Family Evaluation of Hospice Care (FEHC) survey[15,16] modified to examine family member perceptions of the quality of care in the last week of life. The FEHC is a postdeath survey that examines the quality of hospice care from the family's perspective and that the National Hospice and Palliative Care Organization (NHPCO) has adopted as a benchmarking and quality improvement tool. These eight core items are based on a conceptual model of patient-focused, family-centered care at the end of life that defines high-quality care as providing the desired amount of physical comfort (2 items), providing the family with information on what to expect (3 items) and the desired emotional support (2 items), and treating the person with respect (1item). Each of these questions is listed in Table 2, and the items with the response category are available online (Appendix S1). The survey asked about concerns of quality of care using patient-centered reports developed previously[17,18] and unmet needs.[19] Survey responses were used to calculate a composite problem score, with each nonoptimal response representing an opportunity to improve end-of-life care. An example of a nonoptimal response is an answer by the family member that they did not receive the "right amount" of emotional support or wanted more information about what to expect while dying. Each nonoptimal response was added to create a count of opportunities to improve the quality of care. The questions are provided online. The eight items in the problem score had a Cronbach alpha of 0.73.

In addition to the core questions of the FEHC, two other measures of family member perceptions of the quality of care were reported. The first was family member ratings of four aspects of the quality of care (respecting that person's wishes, communication about the outcomes of care, desired level of symptom control, and provision of emotional support) using a response scale of 0 (worst possible care) to 10 (best possible care). These scores were added to form a 40-point composite score. A second measure asked the respondent to rate of the quality of dying. Based on previous work,[20] respondents used a scale of 1 to 10 to rate their perceptions of the decedent's peacefulness during death and the overall quality of the decedent's dying experience.

Analytic Approach

The univariate association between the use of hospice services and each of the outcomes was examined using nonparametric one-way analysis of variance. Previous research has found a higher rate of reported concerns, unmet needs, and lower satisfaction with hospice services when the decedent is referred "too late."[21] Therefore, analysis of the three main outcomes was stratified according to family member perceptions of the timing of hospice referral (too late vs right time or too soon). Because of the skewed distribution, each of the dependent measures was categorized in three or four ordered categories. In the case of the composite problem score, the categories were zero, one, two, three, and four or more problems or concerns with the quality of care. The 0 to 40 rating scale of the quality of care was categorized based on distribution into four categories (0–27, 28–35, 36–39, and 40). The question that asked the family member to rate the peacefulness of dying and quality of dying was classified into three categories based on the distribution of the response (0, 1–4, 5–10 for peacefulness of dying and 0–5, 6–9, and 10 for quality of dying). In the cases of the composite score, up to two out of eight items were imputed using the modal response. For the four rating questions regarding the quality of care, up to one item was imputed. A multivariate cumulative logistic model was used to examine the association between hospice use and each outcome, adjusting for sociodemographic characteristics, state, relationship between the respondent and the decedent, and whether decedents were referred to hospice too late. In the cases of the composite FEHC score and 0 to 40 rating scale of the quality of care, the analyses were conducted with and without imputation; no significant difference was found, so the model with the imputed results is reported. The Huber-White correction was applied for sampling of death certificates according to hospital referral region.

RESULTS

Decedent and Respondent Demographics

Five hundred thirty-eight respondents reported whether their loved one received hospice services. The majority of decedents (73.2%) died in the nursing home. The hospice (n = 278) and nonhospice groups (n = 260) had similar decedent and respondent characteristics. Decedents were mostly white in both groups (82.4% and 88.5%), and death occurred predominantly in nursing homes (74.5% and 71.6%). Respondents were mostly female (64.8% and 68.5%) and children of the decedents (60.1% and 63.9%). Differences between the groups in decedent ethnicity, respondent sex, relationship to decedent, and education were not statistically significant (Table 1).

Quality of Care of Those with and without Hospice Services

Table 2 examines family member perceptions of the quality of care and their ratings of the quality of dying using three types of outcome measures. This analysis is stratified based on family member perceptions of whether hospice was instituted at the right time or “too late.” Only four persons reported that hospice was received “too early,” and 15 persons did not answer the question regarding the timing of hospice services. The first outcome measure is a modified problem score based on the FEHC. Table 2 reports the composite problem score and results of each item that composed the composite score. A multivariate ordinal logistic model was completed for the overall problem score and each item that composed that score.

