Hospice Care for Patients with Dementia

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Abstract
Dementia is a leading cause of death in the USA. Although guidelines exist to determine hospice eligibility for dementia, only a small percentage of patients dying with this condition receive hospice care. Hospice recipients with dementia have not been well characterized, and little is known about the quality of care they receive. The Family Evaluation of Hospice Care (FEHC) survey was adopted by the National Hospice and Palliative Care Organization (NHPCO) in 2003 as a standard benchmarking tool. The FEHC collects data from bereaved families regarding the quality of hospice care. An online repository of 2005 FEHC data was used to describe hospice recipients over 65 years of age who died with dementia and to examine their families’ evaluation of hospice care. Decedents with cancer and chronic terminal conditions were also analyzed for comparison purposes. A total of 77,123 surveys submitted by 796 hospices nationwide met the study’s eligibility criteria. Decedent diagnoses were as follows: dementia, n = 8,686 (11.3%); cancer, n = 35,693 (46.3%); and other chronic diseases, n = 32,744 (42.4%). Decedents with dementia were more likely to be >85 years, female, and have length of stays >180 days. Evaluation of care in all FEHC domains did not significantly differ between groups. Approximately three-quarters of bereaved family members of decedents in all groups perceived the overall quality of care as excellent; however, opportunities to improve care were also identified. These data suggest that the evaluation of hospice care for older patients is generally high, and does not vary with respect to terminal diagnoses.

Introduction
In 2004, Alzheimer’s disease was the fifth leading cause of death among Americans older than 65 years. The mortality rate due to Alzheimer’s disease is increasing faster than any other leading fatal condition. Although recent initiatives have highlighted the need to
improve end-of-life care, surprisingly little effort has focused on the growing number of Americans dying with dementia. A small, but emerging body of data suggests that the end-of-life experience of this population is not optimal.3–5

Hospice is a key provider of palliative care for Americans who are near the end of life. Dying patients and their families have been shown to benefit from hospice by experiencing better pain control, fewer terminal hospitalizations and invasive treatments, and greater overall satisfaction with end-of-life care.6–9 Hospice was originally designed to care for persons dying with cancer, which remains the most common diagnosis among recipients. Prior reports indicate that only 1%–4% of hospice recipients in the community10 and 7%–16% in nursing homes have a primary diagnosis of dementia.6,7,11 Several recognized barriers to hospice enrollment for dementia patients include challenges estimating six month prognosis,3,12–15 lack of recognition of dementia as a terminal condition,3,4,16 and accessibility of hospice services in nursing homes.6,7,11 In addition, the clinical problems encountered in advanced dementia are unique (i.e., symptom control in the cognitively impaired, behavior problems, reliance on substitute decision making). Whether or not hospice meets the specific palliative care needs in advanced dementia has not been well studied.

A first step toward improving hospice services for dementia patients is to better understand the quality of care hospices currently provide to this population. Prior work has demonstrated that families provide valuable feedback not only about the patients’ dying experience, but also about their own experiences during this time.17 Thus, this study examined a repository of over 120,000 surveys collected nationwide in 2005 from bereaved family members’ whose loved ones received hospice care at the end of life.18 The objectives were to characterize hospice recipients who died with dementia and to describe their family’s evaluation of hospice care. Two comparative groups were identified to contrast the experience of dementia decedents to that of older persons with other common terminal illnesses, specifically cancer and end-stage chronic diseases (e.g., cardiovascular, pulmonary, and kidney disease).

Methods

The conduct of this study was approved by the Institutional Review Board at Hebrew SeniorLife.

