Original Article

Hospice Care in a Cohort of Elders with Dementia and Mild Cognitive Impairment

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Abstract

The objectives of this study were to identify the characteristics associated with hospice enrollment, to determine whether enrollment in hospice was associated with less pain and psychiatric symptoms, and to assess caregiver satisfaction with care near death in a sample of patients with dementia and mild cognitive impairment (MCI). Participants included decedents with dementia or MCI and other medical illnesses whose deaths were expected (n = 81) during a 3-year prospective, longitudinal, community-based cohort study. A total of 29.6% (n = 24) of participants received hospice care prior to death. Participants in hospice experienced less pain compared to those not in hospice, but this did not reach statistical significance (41.7% vs. 62.5%, \( P = 0.085 \)). They were 65% more likely to be free of psychiatric symptoms (including restlessness, sleep problems, agitation, nervousness, and aggression toward others) during their final illness prior to death (OR = 0.35; 95% CI 0.13–0.96). In this cohort of people with dementia and MCI who died, several markers of quality of care suggest that hospice care can be beneficial for patients with dementia or MCI. J Pain Symptom Manage 2005;30:208–214. © 2005 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Dementia, hospice, symptoms, pain, mild cognitive impairment

Introduction

The predicted increase in both prevalence and in absolute numbers of people with dementia over the next 50 years concerns policymakers and providers who are now compelled to consider how people with dementia will be cared for at the ends of their lives.\(^1\) Hospice care has been suggested as a means for quality end-of-life care for patients with advanced dementia.\(^2\) It is proposed to be of specific benefit to patients with dementia because of its emphasis on supportive care (including support for family), quality of life, aggressive symptom control, attention to formulating goals of care that guide medical decision making, creation of a comfortable
end-of-life experience, and bereavement services. Palliative care for dementia is strongly favored by health care providers and families of patients with dementia.

In spite of the many potential benefits, the percent of patients in hospice who were enrolled for advanced dementia was reported in 1995 to be less than 1%. More recent data from the 2000 National Home and Hospice Care Survey show that patients with a primary diagnosis of dementia comprise 6% of admissions. Multiple barriers limit the number of patients admitted to hospice for advanced dementia. Medicare guidelines require a 6-month prognosis for admission to hospice. Current prognostic tools for dementia are poor, although recent prospective studies may offer new prognostic guidance. To our knowledge, no studies have prospectively evaluated length of survival for patients admitted to hospice with dementia. In addition, little is known about the characteristics or quality of care received by patients with dementia who are in hospice.

The objectives of this study were to identify the characteristics associated with hospice enrollment, to determine whether enrollment in hospice was associated with less pain and psychiatric symptoms, and to assess caregiver satisfaction with care near death in a sample of patients with dementia and mild cognitive impairment (MCI) and other medical illnesses. We hypothesized that participants in this sample with dementia or MCI who were enrolled in hospice would be more likely to have cancer and would have a lower psychiatric symptom burden because of the hospice emphasis on symptom control compared to those who did not enroll in hospice.

Methods

Study Design

This study used data from the Memory and Medical Care Study (MMCS) conducted at the Johns Hopkins Medical Institutions. The MMCS is a community-based prospective observational cohort study of elders at risk for dementia conducted from 1998 to 2002. Detailed information on the study design and methods are available elsewhere.

Setting and Participants

Participants were identified from three previous population-based studies, two of which were conducted in the Baltimore, Maryland, area and the third in rural Maryland. These studies screened over 12,000 elders with the Mini-Mental State Examination (MMSE). Of the 1,802 participants scoring less than 24 on the MMSE or having a decline of 4 or more points over 2 administrations, 724 were alive and not institutionalized at the start of the MMCS. Of these, 512 (71%) were enrolled in the MMCS.

