Spousal Characteristics and Older Adults' Hospice Use: Understanding Disparities in End-of-Life Care

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Abstract

Background: Hospice use has been shown to benefit quality of life for patients with terminal illness and their families, with further evidence of cost savings for Medicare and other payers. While disparities in hospice use by patient diagnosis, race, and region are well documented and attention to the role of family members in end-of-life decision-making is increasing, the influence of spousal characteristics on the decision to use hospice is unknown.

Objectives: To determine the association between spousal characteristics and hospice use.

Design: We used data from the Health and Retirement Study (HRS), a prospective cohort study, linked to the *Dartmouth Atlas of Health Care* and Medicare claims.

Setting: National study of 1567 decedents who were married or partnered at the time of death (2000–2011).

Measures: Hospice use at least 1 day in the last year of life as measured via Medicare claims data. Spousal factors (e.g., education and health status) measured via survey.

Results: In multivariate models controlling for patient factors and regional variation, spouses with lower educational attainment than their deceased spouse had decreased likelihood of hospice use (odds ratio [OR] = 0.58; 95% confidence interval [CI] = 0.40–0.82). Health of the spouse was not significantly associated with likelihood of decedent hospice use in adjusted models.

Implications: Although the health of the surviving spouse was not associated with hospice use, their educational level was a predictor of hospice use. Spousal and family characteristics, including educational attainment, should be examined further in relation to disparities in hospice use. Efforts to increase access to high-quality end-of-life care for individuals with serious illness must also address the needs and concerns of caregivers and family.

Introduction

HOSPICE CARE addresses the multidimensional needs of individuals with terminal illness while simultaneously supporting family members during a patient's illness and after their death. Hospice use is on the rise in the United States, with 45% of deaths occurring under hospice care, which is a 21% increase in the last decade.[1,2] Hospice provides many benefits for individuals and families, including enhanced quality of life for patients near the end of life[3–5] and also saves Medicare costs.[6] Hospice also has beneficial ef-

fects for families and caregivers by improving family functioning,[7] bereavement adjustment[7–9] satisfaction with care,[8,10–12] and mental health.[3,13–15]

Despite the potential benefits of hospice enrollment for individuals and families, the majority of patients with serious illness still do not use hospice.[1] Furthermore, most individuals who use hospice are admitted very close to the end of life. Short hospice stays (≤3 days) have increased to 28.4% of all hospice stays[1] and 14.3% of patients with cancer who enroll in hospice do so in the last 3 days of life.[16] While lack of hospice utilization or underutilization may be attributable

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to documented differences in patient characteristics (e.g., diagnosis, race, ethnicity, and income[17–22]), and geographic region (e.g., hospice resources available, variation in services hospices provide[23–25]), the decision-making process regarding hospice enrollment is often based within the family unit.[22,26–29] While the family has a crucial role in determining hospice utilization, little is known about how family characteristics are associated with the decision to use hospice.

As conceptualized by Kelley et al.,[30] family characteristics and preferences may determine treatment intensity (including hospice utilization) for patients with serious illness in addition to individual, regional, and physician characteristics. The health and ability of the family to provide support at the end of life may impact hospice enrollment and ability to participate in home hospice care. Among patients receiving hospice care at home, those who lack a caregiver in the home are likely to require more frequent and intensive home visits. While Medicare may not explicitly deny hospice services for persons without caregivers, 12% of hospices reported not enrolling patients without an available caregiver.[25] The presence of an in-home network of caregivers is associated with increased duration of use of hospice, although not access to hospice overall.[31]

Because spouses play an important role in caregiving and adaptation to serious illness,[32] an in-depth examination of spousal characteristics related to hospice use may help elucidate barriers to this aspect of high-quality end-of-life care. Although level of spousal educational attainment has not been previously studied directly, spousal beliefs and knowledge as a factor in shaping hospice utilization has been examined. In particular, family members, particularly spouses, may have concerns about hospice care including feelings of guilt and concern over lack of control of the caregiving process.[22,28] These concerns may be associated with likelihood of hospice use. For example, qualitative data suggest that increased knowledge about the benefits of hospice increases likelihood of hospice enrollment.[33] Furthermore, having a caregiver with strong religious beliefs is associated with lower likelihood of utilizing hospice services among Latinos and African Americans[34] while other studies find no association between caregiver characteristics and hospice use among those with dementia.[35]

The aim of this study was to determine whether spousal health-related characteristics and educational attainment independently impact use of hospice among patients with serious illness. We hypothesized that after controlling for known predictors of hospice use, poor spousal health and lower educational attainment would independently predict lower likelihood of hospice enrollment at the end of life.