Data Sources

Data describing hospice decedents, their family members, and the family’s experience with hospice care were obtained from Family Evaluation of Hospice Care (FEHC) surveys collected between January 1, 2005 through December 31, 2005 by the National Hospice and Palliative Care Organization (NHPCO).18 The NHPCO is a nonprofit organization that represents 80% of hospices nationwide (≈3000). In 2003, the NHPCO adopted the FEHC as a standard tool for benchmarking and quality improvement purposes.18 The FEHC questionnaire examines the quality of hospice care from the bereaved family’s perspective. Although the NHPCO has encouraged all hospices to implement the FEHC, participation is voluntary. Approximately, 819 hospices from 51 states, the District of Columbia, and Puerto Rico used the FEHC in 2005 and contributed data to this study. FEHC data are collected either by an individual hospice or by a hired vendor. The latter method is preferred to encourage candid reporting. Family members are contacted one to three months after the patient’s death to solicit their participation. Surveys are conducted by mail and take approximately 20 minutes to complete. The NHPCO maintains a web site for individual hospices to electronically submit their data to a common repository.

To compare the characteristics of hospice programs and recipients that participated in the FEHC survey with those from hospices nationwide, data were obtained from a published Medicare Payment Advisory Commission (MedPAC) report.19 This report included the following demographic characteristics describing 68,725 hospice recipients across the United States based on Medicare claims data: age, gender, race, and diagnosis (cancer vs. noncancer). In addition, the report describes features of approximately 2,895 US hospices in terms of type (i.e., freestanding, hospital-based, or home health agency) and profit vs. nonprofit status.
Study Population

The study sample was identified and characterized using FEHC data provided by bereaved family members who responded to the survey. Respondents were asked to choose the primary illness leading to hospice referral from a list of diseases (i.e., close-ended question). Based on their responses, hospice recipients with the following conditions were selected: 1) dementia (Alzheimer’s disease or other), 2) cancer (all types), and 3) chronic diseases. Chronic diseases included the following: heart and circulatory diseases, lung and breathing diseases, kidney diseases, liver diseases, strokes, and frailty/decline due to old age. Decedents whose primary reason for hospice referral was AIDS or unknown were excluded. As dementia primarily affects older persons, decedents younger than 65 years of age at the time of death were also excluded.

Other decedent characteristics obtained from the FEHC included age at death, gender, education (≥high school education), race (white vs. other), and length of hospice stay. For analytic purposes, decedent age was dichotomized at ≥85 years, and length of stay in hospice was categorized as follows: 0–7, 8–29, 30–180, and >180 days.

Respondent variables were also obtained from the FEHC survey, including age (14–44, 45–54, 55–64, 65–74, and ≥75 years), gender, education (≥high school education), and race (white vs. other). The FEHC asks respondents to identify their relationship to the decedent as one of the following: spouse, partner, child, parent, sibling, other relative, friend, or other. Based on the distribution of this variable, relationship to decedent was further categorized as spouse, child, or other for these analyses. Finally, respondents were asked to state whether they felt the timing of hospice referral was too early, at the right time, or too late.

Hospice Program Characteristics

Individual hospices provide descriptive program information when they first access the NHPCO web site to submit FEHC data and are prompted to update this information each time they submit data. Several hospice characteristics obtained from the FEHC database were used in this study. The type of hospice was categorized as freestanding, hospital-based, home health agency-based, or other (e.g., health care plan, Veteran’s Administration, prison). Hospices were designated as for profit or not for profit. Location was categorized as either rural or urban by linking hospice zip codes with the 2005 Area Resource File (ARF).20 The ARF is a county-based national health resource information database that provides an urban/rural designation for regions throughout the United States.

The average daily census for each hospice was provided on a quarterly basis. Census data reported in the second quarter of 2005 were arbitrarily chosen for these analyses and categorized as follows: <50, 51–100, 101–250, and >250 hospice recipients. The volume of dementia patients served by the individual hospices was estimated by calculating the proportion of all decedents who had a primary diagnosis of dementia based on the FEHC survey responses. The volume of dementia patients was dichotomized as ≥10%, as this value included approximately half of all hospices.

