Impact of Hospice Disenrollment on Health Care Use and Medicare Expenditures for Patients With Cancer

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ABSTRACT

Purpose

Patients with cancer represent the largest diagnostic group of hospice users, with 560,000 referred for hospice in 2008. Oncologists rely on hospice teams to provide care for patients who have completed disease-directed treatment and desire to remain at home. However, 11% to 15% of hospice users disenroll from hospice, and little is known about their health care use and Medicare expenditures.

Patients and Methods

We used Surveillance, Epidemiology and End Results–Medicare data for hospice users who died as a result of cancer between 1998 and 2002 ($N = 90,826$) to compare rates of hospitalization, emergency department, and intensive care unit admission and hospital death for hospice disenrollees and those who remained with hospice until death. We also compared per-day and total Medicare expenditures across the two groups.

Results

Patients with cancer who disenrolled from hospice were more likely to be hospitalized (39.8% v 1.6%; $P < .001$), more likely to be admitted to the emergency department (33.9% v 3.1%; $P < .001$) or intensive care unit (5.7% v 0.1%; $P < .001$), and more likely to die in the hospital (9.6% v 0.2%; $P < .001$). Patients who disenrolled from hospice died a median of 24 days following disenrollment, suggesting that the reason for hospice disenrollment was not improved health. In multivariable analyses, hospice disenrollees incurred higher per-day Medicare expenditures than patients who remained with hospice until death (higher per-day expenditures of \$124; $P < .001$).

Conclusion

Hospice disenrollment is a marker for higher health care use and expenditures for care. Strategies to manage a patient's care and support family caregivers following hospice disenrollment may be beneficial and should be explored.

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INTRODUCTION

Hospice is an integral part of the continuum of care for more than one-half million individuals with cancer each year. Patients with cancer comprise the largest diagnostic group of hospice users and account for approximately 40% of annual hospice admissions.¹ Hospice teams assist oncologists by assuming the symptom management, home care, and personal care needs of patients with terminal cancer who have completed disease-directed treatment. In particular, hospice teams assist oncologists in the care of their patients by providing home symptom management, medication delivery, home crisis intervention, and psychosocial support during one of the most difficult and emotionally demanding phases of the patient's illness. As such, hospice not only supports the needs of patients and caregivers but has the poten-

tial to alleviate some of the pressing workforce issues facing the oncology field due to the increasing chronic care demands of patients with cancer.^{2,3}

Recent evidence indicates that 11% to 15% of patients with cancer who enroll with hospice eventually disenroll from hospice before death.^{4,5} Hospice disenrollment may be initiated by either the patient or the hospice. Possible causes of hospice disenrollment include patient preferences, dissatisfaction with hospice care, admission to a hospital that does not have a hospice contract, or becoming ineligible for the Medicare Hospice Benefit (MHB), which covers the financial cost of hospice services for patients whose physician indicates that he or she has a life expectancy of ≤ 6 months. Previous studies have identified younger age,^{5,6} nonwhite race,^{4,6} male sex,^{4,5} and noncancer diagnosis^{5,6} as being factors associated with hospice disenrollment. Disenrollment rates vary dramatically

across hospices: smaller and newer hospices have significantly higher disenrollment rates than larger and more established hospices.⁴ What is not known, and is particularly relevant to oncologists who refer patients for hospice care, is the experience of patients with cancer who disenroll from hospice, including their subsequent health care use and Medicare expenditures. These data have important implications for cancer centers, medical home models for patients with cancer, referring oncologists, and the Centers for Medicare & Medicaid Services.

In this article, we describe the association between hospice disenrollment and health care use and Medicare expenditures of patients with cancer. Specifically, we used linked Surveillance, Epidemiology, and End Results (SEER)–Medicare data to identify individuals who used hospice and died as a result of cancer between 1998 and 2002 and evaluated hospitalization rates, intensive care unit (ICU) and emergency department (ED) admission rates, site of death, and total and per-day Medicare expenditures from hospice enrollment to death for individuals who disenroll from hospice compared with patients who remained enrolled with hospice until death. As oncologists continue to refer patients for hospice, it is important to better understand the patterns of care for the subset of those patients who disenroll from hospice.