Design and Methods

Data sources

The study cohort comes from the Health and Retirement Study (HRS), a nationally representative longitudinal survey of U.S. adults 50 years of age and older.[36] Participants are interviewed every 2 years. The original sample was assembled in 1992, and more than 30,000 persons have been enrolled. During each interview cycle, the HRS identifies participants who died since the last core interview, and "exit" interviews are conducted with proxies knowledgeable about the deceased participant. Together, the core and exit interviews include the participant's demographic, economic,

social, and functional characteristics. The HRS obtains dates and causes of death from the Centers for Disease Control and Prevention National Death Index. If participants are married or living with a partner, "spouses" are recruited and surveyed regardless of their age. Survey data are linked for eligible participants with individual Medicare claims. Study participants provided informed consent upon enrollment and again for linkage to Medicare claims.

Based on postal code of residence, each decedent identified in HRS was linked to a hospital referral region (HRR) as defined by the *Dartmouth Atlas of Health Care*.[37] The *Dartmouth Atlas* database provides information about the supply of medical resources in each hospital referral region, including the numbers of acute care hospital beds, physicians and specialists per capita, and a measure of local practice pattern intensity (the Hospital Care Intensity Index) that reflects the average amount of time Medicare beneficiaries spend in hospitals and the intensity of physician services delivered during hospital stays.

Sample

We examined HRS participants who died between 2000 and 2011, had linked Medicare data, and participated in fee-for-service Medicare for at least the last 6 months of life ($n = 5,035$). Because our primary interest was the impact of spousal characteristics on hospice use, we limited our analytic sample to decedents who were married/partnered at the time of death and whose spouse had a predeath interview ($n = 1,794$). Finally, to focus on respondents with serious illness, we limited the sample to those 1,673 decedents with at least one chronic condition identified in claims data up to 1 year prior to death and excluded decedents whose cause of death was documented as an accident, suicide, or homicide ($n = 84$). The final analytic sample included 1,567 decedents with complete covariate data (94%).

Measures

Outcome variable. We determined hospice enrollment from individual Medicare hospice claims. We focused on hospice use defined as ≥1 day in the last year of life.

Independent variables. Based on a conceptual framework that suggests that patient, family, and regional factors may all simultaneously determine treatment intensity for patients with serious illness,[30] and a review of the literature on predictors of hospice use, we examined the relation between a host of factors (patient, spousal, regional) and hospice use.

Patient variables were extracted from decedents' final HRS core interview, postdeath exit interview, and Medicare claims. Demographic variables from HRS included age, gender, race and ethnicity, educational attainment, net worth, religiosity, presence of a relative living nearby (other than those coresiding), and residential status (nursing home or community dwelling). Functional status was measured as a binary variable, indicating whether the participant had difficulty with one or more basic activities of daily living (ADLs). Two variables were extracted from the next of kin interview after death: whether the subject had completed an advanced directive and whether the death was "expected." Chronic medical conditions were identified by *the International Classification of Diseases, Ninth Revision, Clinical*

Modification criteria using Medicare claims from 12 months preceding death. Medicare claims were also used to extract hospital utilization in the last 2 years of life.