Finally, the survey response rate was reported at each quarter by the hospices (i.e., proportion of mailed surveys that were completed and returned by respondents). For these analyses, a mean annual response rate was calculated for each hospice by averaging the four quarterly response rates in 2005. Hospices whose mean annual survey response rate was <20% were excluded, as the investigators considered this value to be a reasonably low threshold of survey response to warrant exclusion (n = 23 hospices). The main outcomes of the study were then examined using several cutoff values for mean annual response rates (i.e., 20%, 30%, 40%, 50%, and 60%). Given that the main findings of the study did not differ based on these cut-points, all hospices with response rates ≥20% were included. However, hospice annual survey response rate was also analyzed as a covariate and categorized based on tertiles: 20%–38%, 39%–41%, and >41%.

FEHC

The FEHC survey is a modified version of the original After-Death Family Interview, a validated instrument measuring key palliative care outcomes based on a patient-focused, family-centered conceptual model.17,21 The FEHC survey contains 61 close-ended questions.
that are grouped into domains that can be administered separately and maintain psychometric integrity. Details of the FEHC survey contents and scoring scheme are described elsewhere. For the purposes of this study, the following domains were examined as follows: 1) coordination of care, 2) attending to family needs for information, 3) attending to family needs for support, and 4) provision of physical comfort and emotional support to the patient. In addition, a single question asked respondents to rate overall hospice care as being excellent, very good, good, fair, or poor.

Problem scores were used to quantify three domains: coordination of care, attending to family needs for information, and attending to family needs for emotional support. Problem scores sum the negative responses for a set of questions within a domain. Thus, higher problem scores represent more opportunities to improve care. For example, the coordination of care domain consisted of three questions, with a possible range of scores from 0 to 3. These three questions were the following: 1) how often did the family get confusing or contradictory information (always, usually, sometimes, or never) (a response of “always” or “usually” gets one point); 2) was one nurse identified as being in charge (yes/no), (a response of “no” gets one point); and 3) was there a problem with hospice doctors or nurses not knowing enough about the patient’s history (yes/no) (a response of “no” gets one point).

The domain examining the information needs of the family consisted of two separate problem scores: 1) information provided about the patient’s condition and what to expect during the dying process (two questions; problem score range 0–2), and 2) information provided about the treatment of symptoms (four questions; problem score range 0–4).

The domain examining the emotional needs of the family included four questions, with a possible problem score range of 0–4. All problem scores were dichotomized in the analyses into 0 vs. ≥1 (i.e., at least one problem) because the majority of respondents did not report any problems.

The domains examining the provision of physical comfort and emotional support to the patient examined whether or not the patient had unmet needs for three distressing symptoms: pain, dyspnea, and anxiety/sadness. For each symptom, respondents were asked whether the treatment provided to the patient was less than what was wanted, just the right amount, or more than what was wanted. In these analyses, an unmet need was defined as receiving less or more treatment than was wanted (i.e., undesirable), as opposed to just the right amount of treatment (desirable).

Analysis

The decedent was the unit of analyses throughout the study. Frequencies were used to describe the decedent characteristics, respondent characteristics, features of the hospice programs, and evaluation of hospice care using the aforementioned domains from the FEHC survey. Frequencies were calculated for all eligible decedents, as well as stratified by the three decedent groups (i.e., dementia, cancer, and chronic diseases). Chi-squared tests were used to detect statistically significant differences in decedent, respondent, and hospice program characteristics among the three groups. Mantel-Haenszel tests were used to determine if statistical differences among groups were present in the analyses examining the FEHC domains as outcome measures. However, due to the large sample size and potential for Type I errors, only proportions that differed by 5% between groups were considered clinically meaningful.

Although the proportion of missing values varied for each independent variable, the distribution of missing values for each variable did not significantly differ across disease groups. Several reasons accounted for these missing values, including the following: respondents did not answer a question; individual hospices chose not to include a particular set of questions in the survey; and the existence of logical skip patterns within the survey, primarily for the domain assessing unmet patient needs. For example, in reference to the logical skip patterns, if a decedent did not experience pain, then the respondent was instructed to skip the question about unmet needs for pain control. The proportion of missing values for the three variables assessing unmet needs were as follows: pain, 21%; dyspnea, 48%; and anxiety/sadness, 58%. In addition, several hospices opted not to include
respondent demographic questions in the survey; thus, approximately 28% of responses to these questions were missing. The proportion of missing values ranged from 0% to 11% for the remaining variables.

