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Original Study

Hospice Care for Patients With Dementia in the United States: A Longitudinal Cohort Study

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A B S T R A C T

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Background: Patients with dementia form an increasing proportion of those entering hospice care. Little is known about the types of hospices serving patients with dementia and the patterns of hospice use, including timing of hospice disenrollment between patients with and without dementia.

Objectives: To characterize the hospices that serve patients with dementia, to compare patterns of hospice disenrollment for patients with dementia and without dementia, and to evaluate patient-level and hospice-level characteristics associated with hospice disenrollment.

Methods: We used data from a longitudinal cohort study (2008–2011) of Medicare beneficiaries (n = 149,814) newly enrolled in a national random sample of hospices (n = 577) from the National Hospice Survey and followed until death (84% response rate).

Results: A total of 7328 patients (4.9%) had a primary diagnosis of dementia. Hospices caring for patients with dementia were more likely to be for-profit, larger sized, provide care for more than 5 years, and serve a large (>30%) percentage of nursing home patients. Patients with dementia were less likely to disenroll from hospice in conjunction with an acute hospitalization or emergency department visit and more likely to disenroll from hospice after long enrollment periods (more than 165 days) as compared with patients without dementia. No significant difference was found between patients with and without dementia for disenrollment after shorter enrollment periods (less than 165 days). In the multivariable analyses, patients were more likely to be disenrolled after 165 days if they were served by smaller hospices and hospices that served a small percentage of nursing home patients.

Conclusion: Patients with dementia are significantly more likely to be disenrolled from hospice following a long enrollment period compared with patients without dementia. As the number of individuals with dementia choosing hospice care continues to grow, it is critical to address potential barriers to the provision of quality palliative care for this population near the end of life.

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Dementia is the sixth leading cause of death in the United States and the number of individuals dying of dementia is steadily increasing.¹ Between 2000 and 2015, the number of individuals who died from Alzheimer disease increased by 123% (or 61,000 individuals).² An increasing number of people with dementia are

enrolling with hospice at the end of life and they represent the fastest growing group of hospice users.³ As codified under Medicare, hospice provides a package of clinical and psychosocial services to Medicare beneficiaries who are considered to have a terminal diagnosis (defined as a life expectancy of ≤ 6 months) and who are willing to forgo Medicare coverage for curative treatment.⁴ In the late 1990s, only 3.3% of those who used hospice had a primary diagnosis of dementia.⁵ By 2014, an estimated 14.8% of hospice users had a primary diagnosis of dementia. Although an increasing body of evidence has identified the complexity of caring for those with dementia at the end of life,^{6,7} little is known about the types of hospices providing care for them.

Evidence suggests that patterns of hospice use for individuals with a diagnosis of dementia differ from those with other diseases. They tend to be either enrolled in hospice for a very short (1 week or less) or a very long (longer than 6 months) period of time.^{8–11} Moreover, patients

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with dementia have higher rates of disenrollment from hospice before death compared with others.¹² In the context of the current regulatory environment in the United States, patients may be disenrolled from hospice for 4 reasons: (1) if their condition stabilizes or improves over time and the certifying physician is unable to recertify a prognosis of 6 months or less; (2) if the patient moves out of the hospice service area or is admitted to a hospital that does not have a hospice contract; (3) if a patient or surrogate desires to resume curative care; or (4) if a patient or family no longer wants hospice care.¹³ Disenrollment from hospice represents a disruption in continuity of care and has been associated with higher rates of subsequent hospitalizations and a greater likelihood of emergency department (ED) use, intensive care unit admission, and hospital death.^{14,15} Although our prior work has identified distinct patterns of hospice disenrollment and their associations with intensity of care at the end of life for patients with cancer,¹⁶ there are no studies to our knowledge that evaluate the patterns of disenrollment among a large national sample of individuals with dementia.

Therefore, the objectives of this study were (1) to characterize hospices that serve patients with a diagnosis of dementia (both as the primary diagnosis or as a comorbidity), (2) to compare patterns of hospice disenrollment for patients with a primary diagnosis of dementia and patients with a primary diagnosis other than dementia, and (3) to evaluate patient-level and hospice-level characteristics associated with different patterns of hospice disenrollment. Characterizing the types of hospices that care for patients with dementia and examining the patterns of hospice disenrollment for patients with and without dementia is a first step toward identifying hospices with “best practices” that may be replicated to provide higher-quality hospice care for this growing population.