Spousal variables were extracted from the spouse's last HRS core interview before the patient's death (mean = 13.1 months, standard deviation [SD] = 8.3). Because spouse demographic variables (age, gender, educational attainment, race, and ethnicity) were highly correlated (≥0.5) with decedent demographic variables, they were not retained in multivariate models. We categorized spouses as being in a lower educational category (high school degree, less than high school, or greater than high school), the same educational category, or higher educational category than their spouses. Similarly, we also examined spousal age category (younger, same, older) relative to decedent age based on the following age categories: <75, 75–84, ≥85. Self-reported health was categorized as poor/fair versus good/very good/ excellent. Spouses self-reported the following diseases in HRS: cancer, lung disease, heart disease, congestive heart failure, stroke, memory disease, hypertension, and diabetes. These were used to determine a comorbidity count divided as none (0), mild (1–3), and moderate/severe (≥4). Presence of a psychiatric condition was determined based on self-report of physician diagnosis or treatment. Functional status was measured by assessing whether the spouse had difficulty with one or more basic ADLs or instrumental activities of daily living (IADLS). Finally, we categorized spouses as either: (1) noncaregivers, (2) caregivers at time of death only, or (3) longterm caregivers based upon whether the spouse was reported to be the primary helper with decedent's activities of daily living or instrumental activities of daily living in the last 3 months of life and at the decedent's core interview prior to death.

Regional variables drawn from the *Dartmouth Atlas* included the number of acute care hospital beds per 1,000 residents, the number of specialists per 100,000 residents, and the Hospital Care Intensity (HCI) Index, which is calculated as a standardized ratio of the average number of days individuals in that hospital referral region spend in the hospital and the average number of physician encounters they experience during each hospital stay compared with the national average.

Analysis

χ^2 and *t*-tests were used to determine factors associated with hospice use in bivariate analysis. We used multivariate logistic regression modeling to predict likelihood of hospice use with clustering of standard errors by hospital referral region. We included variables that were associated with hospice use in bivariate analysis ($p < 0.15$) in multivariate models.

Stata 13 was used for all statistical analyses (StataCorp LP, College Station, TX). The Institutional Review Board at the Icahn School of Medicine at Mount Sinai approved the study.

Results

Descriptive analyses indicate that 70% of the decedents with surviving spouses were men, 81.6% were non-Hispanic white, and 67.0% had at least a high school education. The 37.1% of decedents who used hospice did so a median of 15 days (interquartile range = 1–353 days). Surviving spouses were mean age 75.5 years (SD = 9.5) at the time of their spouse's death and 72.1% had at least a high school educa-

tion. One-third reported being in fair or poor health and 20.7% reported having difficulty with at least one ADL.

Hospice users were more likely than those who did not use hospice to be older (79.2 versus 78.0 years at death, $p = 0.005$), have a high school degree or higher educational attainment (70.3% versus 65.1%, p = 0.03), be white (85.7% versus 79.1%, $p = 0.003$), have advance directives (69.9% versus 54.6%, $p < 0.001$), and have cancer diagnoses (37.8% versus 20.8%, $p < 0.001$). Similarly, hospice users were less likely than those who did not use hospice to have chronic kidney disease (47.7% versus 41.9%, $p = 0.03$), and congestive heart failure (56.6% versus 47.6%, $p = 0.001$; Table 1). Although not statistically significant, hospice users tended to live in regions with less specialist availability (121.1 versus 123.0 specialists per 100,000 residents, $p = 0.11$) and were less likely to reside in nursing homes at their last core interview before death (7.7% versus 10.5%, $p = 0.075$).

The following spousal factors measured before death were associated with a lower likelihood of hospice use in bivariate analysis: poor/fair self-reported health ($p = 0.04$), caregiver status ($p < 0.001$), age ($p = 0.005$), and spousal educational attainment ($p = 0.007$). Additionally, the spouse having lower educational attainment than the decedent was associated with no hospice use ($p = 0.015$). Spousal age (relative to the decedent), psychiatric condition, and functional status were not associated with hospice use (Table 1). More than 95% of spouse study interviews occurred prior to the initiation of any hospice services.