Participants were classified as having dementia (n = 349), mild cognitive impairment (MCI, n = 133), neither dementia nor MCI (n = 16), or indeterminate (n = 14) based on a neuropsychological battery of four tests. Three of the tests were from a battery used by the Consortium to Establish a Registry for Alzheimer’s Disease (CERAD): the Boston Naming Test, the Verbal Fluency Test, and the Word List Memory Test. The fourth measure was the Digit Symbol subscale of the Wechsler Adult Intelligence Scale-Revised. Using published age and education norms for these four tests, participants scoring at or below 2.0 standard deviations (SD) from the mean for normal subjects of matched age and education were classified as having dementia. Participants were classified as having MCI if they did not meet criteria for dementia and scored either: 1) at or below 1.5 SD from the mean on any one of the four tests, or 2) at or below 1.0 SD from the mean on at least two of the four tests. Details on why these criteria were used can be obtained elsewhere. During follow-up, degree of dementia was evaluated with the Telephone Interview for Cognitive Status (TICS), a validated telephone version of the MMSE that has good sensitivity and specificity for cognitive impairment. The TICS is scored from 0 to 41, is highly correlated with the MMSE (Pearson correlation = 0.94), and has high test-retest reliability (r = 0.97). A score below 31 suggests poor cognitive function.

Subjects with dementia or MCI were included in the study (n = 482). A knowledgeable informant (KI) was identified for each subject. These KIs completed baseline and follow-up interviews. The sample analyzed here consists of a subset of the sample of
subjects who had died \((n = 143)\) during the study and whose death was considered predictable or expected by KIs \((n = 89)\), that is, subjects for whom hospice care might have been appropriate. Of these 89 subjects, adequate follow-up data were available for 81 of them. When participants died, a special questionnaire was administered to KIs. This questionnaire included the following yes/no questions: “During [the patient’s] final illness, was he/she in pain? Was he/she experiencing any of the following problems: Restlessness? Sleep problems? Agitation or nervousness? Being aggressive with others?” The phrase “final illness” was used in order to ascertain presence of these systems close to death. Two-thirds of KIs completed the questionnaire within 6 months of patient deaths; all were completed within one year. Medical diagnoses were obtained from medical records and Medicare claims data.

Satisfaction with care was assessed in several ways. KIs were asked whether the study participant was seen by a doctor within the month prior to death, and if so \((n = 74)\), whether more could have been done to keep them comfortable during the final illness. They were also asked if treatment decisions would have changed if more information had been given to them and how they felt overall treatment quality was during the final illness.

The protocol was approved by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board. Informed consent was obtained from each subject or from the subject’s surrogate decision-maker if the subject was unable to give informed consent. All participants with surrogate decision-makers (all of whom were KIs) assented to participate. The KIs also gave informed consent to participate.

Statistical Methods

Data were analyzed using the Stata (Stata 8, 2003) statistical package. The associations between demographic characteristics, medical illnesses, and symptoms with enrollment in hospice were analyzed. Chi-square \((\chi^2)\) analysis with Fisher exact test when appropriate was used for categorical variables; independent-sample \(t\) tests were used to examine continuous variables. All comparisons were two-tailed and \(\alpha\) was set at 0.05. Participants with any psychiatric symptom of dementia (including restlessness, sleep problems, agitation, nervousness, or being aggressive with others) were compared to those without any symptoms to test the hypothesis that hospice care was associated with fewer symptoms.

Results

Characteristics of Patients with Dementia or MCI Associated with Hospice Enrollment

Of the 81 expected deaths, 24 (29.6%) received hospice care. Sociodemographic characteristics of this population are shown in Table 1. All of the participants were older than age 70. The mean age for hospice patients (86.7 yrs) was similar to that of non-hospice patients (85.3 yrs, \(P = 0.436\)). Over two-thirds of each group had less than a 12th-grade education. No significant differences