People who received hospice services “at the right time” had lower problem scores than those who did not receive hospice services (mean 0.8 vs 1.2, $P < .001$). A multivariate logistic regression, after controlling for sociodemographic characteristics, state, and respondent characteristics, found that family members of people receiving hospice services were 51% less likely (adjusted odds ratio (AOR) = 0.49, 95% confidence interval (CI) = 0.33–0.74) to report unmet needs and concerns with the quality of care than family members of people who did not receive hospice services. The 33 respondents who indicated that their family members were referred to hospice too late had the highest problem scores (mean 2.7). Table 2 lists each of the eight items of the composite problem score and allows a better understanding of the areas that family members perceived better quality of care with hospice services provided at the right time. Nearly one in five decedents who died without hospice services reported a need for additional help in the treatment of dyspnea. Only 6.1% of decedents receiving hospice at the right time reported wanting additional symptom amelioration for dyspnea. As reported in the fifth column, these differences persisted even after adjustment for decedent and family member sociodemographic characteristics and state in which the person died, as indicated by an AOR of 0.22, indicating that family members who reported receiving hospice services at the right time had a 78% lower rate of unmet needs in dyspnea than those of decedents who did not receive hospice services. Family members who said that the decedent received hospice services at the right time had fewer concerns about not receiving enough information about the treatment of symptoms, about what to expect while the person was dying, and about what to do at the time of death. Similarly, these family members reported fewer unmet needs in terms of spiritual and emotional support before death.

The mean quality of care rating across the four quality items for family members of persons receiving hospice services at the right time was 34.3, compared with a mean score of 31.6 for family members of persons who did not receive hospice services. After adjustment for demographic characteristics, family members of people with dementia who received hospice services had higher overall ratings of the quality of care (AOR = 2.30, 95% CI = 1.69–3.13). Respondents whose family member received hospice services at the right time reported a higher rating of the quality of care for each of the four items that composed the scale.

Family members rated the peacefulness of dying and overall quality of dying using a 1 to 10 rating scale. Families of people who received hospice services gave higher ratings of peacefulness of dying than families of people who did not receive hospice services (mean 1.2 vs 1.8, $P = .004$; 1 = very much at peace) and believed there was higher quality of dying (8.8 vs 8.4, $P = = .008$, 10 = a very good death). As shown in Table 2, both of these results persisted after adjustment for state and sociodemographic characteristics.

DISCUSSION

The current policy debate has focused on the rising Medicare costs for hospice services, especially persons with dementia who receive hospice services in the nursing home setting. There have also been concerns about whether these services duplicate existing care provided by the nursing home and whether these services offer an additional benefit for people who are dying and their family members. This is the first study that provides evidence that the provision of hospice services, especially when they are initiated “at the right time” for persons with dementia, improve family members’ perceptions of the quality of care. Consumer perceptions, in this case from bereaved family members, are an important measure of whether the care is patient and family centered. Hospice services were associated with fewer unmet needs, fewer reported concerns with the quality of care, and higher family ratings of the quality of care. Additionally, family members reported that decedents who received hospice services had better quality of dying than those who did not receive hospice services.

There are several limitations to this study that should be considered when examining the findings. First, the survey relied on family members and their perceptions of care. In the case of persons with advanced dementia, only family members can be interviewed, and not the person with dementia. Nevertheless, end-of-life care affects not only people who are dying, but surviving family members as well. Second, the survey sample was drawn from only five states, which were selected based on their rates of feeding tube insertions in people with dementia because that was the primary focus of the original study. Consequently, the results may not be generalizable to other parts of the country. Third, only 70.7% of located family members agreed to participate in the survey. Fourth, cases were sampled based on death certificates listing cause of death as dementia. The potential bias is that only cases in which a physician recognized dementia as cause of death were studied, and thus, the rate of concerns and unmet needs may have been underestimated.

The results of the study are in contrast to those of previous smaller studies that suggested that hospice did not result in improvement in pain management,[12] unmet needs, or family member ratings of the quality of care.[13] Rather, the current study found that family members who reported receiving hospice services at the right time reported fewer unmet needs and concerns with quality of care. The individual items of the composite quality-of-care problem score best illustrate the differences in family member perceptions of the quality of quality of care. For example, nearly three times as many family members of decedents who died without hospice services reported that they believed that their dying relative needed more help with management of their dyspnea.

The two measures that relied on rating scales did not show a similar magnitude of association with hospice services. In part, this reflects previous research that has found that satisfaction measures that use rating questions are often skewed. The use of consumer ratings of the quality of care have been plagued with the concern of high satisfaction even though the respondent reported important quality-of-care concerns such as severe pain.[22–24] These important concerns with current satisfaction measures have led to the development of new strategies to measure decedent and family perspectives on the quality of medical care. Patient-centered surveys of medical care[25] ask a factual question (e.g., “Did someone speak to you about treatment of pain?”) or ask a person to judge one specific aspect of his or her medical treatment (e.g., “Were you told the purpose of your medications in a way that you could understand?”).[25] In the development of patient-centered reports, questions were framed “to be as specific as possible, to minimize the influence of confounding factors such as the person’s expectations, personal relationship, gratitude, or response tendencies related to gender, class or ethnicity.”[25]

The results of the current study are consistent with the results of a randomized controlled trial that improved access to hospice in the nursing home and found that family members whose loved ones received hospice services reported greater overall satisfaction.[26] Additionally, the current results are consistent with previous published research that found that families of persons referred to hospice “too late” report more concerns with the quality of care and unmet needs. Although only a few respondents reported that residents were referred to hospice services “too late,” findings show that timely referral to hospice services is related to perceived quality of care.[21,27] Therefore, it is not only receipt of hospice services, but also whether the family member believes that they received hospice services in a timely manner that is an important quality concern.