The majority of spouses (63.0%) had the same educational attainment as their partner (categorized as high school, less than high school, or more than high school). As shown in Table 2, for those decedents with a high school education, having a spouse with less than high school degree resulted in a lower likelihood of hospice use (26.2% versus 41.7%, $p = 0.001$) compared with having a spouse with a high school degree. Among decedents with more than a high school degree, those with spouses with less than high school education were less likely to use hospice than those with a high school education or more than a high school education ($p = 0.05$).

In multivariate models we continued to see associations between hospice use and decedent age, nursing home residence, advance directives, ''death expected,'' spouse caregiver status, and individual disease status. After controlling for patient and regional factors associated with hospice use, the spouse having lower educational attainment than the decedent resulted in a 42% decreased odds of using hospice (OR = 0.58; 95% CI = 0.40--0.82; Table 3).

Discussion

Using linked personal interviews and Medicare claims for married or partnered decedents in a large, national cohort study, our results suggest that spousal educational attainment relative to decedent education is an important variable in understanding disparities in hospice enrollment.

The decision to enroll in hospice is complex. One has to agree to stop curative or disease-directed treatments, some of which may also offer palliative benefits. Furthermore, hospice may also be used in ways that limit its benefits. In 2010 more than half of all Medicare decedents who used hospice had either very short or very long hospice enrollment or disenrolled from hospice before death.[38] While previous research

	Hospice users (n=582) %	No hospice use (n=985) %	p
Decedent factors			
Age at death, years, mean (SD)	79.20 (8.04)	77.96 (8.66)	0.005
Net worth quartile 1, lowest	17.18	20.51	0.189
Net worth quartile 2	26.46	28.32	
Net worth quartile 3	29.04	25.28	
Net worth quartile 4, highest	27.32	25.89	
<High school degree	29.73	34.92	0.071
High school degree	53.26	47.72	
>High school degree	17.01	17.36	
White, non-Hispanic	85.74	79.09	0.004
Black, non-Hispanic	9.28	12.28	
Hispanic	4.47	6.60	
Other race, non-Hispanic	NR	2.03	
Female	30.24	29.34	0.706
Nursing home resident	7.73	10.46	0.075
Religion very important	65.12	64.26	0.732
Relatives nearby	34.88	32.59	0.353
Death expected by family	84.36	43.96	<0.001
Documented advance directive	69.93	54.62	<0.001
ADL difficulty	52.75	46.40	0.015
IADL difficulty	51.37	45.89	0.036
Count comorbidities, mean (SD)	8.28 (3.33)	7.90 (3.60)	0.037
Alzheimer's/dementia	33.51	27.61	0.014
Chronic kidney disease	41.92	47.72	0.026
Ischemic heart disease	54.12	63.25	<0.001
Congestive heart gailure	47.59	56.55	0.001
Diabetes	38.14	45.18	0.007
COPD	53.61	48.12	0.036
Stroke or TIA	27.66	29.04	0.561
Cancer	37.80	20.81	<0.001
Atrial fibrillation	36.60	37.36	0.763
Hip fracture	6.19	5.18	0.400
Depression	24.40	19.09	0.013
Osteoporosis	14.09	10.56	0.037
Arthritis	28.87	31.57	0.261
Hospital nights last 2 years of life	20.60	20.00	0.623
Spousal factors			
Age at death, mean (SD)	76.51 (9.04)	75.00 (9.76)	0.005
Same age category	67.24	67.41	0.962
Spouse older	7.41	7.72	
Spouse younger	25.34	24.87	
Education <high school	23.54	30.46	0.007
High school degree	56.19	52.99	
>High school	20.27	16.55	
Same education category	66.84	60.71	0.015
Spouse more education	20.27	21.22	
Spouse less education	12.89	18.07	
Comorbidities=none	19.34	18.14	0.323
Mild 1–3	72.47	71.41	
Moderate/severe 4–7	8.19	10.45	
SRH poor/fair	30.07	35.13	0.040
Psychiatric condition	18.07	18.07	1.000
ADL difficulty	20.45	20.91	0.826
IADL difficulty	18.90	20.71	0.387
Not primary caregiver	34.19	47.82	<0.001
Primary caregiver end-of-life only	36.25	27.41	
Primary caregiver long-term	29.55	24.77	
Regional factors			
Hospital care intensity index	0.99	1.01	0.161
Hospital beds per 1,000 residents	2.53	2.55	0.473
Specialists per 100,000 residents	121.09	122.96	0.105

Hospice users defined as individuals who used hospice ≥1 days in last year of life. Regional level variables are at the hospital referral region level, matched by decedent zip code; net worth quartiles defined as follows: 25%=$51,401; 50%=$208,470; 75%=$572,199. Age category defined as <75, 75–84, ≥85.