<table>
<thead>
<tr>
<th>Table 1 Characteristics of Participants</th>
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<tbody>
<tr>
<td>Characteristic</td>
</tr>
<tr>
<td>Age</td>
</tr>
<tr>
<td>70–79</td>
</tr>
<tr>
<td>80–89</td>
</tr>
<tr>
<td>90–99</td>
</tr>
<tr>
<td>&gt;100</td>
</tr>
<tr>
<td>Female n (%)</td>
</tr>
<tr>
<td>Non-white n (%)</td>
</tr>
<tr>
<td>Education n (%) yrs</td>
</tr>
<tr>
<td>&lt;12</td>
</tr>
<tr>
<td>≥12</td>
</tr>
<tr>
<td>Below poverty level (a) n (%)</td>
</tr>
<tr>
<td>Living alone (b) n (%)</td>
</tr>
<tr>
<td>Dementia n (%)</td>
</tr>
<tr>
<td>Mild Cognitive Impairment (MCI) n (%)</td>
</tr>
<tr>
<td>Cancer, n (%)</td>
</tr>
<tr>
<td>Mean TICS Score (\text{(measure of cognitive impairment)})</td>
</tr>
</tbody>
</table>

\(^a\)Based on household size. \n\(^b\)Data on some participants missing. \n\(^c\)P-value is for the comparison of dementia to MCI in hospice patients versus non-hospice patients.
were observed between hospice and non-hospice patients in sex, race, education, and percentage above/below poverty level. More patients in hospice lived alone (34.8%) compared to non-hospice patients (17.3%), although this was not statistically significant ($P = 0.096$).

Medical diagnoses of the participants within 6 months of death were examined to determine if they were associated with enrollment in hospice. A diagnosis of dementia compared to a diagnosis of MCI based on neuropsychological testing was not associated with placement in hospice. The mean TICS score was lower in the group in hospice, but this difference did not reach statistical significance. Having a diagnosis of cancer was associated with hospice care with an odds ratio of 4.08 (95% CI 1.04--16.4). Other illnesses, including cardiopulmonary illness (heart failure, COPD, ischemic heart disease), cerebrovascular disease, and hip fracture were not associated with hospice care.

**Pain and Psychiatric Symptom Control Near the End of Life**

The data on pain and psychiatric symptoms during patient’s final illness as reported by KIs are presented in Table 2. Participants in hospice had less pain compared to those not in hospice, but this did not reach statistical significance (41.7% vs. 61.4%, $P = 0.085$). When participants with any psychiatric symptom associated with dementia (including restlessness, sleep problems, agitation, nervousness, or being aggressive with others) were compared to those who were symptom-free, participants in hospice were 65% more likely to be symptom-free during their final illness prior to death (OR = 0.35; 95% CI 0.13--0.96).

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Hospice patients ($n = 24$)</th>
<th>Non-hospice patients ($n = 57$)</th>
<th>$P$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>10 (41.7)</td>
<td>35 (61.4)</td>
<td></td>
</tr>
<tr>
<td>Restlessness</td>
<td>10 (41.7)</td>
<td>28 (49.1)</td>
<td></td>
</tr>
<tr>
<td>Sleep problems</td>
<td>8 (33.3)</td>
<td>23 (40.4)</td>
<td></td>
</tr>
<tr>
<td>Agitation or nervousness</td>
<td>6 (25.0)</td>
<td>23 (40.4)</td>
<td></td>
</tr>
<tr>
<td>Being aggressive with others</td>
<td>5 (20.8)</td>
<td>9 (15.8)</td>
<td></td>
</tr>
</tbody>
</table>

*Table 2 Pain and Psychiatric Symptoms Near Death According to Hospice Enrollment*

Differences in each symptom between hospice and non-hospice patients were not significant.

**Duration of Hospice Care**

Data were available on hospice duration for 22 of the 24 participants who received hospice care. Median hospice duration was 38.5 days, the mean was 89.0 days, and the range was 1--304 days; 18.2% of hospice patients were enrolled in hospice for over 6 months. Median duration of hospice was 36.2 days (mean 73.8 days) for those with cancer receiving hospice care ($n = 8$) and 42.0 days (mean 97.8 days) for those receiving hospice care who did not have cancer ($n = 14$). Of hospice enrollees, 35.7% without cancer were in hospice care for 6 months or more compared to 12.5% with cancer ($P = 0.240$).

**Satisfaction with Care and Decision Making Near Death**

KIs reported that no more could have been done in 95.0% of the participants enrolled in hospice compared to 72.2% of those not enrolled in hospice ($P = 0.103$) (Table 2). For participants in hospice, 85.0% of KIs rated overall treatment by physicians/nurses as excellent or very good. Similar ratings were made of overall treatment of family members by physicians/nurses.