PATIENTS AND METHODS

Sample and Data

We analyzed data from 90,826 patients served by 1,384 hospices in the linked SEER–Medicare database⁷ who died with a primary diagnosis of cancer between 1998 and 2002 at age 66 years or older and who used hospice during any part of the 6 months before death. We limited the sample to patients age 66 or older to ensure that individuals were eligible for Medicare in the year before death so that we could access data on comorbidity in the year before death. A primary diagnosis of cancer was identified as one with an International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) code⁸ between 140 and 239. We excluded patients who were enrolled in a Medicare managed care organization because their nonhospice claims and use data were not available in the SEER–Medicare database. The Medicare claims data include information on Medicare beneficiaries' enrollment, entitlement, demographics, and health maintenance organization membership, and claims for hospital, outpatient, physician, home health care, and hospice use. We linked the SEER–Medicare database to the Medicare Provider of Services file to obtain information on hospice characteristics. Approval for this study was obtained from the Yale School of Medicine Human Investigations Committee.

Outcome Measures

We used Medicare claims data to identify the following for each individual from the time of hospice enrollment until death: ED and ICU use, inpatient hospitalization, and hospital death. In addition, for patients who were hospitalized, we calculated the average number of days in the hospital. Patients were identified as having disenrolled from hospice if the date of their last hospice claim was before the date of their death. For patients who disenrolled from hospice and were immediately hospitalized (ie, with 48 hours of disenrollment), we categorized and reported the top five most frequent admission diagnoses on the hospital claim. We estimated total Medicare expenditures and average per-day Medicare expenditures for each individual from hospice enrollment until death. Medicare expenditures included expenditures for hospice care, hospital care, outpatient and physician services, home health care, and durable medical equipment and supplies (DMES). Per-day expenditures were calculated as average expenditures per day from hospice enrollment until death. All expenditures were adjusted to 2002 dollars using the Medical/Surgical Producer Price Index from the US Bureau of Labor Statistics.⁹

Independent Variables

Patient demographic characteristics were age at death, reported race/ethnicity, sex, and marital status at the time of entry into the SEER cancer

registry. Patient clinical characteristics were primary cancer diagnosis (colon, pancreatic, lung, breast, ovarian, prostate, kidney, bladder, uterine, lymph, or other), Charlson comorbidity index^{10,11} using the comorbidity weights and methodology suggested by the National Cancer Institute for use with the SEER–Medicare data,¹² receipt of only the home hospice level of care compared with at least 1 day of the inpatient level of care, whether the patient disenrolled from hospice, the log-transformed number of days from hospice enrollment to death, and patient's year of death.

Statistical Analyses

We summarized patient demographic and clinical characteristics of the sample patients. We compared the rate of ED use, ICU use, inpatient hospitalization, and hospital death for patients who disenrolled from hospice compared with patients who remained with hospice until death using χ^2 tests. We then compared the predicted probability of ED use, ICU use, inpatient hospitalization, and hospital death for patients who disenrolled from hospice compared with patients who remained with hospice until death adjusted for the number of days from hospice enrollment to death using logistic generalized estimating equations (GEEs). Consistent with the literature on modeling health care cost data,^{14,15} we conducted a multivariable regression analysis using GEEs¹³ with a gamma distribution and log link to estimate the associations between hospice

Table 1. Demographic and Clinical Characteristics of Patients

Characteristic	Total No. of Patients (N = 90,826)	%
Age at death, years		
< 70	10,682	11.8
70-74	18,641	20.5
75-79	21,917	24.1
80-84	19,912	21.9
≥ 85	19,674	21.7
Race		
White non-Hispanic	77,662	85.5
White Hispanic	3,540	3.9
Black	6,672	7.3
Other	2,829	3.1
Unknown	123	0.1
Sex		
Female	47,168	51.9
Male	43,658	48.1
Marital status		
Married	44,332	48.8
Not married	42,483	46.8
Unknown	4,011	4.4
Site of primary cancer		
Lung	23,550	25.9
Colon	10,839	11.9
Prostate	8,066	8.9
Breast	6,432	7.1
Pancreas	5,869	6.5
Bladder	3,126	3.4
Lymph	2,954	3.3
Ovarian	2,280	2.5
Kidney	2,108	2.3
Uterine	1,721	1.9
Other	23,881	26.3
Comorbidity index value		
0	35,642	39.2
≥ 1	55,184	60.8
Type of hospice care		
Home hospice only	78,495	86.4
Any inpatient	12,331	13.6

disenrollment and both total and per-day Medicare expenditures, controlling for patient demographic and clinical characteristics, the number of days from hospice enrollment to death, and year. We used GEE models to account for the clustering of patient observations within hospices. We centered all independent variables on their means, so that we could directly transform model coefficients to their natural units (dollars) to facilitate interpretation.