SD, standard deviation; ADL, activities of daily living; IADL, instrumental activities of daily living; COPD, chronic obstructive pulmonary disease; TIA, transient ischemic attack; SRH, self-reported health; NR, not reported due to Health and Retirement Study (HRS) restrictions on reporting cell size less than 10 observations.

TABLE 2. HOSPICE USE BY SPOUSE AND DECEDENT EDUCATION (N=1,567 DYADS)

	Spouse					
	High school education		High school education		>High school education	
	n	% hospice use	n	% hospice use	n	% hospice use
Decedent						
<High school education	300	34.33%	200	31.00%	17	NR
High school education	126	26.19%	527	41.75%	127	44.88%
>High school education	11	NR	122	36.89%	137	38.69%

NR, not reported due to Health and Retirement Study (HRS) reporting restrictions.

TABLE 3. ASSOCIATION BETWEEN DECEDENT, SPOUSAL, AND REGIONAL CHARACTERISTICS AND HOSPICE USE (N=1,567)

	Hospice use adjusted OR	95% CI	p
Decedent factors			
Age 75–84	1.356	1.053–1.747	0.02
Age 85+	1.406	1.026–1.926	0.03
High school degree	1.220	0.960–1.549	0.10
Female	0.933	0.690–1.261	0.65
Non-Hispanic white/caucasian	1.008	0.695–1.464	0.96
Nursing home resident	0.456	0.281–0.740	<0.01
Has advance directive	1.762	1.347–2.305	<0.01
Death expected by family	6.029	4.652–7.812	<0.01
ADL difficulty	1.265	0.941–1.700	0.12
IADL difficulty	1.329	0.982–1.800	0.07
Chronic kidney disease	0.828	0.633–1.083	0.10
Ischemic heart disease	0.772	0.604–0.986	0.03
CHF	0.821	0.635–1.061	0.08
Diabetes	0.891	0.696–1.142	0.55
COPD	1.094	0.841–1.424	0.50
Cancer	1.881	1.460–2.424	<0.01
Depression	1.431	1.042–1.964	0.03
Osteoporosis	1.236	0.823–1.857	0.31
Spousal factors			
Spouse more education than decedent	0.825	0.578–1.176	0.29
Spouse less education than decedent	0.578	0.405–0.825	0.00
Self-rated health: Poor/fair	0.884	0.670–1.166	0.38
Primary caregiver end-of-life only	1.628	1.223–2.166	<0.01
Primary caregiver long-term	1.090	0.814–1.459	0.56
Regional factors			
No. specialists per 100,000 residents	0.995	0.989–1.000	0.06

Fully adjusted logistic regression model with robust standard errors clustered by hospital referral region (HRR). Referent categories are: decedent age <75, decedent less than high school education, spouse and decedent have same education level.

OR, odds ratio; CI, confidence interval; ADL, activities of daily living; IADL, instrumental activities of daily living; CHF, congestive heart failure; COPD, chronic obstructive pulmonary disease.

has examined barriers to hospice use by documenting existing differences in hospice utilization based on race, marital status, and the role of regional supply factors (e.g., availability of specialists),[25,39] the attributes of family caregivers, particularly spouses, have yet to be examined systematically.