Regarding decision making in those enrolled in hospice, 90.0% of KIs felt that treatment decisions would not have changed if more information had been given to them, compared to 74% in the non-hospice population ($P = 0.456$). Of KIs in the hospice population, 15% wanted to be more involved with the participant’s care, compared to 31.5% of KIs in the non-hospice population ($P = 0.156$). A majority of participants in both groups had advance directives (Table 3). Of those who had any type of advance directive, 63.1% of KIs in the hospice group and 62.9% of KIs in the non-hospice group said it helped “a great deal.” One KI in the total sample (who was in the non-hospice group) said it caused some problems.

**Discussion**

In this prospective community sample of people with dementia or MCI and other comorbid medical illnesses, almost one-third (29.6%) of subjects who died and whose death was anticipated were enrolled in hospice care. The median length of stay in this sample (39
days) was longer than the median length of stay in hospice found in large databases (25–36 days).\textsuperscript{15} Median length of stay was even longer for patients in hospice without a diagnosis of cancer (42 days), and a large percent of hospice enrollees without cancer (35.7%) were in hospice for longer than 6 months. Our findings of longer lengths of stay for patients with dementia or MCI who did not have cancer are consistent with those found in the Christakis et al. sample.\textsuperscript{15} They found that Medicare beneficiaries enrolled in hospice programs for a diagnosis of dementia had a median survival of 74 days and 34.7% lived longer than 180 days. Of their total sample, 14.9% of hospice enrollees lived longer than 180 days. These numbers should be of concern to policy makers. The 6-month prognosis requirement for admission to hospice may be inadequate for people with dementia who do not have cancer. If hospice is chosen as a mode of care for advanced dementia, modifications may need to be made in eligibility criteria. The 6-month prognosis requirement for admission to hospice may be inadequate for people with dementia who do not have cancer. If hospice is chosen as a mode of care for advanced dementia, modifications may need to be made in eligibility criteria. The 6-month prognosis requirement for admission to hospice may be inadequate for people with dementia who do not have cancer. If hospice is chosen as a mode of care for advanced dementia, modifications may need to be made in eligibility criteria. The 6-month prognosis requirement for admission to hospice may be inadequate for people with dementia who do not have cancer. If hospice is chosen as a mode of care for advanced dementia, modifications may need to be made in eligibility criteria. The 6-month prognosis requirement for admission to hospice may be inadequate for people with dementia who do not have cancer. If hospice is chosen as a mode of care for advanced dementia, modifications may need to be made in eligibility criteria. The 6-month prognosis requirement for admission to hospice may be inadequate for people with dementia who do not have cancer. If hospice is chosen as a mode of care for advanced dementia, modifications may need to be made in eligibility criteria. The 6-month prognosis requirement for admission to hospice may be inadequate for people with dementia who do not have cancer. If hospice is chosen as a mode of care for advanced dementia, modifications may need to be made in eligibility criteria. The 6-month prognosis requirement for admission to hospice may be inadequate for people with dementia who do not have cancer. If hospice is chosen as a mode of care for advanced dementia, modifications may need to be made in eligibility criteria. The 6-month prognosis requirement for admission to hospice may be inadequate for people with dementia who do not have cancer. If hospice is chosen as a mode of care for advanced dementia, modifications may need to be made in eligibility criteria. The 6-month prognosis requirement for admission to hospice may be inadequate for people with dementia who do not have cancer. If hospice is chosen as a mode of care for advanced dementia, modifications may need to be made in eligibility criteria. The 6-month prognosis requirement for admission to hospice may be inadequate for people with dementia who do not have cancer. If hospice is chosen as a mode of care for advanced dementia, modifications may need to be made in eligibility criteria. The 6-month prognosis requirement for admission to hospice may be inadequate for people with dementia who do not have cancer. If hospice is chosen as a mode of care for advanced dementia, modifications may need to be made in eligibility criteria. The 6-month prognosis requirement for admission to hospice may be inadequate for people with dementia who do not have cancer. If hospice is chosen as a mode of care for advanced dementia, modifications may need to be made in eligibility criteria. The 6-month prognosis requirement for admission to hospice may be inadequate for people with dementia who do not have cancer. If hospice is chosen as a mode of care for advanced dementia, modifications may need to be made in eligibility criteria. The 6-month prognosis requirement for admission to hospice may be inadequate for people with dementia who do not have cancer.