Methods

Study Design and Sample

We conducted a longitudinal cohort study of Medicare beneficiaries cared for by a national random sample of hospices that responded to the National Hospice Survey. As described elsewhere,¹⁷ data from the 577 hospices included in the National Hospice Survey data were linked to Medicare claims for beneficiaries newly enrolled in those hospices in 2008–2009 and followed until their death (2008–2010). Patients who were not eligible for both Medicare Parts A and B ($n = 2111$), who were enrolled in a managed care organization ($n = 46,567$), or who were younger than 66 years ($n = 15,003$) were excluded from our analyses. The final sample included a total of 149,814 hospice enrollees who were cared for by a total of 577 hospices.

Measurements

Dementia diagnosis and patient characteristics

A primary diagnosis of dementia was identified on Medicare hospice claims data and defined based on the International Classification of Diseases, Ninth Revision (ICD-9) codes (290.0–290.4x, 294.0, 294.1, 294.8, 331.0–331.2, and 331.7). The following patient demographic and clinical characteristics were also obtained from Medicare hospice claims data: age (categorized as 65–84 years and 85 years and older), sex, and reported race/ethnicity (white or other), and the count of chronic conditions (fewer than 5 vs more than 5). Information regarding the number of chronic conditions was obtained by examining all Medicare hospital inpatient and outpatient claims for each individual for the 12 months before their hospice enrollment.

Hospice characteristics

The following hospice agency characteristics were obtained from the National Hospice Survey and included in our analyses given their association with patterns of hospice care^{16,18}: hospice ownership, size

(defined as the number of patients per day in the past 12 months), whether or not the hospice has an open access policy (ie, whether a hospice offers palliative services to non-hospice patients), years of providing hospice care (measured as <5 years or ≥ 5 years), whether the hospice was part of a chain of hospices, proportion of patients served in the nursing home (categorized as $<10\%$, $10\%–20\%$, $20\%–30\%$ and $>30\%$, based on the quartile values of the distribution), urban/rural location (measured as whether the hospice's county had ≥ 1 million population) and census region of the hospice.

Patterns of hospice use

We measured hospice length of stay for each patient using the Medicare hospice claims data. Length of hospice stay from hospice enrollment to death or disenrollment was included in all models as a potential confounder of the association between hospice characteristics and disenrollment, based on our prior work.^{3,4,16} Consistent with prior work, we identified individuals as having disenrolled from hospice if: (1) they had only 1 hospice enrollment period and the patient status indicator code on the final hospice claim indicated that the patient was discharged (rather than died) and there was no date of death on the final hospice claim; or (2) if they had >1 hospice enrollment period. We categorized patterns of hospice disenrollment as (1) disenrollment in conjunction with an acute hospitalization or ED visit, (2) disenrollment following long hospice stays (defined as more than 165 days), and (3) disenrollment following hospice stays shorter than 165 days. Disenrollment from hospice in conjunction with an acute hospitalization (including intensive care unit admission) or ED visit was defined as hospice discharge within 1 day of an acute hospitalization or ED visit. We categorized hospice disenrollment after a long stay as being a stay that is more than 165 days because hospice enrollees with stays 180 days or more are required by the Medicare Hospice Benefit to be re-certified as terminal, and this recertification (or disenrollment) is likely to occur within 2 weeks of the 180-day period. We performed sensitivity analyses with alternative cutoffs of 160 days, 170 days, and 180 days, and results are not materially different.

Statistical Analysis

We summarized the characteristics of our sample by patient demographic and clinical characteristics and hospice characteristics. We compared the prevalence of patient and hospice characteristics as well as the patterns of hospice disenrollment for the dementia and non-dementia group using χ^2 tests. To characterize the hospices that serve patients with dementia, we examined the associations between hospice-level characteristics and the percentage of any patients with dementia they serve (both patients with a primary diagnosis of dementia and patients with a coexisting diagnosis of dementia), using generalized linear models. We estimated separate multivariable models for the 3 patterns of hospice disenrollment. For this, multivariable logistic regression was used to examine the associations between patient and hospice characteristics and the 3 patterns of disenrollment, compared with patients who remained with hospice until death. All tests were performed using techniques to account for the clustering of patient observations within hospices. A 2-tailed $P < .05$ was used to define statistical significance. All statistical analyses were conducted using IBM Statistics SPSS, version 24 (IBM Corp, Chicago, IL) and SAS, version 9.3 (SAS Institute Inc, Cary, NC).

Results

Study Population

Our sample consisted of 149,814 patients who were newly enrolled with 1 of the 577 hospices that responded to the National Hospice Survey. Of these, 7328 patients (4.9%) had a primary diagnosis of

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