RESULTS

Our analysis included 90,826 individuals who died with a primary diagnosis of cancer and used hospice during the period 1998 to 2002. Descriptive characteristics of the sample of patients are provided in Table 1 and described elsewhere.⁴ The average patient age at death was 78.5 years, and 86% of hospice patients were reported to be white non-Hispanic. Fifty-two percent of the patients in the sample were female, and 49% were married. Twenty-six percent of patients had a primary diagnosis of lung cancer, followed by 12% with colon cancer and 9% with prostate cancer. The mean patient Charlson comorbidity index value was 1.2 (standard deviation = 1.3) and the range was 0 to 12. Approximately 86% received only the home hospice level of care. The mean and median numbers of days from hospice enrollment to death were 59.2 days (standard deviation, 152.0 days) and 19 days, respectively. The interquartile range was 7 to 52 days.

Disenrollment Rates of Patients

A total of 9,936 patients (10.9%) disenrolled from hospice before death. Patient and hospice characteristics associated with disenrollment are reported and discussed elsewhere.⁴ The median number of days from hospice enrollment to disenrollment was 28, and the median number of days from hospice disenrollment to death was 24. Fifty-seven percent of patients who disenrolled from hospice died within 30 days of disenrollment. A pattern of disenrollment-enrollment was observed for more than one third of disenrollees. Specifically, 38% of patients who disenrolled from hospice re-enrolled with hospice a median of 28 days later; 17% of these patients disenrolled from hospice a second time. For patients who re-enrolled with hospice and died with hospice, death occurred at a median of 24 days following re-enrollment.

Hospice Disenrollment and Health Care Use

Individuals with cancer who disenrolled from hospice had significantly higher health care use than those who remained with hospice until death (Table 2). Patients who disenrolled from hospice were

more frequently admitted to the ED (33.9% v 3.1%; $P < .001$) and the ICU (5.7% v 0.1%; $P < .001$) and more frequently died in the hospital (9.6% v 0.2%; $P < .001$). Patients who disenrolled were also more likely to be admitted to the hospital as an inpatient (39.8% v 1.6%; $P < .001$) and spent almost three times as many days in the hospital once admitted (an average of 19.3 days v 6.7 days; $P < .001$). Twenty-five percent of patients who disenrolled from hospice were hospitalized within 48 hours of hospice disenrollment, and the most common admission diagnoses on their hospital claims were cancer-related (30%), pain or other symptoms (12%), fracture or injury (9%), infection (7%), and psychiatric illness (5%).

Similarly, in models adjusting for the number of days from the patient's enrollment in hospice to their death, patients who disenrolled from hospice had significantly higher use of health care: ED use (19.8% v 2.8%; $P < .001$), ICU use (3.2% v 0.1%; $P < .001$), and inpatient hospitalization (27.4% v 1.5%; $P < .001$), and they more frequently died in the hospital (12.1% v 0.2%; $P < .001$).

Medicare Expenditures for Hospice Users With Cancer

The distribution of total Medicare expenditures for individuals with a primary diagnosis of cancer who enrolled with hospice was substantially skewed to the right. The 5% of individuals with the highest Medicare expenditures accounted for 40% of total Medicare expenditures during the study period. The mean total Medicare expenditure per individual was \$9,196, the median expenditure was \$3,508, and the 95th percentile expenditure was \$35,479. Average and median expenditures per day from hospice enrollment to death were \$241 and \$148, respectively, and the interquartile range was \$125 to \$222.

For individuals in our study sample, 70% of total expenditures from hospice enrollment to death were for hospice care. Of the remaining 30% of expenditures that were not for hospice care, 15% were for hospitalizations, 10% were for physician visits, 2% were for outpatient care, 2% were for DMES, and 1% were for home health care services.

In multivariable analyses (Table 3), per-day Medicare expenditures for patients with cancer who disenrolled from hospice were \$124 higher ($P < .001$) on average than per-day Medicare expenditures for patients with cancer who remained enrolled with hospice until death. Patients with cancer who disenrolled from hospice had total expenditures that were \$2,475 higher ($P < .001$) on average than the Medicare expenditures for patients with cancer who remained with hospice until death. Analyses are controlled for the number of days from hospice enrollment to death, patient demographic and clinical characteristics, and year of enrollment.