Table 3

<table>
<thead>
<tr>
<th>Care and Decision Making Near Death</th>
<th>Hospice patients (n = 20)</th>
<th>Non-hospice patients (n = 54)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advance directive</td>
<td>19 (79.2)</td>
<td>35 (64.8)</td>
<td>0.205</td>
</tr>
<tr>
<td>Signed Living Will</td>
<td>13 (54.2)</td>
<td>28 (49.1)</td>
<td>0.510</td>
</tr>
<tr>
<td>Signed Durable Power of Attorney</td>
<td>18 (75.0)</td>
<td>31 (54.4)</td>
<td>0.169</td>
</tr>
<tr>
<td>Health Care</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: Pearson chi-square of all ratings. One missing value.

that dementia is independently associated with distress and psychiatric symptoms. In addition, the presence of dementia and cognitive impairment create challenges for pain and symptom assessment and treatment. The findings also suggest that caregivers observe these disturbing symptoms near the end of life in patients with dementia and MCI. This study found that hospice care was associated with a lower symptom burden, suggesting that patients in hospice had more effective symptom management near death.

Many of the participants in this study who had a diagnosis of dementia by neuropsychological testing did not have a diagnosis of dementia found in Medicare claims data or their medical record (Rabins et al., unpublished data). Thus, conclusions from this study pertain to persons with dementia determined by neuropsychological testing, not dementia recognized by a physician.

Increased severity of dementia as measured by cognitive status was not associated with an increased likelihood of enrollment in hospice. This is consistent with previous findings that dementia is not recognized as a “terminal illness” or an illness that would be appropriate for hospice referral.\textsuperscript{18} However, a sensitive, validated scale in the study measured dementia severity, and participants’ physicians or KIs may not have known about participants’ cognitive status. Furthermore, the study only included patients with some degree of cognitive impairment. A different result may be found when the association between cognitive status and hospice enrollment is compared in patients with and without dementia. Finally, the presence of cancer may be confounding this association in this study. The number of patients was too small to perform a stratified analysis by cancer status.

Several previous studies have addressed care for dementia near the end of life. Mitchell et al. used data from the Minimum Data Set to identify persons with advanced dementia and other medical illnesses (but not cancer) who died within 1 year of admission to any New York State nursing home.\textsuperscript{19} They concluded that residents with dementia were not perceived as having a terminal illness and did not receive optimum palliative care. In another retrospective study, patients with and without dementia who died in a variety of settings had
similar rates of antibiotic use and much lower rates of opioid analgesic medications. Volicer et al. conducted a retrospective survey of family caregivers of individuals with dementia and found that dying in the home was associated with fewer symptoms and less discomfort compared to dying in other settings. Medical comorbidities were not reported.

This study has several limitations. First, questions about hospice were only asked of participants whose deaths were “expected.” This resulted in a sample that was not representative of participants with dementia in the community who died. However, this approach excluded persons for whom hospice would not have been relevant. Second, the small sample size may have led to an inability to detect statistically significant differences. Third, questions about participants’ symptoms near the end of life were asked of surrogates rather than the patients themselves. However, surrogate reports have significant importance in evaluating the health status and quality of life of people with cognitive impairment near the end of life.

This study contributes to the literature on dementia and hospice by confirming the longer duration of hospice use by patients with dementia that has been observed in secondary data analyses of Medicare claims data in a prospective, longitudinal study. In addition, the findings of fewer symptom problems and high rates of satisfaction with hospice care raise the possibility that hospice may be beneficial for patients with dementia at multiple time points while in hospice.

Acknowledgments

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References