CONCLUSION

The recent public policy debate on the provision of hospice services to persons with dementia whose last place of care is a nursing home raises important unanswered questions about the effectiveness of hospice services. The current research provides evidence of better family member perceptions of quality of care and quality of the dying experience. These results, in conjunction with research findings of the important concerns with the quality of end-of-life care in nursing homes[2,4,6] and the preliminary evidence that hospice reduces terminal hospitalizations,[28] justify the continued payment for hospice services for nursing home residents who are dying of progressive chronic illnesses such as dementia.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Decedent and Respondent Demographic Characteristics

	n (%)		
Characteristic	**Without Hospice n = 278**	**Received Hospice "At the Right Time" n = 208**	**Received Hospice "Too Late" n = 33**
Site of death			
Hospital	67 (24.1)	26 (12.5)	3 (9.1)
Nursing home	208 (74.8)	146 (70.2)	26 (78.8)
Assisted living facility	3 (1.1)	23 (11.1)	2 (6.1)
Inpatient hospice facility	0 (0.0)	13 (6.2)	2 (6.1)
Decedent ethnicity			
Non-Hispanic white	222 (80.1)	174 (83.6)	28 (84.9)
Non-Hispanic black	35 (12.6)	16 (7.7)	1 (3.0)
Hispanic	12 (4.3)	15 (7.2)	3 (9.1)
Other	8 (2.9)	4 (1.8)	1 (3.0)
Respondent sex			
Male	97 (35.0)	71 (34.1)	5 (15.2)
Female	180 (65.0)	137 (65.9)	28 (84.9)
Respondent relationship to decedent			
Spouse	29 (10.4)	24 (11.4)	4 (12.1)
Child	168 (60.4)	133 (64.0)	23 (69.7)
Sibling	11 (4.0)	3 (1.4)	0 (0.0)
Other relative	65 (23.4)	45 (21.6)	6 (18.2)
Other	5 (1.8)	3 (1.4)	0 (0.0)
Respondent education			
<High school	16 (5.8)	10 (4.8)	1 (3.1)
High school graduate	70 (25.4)	43 (20.8)	6 (18.8)
Some college	94 (34.1)	59 (28.5)	14 (43.8)
4-year college graduate	38 (13.8)	45 (21.7)	4 (12.5)
>4-year college	58 (21.0)	50 (24.2)	7 (21.9)

Results are presented only for family members who stated that the decedent did not receive hospice services, received hospice services at the right time, or received hospice services too late. The four persons who stated that hospice was referred "too early" and the 15 who did not answer the question about the timing of hospice services were not reported in this table.

Table 2

Quality of Care and Quality of Dying in Decedents with and without Hospice

Outcome	Non-Hospice (n = 278)	Hospice (n = 208)	Hospice, Too Late (n = 33)	Adjusted Odds Ratio (95% Confidence Interval)[*]
Overall problem score, mean (range 0–8)[†]	1.2	0.74	2.7	0.49 (0.33–0.74)
Components of the problem score, % with component				
Unmet need for management of pain	11.7	7.0	28.6	0.51 (0.18–1.45)
Unmet need for management of dyspnea	19.1	6.1	31.3	0.22 (0.10–0.54)
Patient was always treated with respect	81.6	79.9	57.6	1.00 (0.62–1.57)
Family wanted more information on what to expect while patient was dying	22.5	11.1	48.5	0.41 (0.23–0.70)
Family wanted more information regarding how pain was managed	16.9	8.1	31.8	0.54 (0.29–1.00)
Family wanted more information on what to do at time of death	25.1	11.8	51.5	0.34 (0.23–0.53)
Family wanted more help regarding spiritual and religious concerns	10.6	7.3	21.2	0.64 (0.37–1.10)
Family wanted more emotional support regarding their grief before patient's death	22.7	14.0	43.8	0.50 (0.36–0.70)
Rating of quality of care, mean[‡]	31.6	34.3	25.4	2.30 (1.69–3.13)
Provided medical care that respected medical wishes, %	8.2	8.8	7.2	1.94 (1.48–2.57)
Symptoms were controlled to desired level, %	8.2	8.7	6.6	1.54 (1.10–2.15)
Emotional support provided to patient and family, %	7.4	8.1	5.5	2.00 (1.36–2.83)
Communicate with family about medical condition, %	7.7	8.5	5.8	2.30 (1.59–3.34)
Peacefulness of dying (1 = very much at peace, 10 = very much not at peace)	1.8	1.1	2.4	0.51 (0.35–0.74)
Quality of dying (1 = a very poor death, 10 = a very good death)	8.4	8.9	7.5	1.68 (1.11–2.56)

[*] Results compare persons receiving hospice at the right time with those who did not receive hospice after adjusting for state, age, sex, race, respondent relationship, and years of education.

[†] Overall problem score is based on 8 items that measure whether the family member had a concern with the quality of care or an unmet need.

[‡] Based on four items that ask the respondent to rate care between 0 (the worst care) and 10 (the best care). The four items are added to create a score between 0 and 40.