Results

There were 121,817 FEHC surveys submitted in 2005 to the NHPCO web site. Table 1 presents the characteristics of the hospice recipients and programs represented in this sample compared to those described in a recent nationwide MedPAC report. Hospice recipients <65 years comprised a greater proportion of hospice recipients in the survey cohort compared to the national sample (15.1 vs. 5.1%); however, this age group was excluded from our analyses. In addition, while all hospice recipients in this study were deceased, only 82.7% of those in the MedPAC sample had died. Otherwise, demographic features of the hospice programs and recipients who contributed data to the FEHC surveys were comparable to those in the MedPAC report.

From among the 121,817 available surveys, \( n = 611 \) (0.5%) were excluded because they were received from hospices with an annual response rate below 20% \( (n = 23/819 \text{ hospices}) \). After excluding decedents younger than 65 years of age \( (n = 16,458) \), those who died from AIDS \( (n = 217) \), and those for whom the primary diagnosis for hospice referral was unknown \( (n = 26,299) \), 77,123 surveys were available for analyses \( (n = 109 \text{ subjects were excluded for more than one reason}) \). The primary illnesses leading to hospice referral among these 77,123 decedents were: dementia, \( n = 8,686 \) (11.3%); cancer, \( n = 35,693 \) (46.3%); and other chronic diseases, \( n = 32,744 \) (42.4%).

Decedent Characteristics

Several characteristics differentiated hospice recipients with dementia from those with cancer and chronic diseases (Table 2). The proportion of decedents older than 85 years was significantly greater in the dementia group (57.2%) compared to the cancer group (23.1%). Hospice recipients with dementia were also more likely to be female (68.9%) compared to those dying with cancer (49.3%) and chronic diseases (58.8%). In addition, a significantly greater proportion of decedents with a primary diagnosis of dementia had a length of stay exceeding 180 days (13.7%), compared to those with cancer (5.3%) and chronic diseases (8.5%). Race and education did not meaningfully differ among groups (i.e., >5.0%), with the majority of all decedents being white and having at least a high school education.

Respondent Characteristics

The characteristics of survey respondents were comparable among all three decedent groups with respect to age, gender, education, and race (Table 2). The relationship of the respondents to the hospice recipients was similar between the dementia and chronic disease groups, such that slightly more than half were the decedents’ children, and one-quarter were spouses. In contrast, survey respondents in the cancer group were more likely to be spouses (45.2%), and less likely to be children...
The respondents’ perception regarding the timing of hospice referral was similar across all groups; the majority felt the timing was about right (88.0%), 1.3% felt it was too early, and 10.8% felt the referral occurred too late.

### Table 2
Decedent, Family, and Hospice Program Characteristics for Hospice Decedents ≥65 years with Dementia (n = 8,686), Cancer (n = 55,693), and Chronic Diseases (n = 32,744)