This gap in the literature is surprising given that spouses have heavy involvement in end-of-life decision-making. For example, in national population-based study, 43% of patients who died required decision-making for treatment in the final days of life; the vast majority of these patients lacked decision-making capacity.[40] Furthermore, almost half (49%) of family members of patients who died in one university-affiliated hospice (n=165) reported that the patient was not involved in hospice enrollment decisions.[27]

Interventions to improve the timing and appropriateness of hospice referral to maximize the full benefits of hospice must include patients and their families. The association we found between educational attainment discordance of spouse and hospice use may be reflective of socioeconomic status, health literacy, realistic expectations about death, or knowledge about hospice. A deeper understanding of the barriers to hospice enrollment, including the concerns of the patient's spouse or partner, is critical to expanding access to hospice for eligible patients. Family members' misunderstandings about the services provided by hospice and their concerns about utilizing this service[22] could be remedied, for example, by greater education about hospice care. This issue may also be an important factor related to hospice disenrollment, an area of increasing concern around hospice quality.[38]

Surprisingly, we did not find that spousal health status was independently associated with hospice use. This remained true in sensitivity analyses that: (1) excluded decedents who were living in nursing homes at the interview before death (n=148); (2) excluded decedents using inpatient hospice (n=98); and (3) excluded spouses who were interviewed concurrent to hospice use (n=27; data not shown). Given that healthier spouses may be more likely to become caregivers,[41] we also examined the association between caregiving and spousal health in our sample. While caregivers were indeed healthier in our sample (better self-reported health, less functional impairment), there was no association between spousal health and hospice use when we limited our sample to those spouses who were caregivers. It is encouraging that spousal health does not seem to be a barrier to hospice enrollment. This finding may be because other caregivers may be involved when spouses are in poor health. Further research should examine the availability and health of all caregivers when determining factors that impact hospice use and what effect hospice may have on the surviving spouses' health.

There are several limitations to this study. First, this study focused on a sample of spousal dyads only. As noted previously, other family members may be involved in health-care decision-making and future work should examine educational differences for all family members, including children, when examining predictors of hospice use. Second, because we used Medicare claims data to measure hospice use and comorbidities, we were limited to decedents with fee-for-service Medicare. We were able to examine some regional supply issues in our model (e.g., availability of specialists), but were not able to capture exact number and size of hospices available in neighborhoods. We also did not examine relationship quality, which may impact end-of-life decision-making[42] and we relied on spousal report of whether death as "expected," which may be subject to recall bias. Furthermore, we used spousal education attainment as a proxy for knowledge about hospice, cultural norms surrounding end-of-life care, as well as health literacy, all measures that may more accurately help us understand why certain individuals may or may not choose to use hospice.

While the HRS includes supplemental questions examining health literacy for a subset of respondents,[43] sample size precluded analysis for surviving spouses. Further examination of spousal knowledge, health literacy and beliefs about hospice using qualitative and quantitative approaches are necessary to better understand spousal involvement in decisions around hospice use. Additionally, further research should not only examine whether individuals actually enrolled in hospice but also collect data on whether decedents were presented with the option of hospice and whether spouses were actually involved in any hospice decision-making. Finally, our focus was on any hospice use although there are also known disparities surrounding timing of hospice enrollment. Unfortunately, we were not able to examine variation in hospice length of stay due to small sample sizes of discordant educational categories among hospice users.

As the evidence base for the benefits of hospice use continues to grow, it is imperative that these services are equally accessible and meet the needs of older adults with serious illness regardless of race, geographic region, or the educational attainment of their spouses. Moreover, not using hospice because of lack of understanding may not only deprive the patient of needed services, but also the caregiver because they are unable to benefit from the supportive services of hospice, including respite services and bereavement preparation.

In conclusion, our work suggests that having a spouse with lower educational attainment decreases likelihood of an individual's hospice use and suggests we must continue to integrate the family into the health care system.[44] The Institute of Medicine's 2014 report, *Dying in America,* concludes that demand for family caregiving is increasing and comprehensive end-of-life care should be family-oriented, taking into consideration the needs of individuals as well as those of their family and/or caregivers.[45] Improving access to hospice care will require working with individual and their families. To truly reduce disparities related to end-of-life decision making and health care use, research must examine these decisions not just from individual perspective but from the larger family context.

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Author Disclosure Statement

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