<table>
<thead>
<tr>
<th>Decedent Group</th>
<th>All (n = 77,123)</th>
<th>Dementia (n = 8,686)</th>
<th>Cancer (n = 55,693)</th>
<th>Chronic Disease (n = 32,744)</th>
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<tbody>
<tr>
<td><strong>Decedent characteristics (%)</strong></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Age, &gt;85 years</td>
<td>40.0</td>
<td>57.2</td>
<td>23.1</td>
<td>53.8</td>
</tr>
<tr>
<td>Female (%)</td>
<td>44.5</td>
<td>68.9</td>
<td>49.3</td>
<td>58.8</td>
</tr>
<tr>
<td>Education, ≥high school</td>
<td>69.9</td>
<td>69.6</td>
<td>73.1</td>
<td>66.5</td>
</tr>
<tr>
<td>White race</td>
<td>93.9</td>
<td>94.0</td>
<td>93.2</td>
<td>94.6</td>
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<tr>
<td>Length of hospice stay (days)</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>0–7</td>
<td>31.8</td>
<td>27.9</td>
<td>26.5</td>
<td>38.5</td>
</tr>
<tr>
<td>8–29</td>
<td>26.5</td>
<td>24.3</td>
<td>28.9</td>
<td>24.5</td>
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<tr>
<td>30–180</td>
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<td>34.0</td>
<td>39.3</td>
<td>28.5</td>
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<td>&gt;180</td>
<td>7.6</td>
<td>13.7</td>
<td>5.3</td>
<td>8.5</td>
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<td><strong>Family characteristics</strong></td>
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<tr>
<td>Age (years)</td>
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<tr>
<td>14–44</td>
<td>7.4</td>
<td>5.2</td>
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<td>6.2</td>
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<td>45–54</td>
<td>19.6</td>
<td>19.3</td>
<td>20.4</td>
<td>18.8</td>
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<td>55–64</td>
<td>27.6</td>
<td>32.8</td>
<td>22.9</td>
<td>31.4</td>
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<td>65–74</td>
<td>23.9</td>
<td>20.5</td>
<td>25.6</td>
<td>22.9</td>
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<tr>
<td>≥75</td>
<td>21.5</td>
<td>22.3</td>
<td>22.1</td>
<td>20.7</td>
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<tr>
<td>Female</td>
<td>73.4</td>
<td>69.7</td>
<td>73.4</td>
<td>74.2</td>
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<tr>
<td>Education, ≥high school</td>
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<td>93.7</td>
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<tr>
<td>White race (vs. other)</td>
<td>94.1</td>
<td>94.4</td>
<td>93.5</td>
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<td><strong>Relationship to patient</strong></td>
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<tr>
<td>Spouse</td>
<td>35.6</td>
<td>26.5</td>
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<td>Child</td>
<td>45.7</td>
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<td>51.9</td>
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<tr>
<td>Other</td>
<td>18.6</td>
<td>20.2</td>
<td>16.6</td>
<td>20.5</td>
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<tr>
<td><strong>Feels timing of hospice referral was</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Too early</td>
<td>1.3</td>
<td>1.6</td>
<td>1.2</td>
<td>1.2</td>
</tr>
<tr>
<td>About right</td>
<td>88.0</td>
<td>86.9</td>
<td>88.8</td>
<td>87.3</td>
</tr>
<tr>
<td>Too late</td>
<td>11.7</td>
<td>11.5</td>
<td>10.0</td>
<td>11.5</td>
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<tr>
<td><strong>Hospice characteristics</strong></td>
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<td></td>
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<tr>
<td>Average daily census</td>
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<td></td>
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<tr>
<td>&lt;50</td>
<td>18.0</td>
<td>14.5</td>
<td>19.1</td>
<td>17.8</td>
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<tr>
<td>51–100</td>
<td>28.0</td>
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<tr>
<td>101–250</td>
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<td>26.9</td>
<td>27.8</td>
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<td>&gt;250</td>
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<td>26.4</td>
<td>26.4</td>
<td>25.3</td>
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<tr>
<td>For profit</td>
<td>13.8</td>
<td>22.9</td>
<td>10.8</td>
<td>14.6</td>
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<tr>
<td>Urban (vs. rural)</td>
<td>87.1</td>
<td>90.2</td>
<td>86.5</td>
<td>87.0</td>
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<tr>
<td>Volume of dementia patients, &gt;10%</td>
<td>55.8</td>
<td>72.2</td>
<td>51.1</td>
<td>56.6</td>
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<tr>
<td>Mean annual survey response rate</td>
<td></td>
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<td></td>
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<tr>
<td>20–38</td>
<td>29.2</td>
<td>34.5</td>
<td>27.9</td>
<td>29.3</td>
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<tr>
<td>38–41</td>
<td>34.2</td>
<td>32.0</td>
<td>34.7</td>
<td>34.1</td>
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<tr>
<td>&gt;41</td>
<td>36.8</td>
<td>33.5</td>
<td>37.4</td>
<td>36.6</td>
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<tr>
<td><strong>Type</strong></td>
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<td></td>
<td></td>
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<tr>
<td>Freestanding</td>
<td>62.1</td>
<td>69.7</td>
<td>60.1</td>
<td>62.3</td>
</tr>
<tr>
<td>Hospital</td>
<td>24.2</td>
<td>19.0</td>
<td>25.6</td>
<td>24.0</td>
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<tr>
<td>Home health agency</td>
<td>9.5</td>
<td>7.5</td>
<td>10.2</td>
<td>9.4</td>
</tr>
<tr>
<td>Other</td>
<td>4.2</td>
<td>3.8</td>
<td>4.1</td>
<td>4.3</td>
</tr>
</tbody>
</table>

*All characteristics differed significantly among the three groups at a P-value <0.001 using Chi-squared tests.*

Hospice characteristics
Decedents with dementia were more likely to receive care from for-profit (22.9%) and freestanding (69.9%) hospices compared to those dying with cancer (for profit, 10.8%;
freestanding, 60.1%) and chronic diseases (for profit, 14.6%; freestanding 62.3%) (Table 2). In contrast, hospice recipients with cancer and chronic diseases were more likely to be in hospital-based hospices. Not surprisingly, subjects dying with dementia also had a higher likelihood of being cared for by hospices in which the volume of dementia decedents exceeded 10%. The hospices’ average daily census, location (i.e., urban vs. rural), and mean annual survey response rates were similar among all three decedent groups.

**Evaluation of Hospice Care**

The majority of survey respondents rated overall hospice care as excellent regardless of the decedents’ primary diagnoses (dementia, 73.2%; cancer, 77.9%; and chronic conditions, 75.6%) (Table 3). Similar proportions of respondents in all groups reported at least one problem with coordination of care (17.5%), information received from health care providers regarding the patients’ overall condition (20.1%), information received about treatment of the patients’ symptoms (12.2%), and the provision of emotional support to the family (29.8%). Unmet patient needs for the treatment of symptoms were less frequent, and also comparable in all decedent groups (pain, 5.5%; dyspnea, 4.7%, and anxiety/sadness, 9.3%).

**Discussion**

In this nationwide study, while only 11% of hospice decedents had dementia, their families’ evaluation of hospice care was similar to that experienced for more common hospice diagnoses (i.e., cancer and chronic end-stage organ failure). Although the majority of respondents rated hospice care as excellent, problems with specific services were not infrequent. For example, approximately one in three families expressed a concern regarding the emotional support they received from hospice providers, and one in five felt they were not adequately informed about what to expect during the dying process. These findings not only demonstrate that the quality of hospice care for terminally ill older patients and their families is perceived to be high, regardless of diagnosis, but also that opportunities for improvement exist.

Comparability of this study to prior reports describing hospice recipients, and specifically those with dementia, is limited because much

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**Table 3**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Decedent Group (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All (n = 77,123)</td>
</tr>
<tr>
<td>Overall hospice care</td>
<td></td>
</tr>
<tr>
<td>Excellent</td>
<td>76.4</td>
</tr>
<tr>
<td>Very good</td>
<td>18.0</td>
</tr>
<tr>
<td>Good</td>
<td>4.0</td>
</tr>
<tr>
<td>Fair</td>
<td>1.0</td>
</tr>
<tr>
<td>Poor</td>
<td>0.6</td>
</tr>
<tr>
<td>Coordination of care</td>
<td></td>
</tr>
<tr>
<td>At least one problem</td>
<td>17.5</td>
</tr>
<tr>
<td>Information provided by health care providers</td>
<td></td>
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<tr>
<td>Patient’s condition/what to expect</td>
<td></td>
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<tr>
<td>At least one problem</td>
<td>20.1</td>
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<tr>
<td>Treatment of symptoms</td>
<td>12.2</td>
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<tr>
<td>Emotional support for family</td>
<td></td>
</tr>
<tr>
<td>At least one problem</td>
<td>29.8</td>
</tr>
<tr>
<td>Unmet patient needs</td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td>5.5</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>4.7</td>
</tr>
<tr>
<td>Emotional</td>
<td>9.3</td>
</tr>
</tbody>
</table>

aMantel-Haenszel test.
bChronic diseases include end-stage cardiovascular, pulmonary, and renal diseases.
of this earlier work was done before 2005, 

includes patients receiving ongoing hospice care 
(i.e., not only decedents), examines selected 
settings (i.e., community or nursing home), 
and is restricted to specific regions in the 
United States. Nonetheless, the characteris-
tics of the hospice decedents and pro-
grams in this sample were similar to those 
described in a recent MedPAC report for Medi-
care beneficiaries nationwide. In particular, 
our study confirms that dementia, compared 
to cancer, remains a far less common terminal 
condition among older hospice decedents, de-
spite the publication of specific hospice eligi-
bility guidelines for noncancer diagnoses in 
1996. However, our findings also support ob-
servations indicating a steady increase in end-
stage dementia as a primary diagnosis leading 
to hospice referral over the past decade. 

For example, two large studies from 1990 
found that only 1%-4% of hospice enrollees 
had dementia, as compared to 11% in 
our sample. 

To be eligible for hospice, patients must 
have an estimated life expectancy of less than 
six months. Prognostication is particularly 
challenging in end-stage dementia, such that 
this requirement has hindered access and 
appropriate timing of hospice referrals for 
dementia patients. The final stage of 
dementia also tends to be longer compared 
to terminal cancer. Thus, we found, as have 
others, that hospice stays exceeding 180 days 
were significantly more common among hospice 
decedents with dementia. Miller et al. reported that 12% of nursing home hospice recipients with dementia had lengths of stay greater than 210 days compared to only 9% of those with cancer. While long length 
of stays may be problematic from the perspec-
tive of hospice providers, it is notable that 
in our study only 1.6% of family members of 
dementia decedents felt that hospice referral 
occurred too early, which was comparable to 
the other disease groups. 

Approximately 70% of Americans older than 
65 years with dementia die in nursing homes, 
as compared to only 21% of those dying with 
cancer, and 28% with other chronic diseases. 
Moreover, the proportion of hospice recipients 
with dementia in the nursing home setting 
exceeds that in the community. The FEHC 
survey does not identify the site of hospice 
care. However, it is reasonable to assume that 
dementia decedents in our sample were 
more likely to be cared for by for profit and 
freestanding hospices, because these organiza-
tional features tend to be more common 
among hospices that provide services in nurs-
ing homes compared to those that do not. 

Several prior reports confirm that families’ 
overall evaluation of hospice care is generally 
high. Bekelman extended this observation 
to dementia patients. However, no prior study 
known to us has directly compared satisfac-
tion with hospice care for dementia to other 
decedent groups. Our findings are encourag-
ing as they suggest that hospice providers are 
able to meet the unique challenges of end-of-
life care in dementia, at least as well as they 
do for the more common diagnoses among 
hospice recipients. However, this study further 
underscores opportunities for hospice to bet-
ter address the needs of patients and families. 

Approximately 70% of Americans older than 
65 years with dementia die in nursing homes, 
as compared to only 21% of those dying with 
cancer, and 28% with other chronic diseases. 

Finally, the site of hospice care (i.e., nurs-
ing home, home) was not available. It is rea-
sionable to assume that a larger proportion of 
dementia decedents received hospice services 
in nursing homes. However, it is unlikely that 
site of care was a confounder in the analyses
because the main outcome measures did not differ across disease groups.

Hospice services have been shown to be beneficial for persons dying with dementia, and our findings further demonstrate that satisfaction with these services is comparable to other terminal conditions. Nonetheless, a relatively small proportion of persons dying with advanced dementia receive hospice care. Thus, our results suggest that current hospice care appears to manage the specific problems in end-stage dementia with reasonable success as perceived by family members, and support efforts toward improving the delivery and quality of hospice services to the growing number of Americans dying with dementia.

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References