Table 2. Hospice Disenrollment and Health Care Use for Patients With Cancer

Health Care Source	Unadjusted		Adjusted*	
	Patients Who Disenrolled From Hospice (%)	Patients Who Remained With Hospice Until Death (%)	Patients Who Disenrolled From Hospice (%)	Patients Who Remained With Hospice Until Death (%)
Emergency department	33.9	3.1†	19.8	2.8‡
Intensive care unit	5.7	0.1†	3.2	0.1‡
Inpatient hospitalization	39.8	1.6†	27.4	1.5‡
Hospital death	9.6	0.2†	12.1	0.2‡

*Predicted probabilities are adjusted for the number of days from hospice enrollment to death.

† P value $< .001$ based on χ^2 test.

‡ P value $< .001$ based on generalized estimating equations model accounting for days from hospice enrollment to death and the clustering of patient observations within hospices.

Table 3. Association Between Hospice Disenrollment and Per-Day and Total Medicare Expenditures for Patients With Cancer

Variable	Marginal Effect on Per-Day Medicare Expenditures (\$)*	Marginal Effect on Total Medicare Expenditures (\$)*
Hospice disenrollment	124†	2,475†
Age at death	−1†	−15†
Race (compared with non-Hispanic white)		
White Hispanic	−1	−14
Black	14†	288†
Other	5	101
Male	3†	54
Not married	0	6
Cancer (reference is lung)		
Colon	−3†	−52
Prostate	0	5
Breast	3	58
Pancreas	3	59
Bladder	−1	−12
Lymph	−1	−22
Ovarian	6	120
Kidney	−4	−85
Uterus	4	85
Other	3	53
Comorbidity index	9†	173†
Home hospice only	−126†	(2,525)†
Region (compared with Northeast)		
Pacific	7	137
Middle Atlantic	−10†	−196
East North Central	−18†	−361†
West North Central	−44†	−887†
South Atlantic	−14†	−282†
East South Central	−15†	−307
West South Central	−20†	−409†
Mountain	−31†	−621†

*Models are estimated using generalized estimating equations with a gamma distribution and log link accounting for days from patient's hospice enrollment to death and year. Medicare expenditures include hospice care, hospital care, outpatient and physician services, home health care, and durable medical equipment and supplies.

†P value < .001.

‡P value < .05.

Types of Medicare Expenditures for Hospice Disenrollees

Individuals with cancer who disenrolled from hospice incurred higher Medicare expenditures across all categories of care: hospice care, hospitalizations, physician visits, outpatient care, DMES, and home health care services (Fig 1). Average total Medicare expenditures for the group who stayed with hospice were \$6,537 from hospice enrollment to death, and 89% of these expenditures were for hospice care. Average Medicare expenditures for individuals who disenrolled from hospice were \$30,848, 39% of which were for hospice care and 38% for hospitalizations.

DISCUSSION

Patients with terminal cancer who disenrolled from hospice had significantly higher rates of hospitalization, including ED and ICU admissions, and were more likely to die in the hospital than pa-

Fig 1. Average total Medicare expenditures for patients with cancer by hospice disenrollment (unadjusted).

tients who remained with hospice until death. More than one in 10 patients with terminal cancer who enrolled in hospice disenrolled. Of the disenrollees, 25% were immediately hospitalized and the majority died within 1 month of disenrollment, suggesting that the reason for hospice disenrollment was not improved health status. Furthermore, 38% of disenrollees exhibited a pattern of hospice enrollment-disenrollment-re-enrollment, the causes and consequences of which are unknown.

Our study has implications for oncologists who refer patients to hospice. The association between hospice disenrollment and higher rates of hospitalization, as well as the cycle of hospice enrollment and disenrollment observed for a subset of these patients, suggests that hospice disenrollment should be considered a marker for case complexity. Oncologists may find that outpatient palliative care teams, where available, may be able to provide some aspects of the multidisciplinary care, symptom control, and end-of-life planning expertise that hospice offers in a context that enables a patient and family to maintain contact with the oncology clinic. Future work should explore the value of nonhospice palliative care teams¹⁶ in managing patients who disenroll from hospice.

Of importance for policy makers, the association between hospice disenrollment and increased health care use translates directly into significantly higher Medicare expenditures for disenrollees. Forty percent of Medicare's total expenditures for hospice users with cancer were accounted for by only 5% of hospice users with cancer, and a primary correlate of higher Medicare expenditures was whether a patient disenrolled from hospice. This finding is salient because expenditures for hospice users under the MHB have grown to \$11.4 billion as of 2008¹⁷ and have become a focus of concern of both the Medicare Payment Advisory Commission (MedPAC) and Congress. Policymakers have called for tightening eligibility restrictions for the MHB as part of a wider effort to reduce high Medicare expenditures;¹⁸ our results suggest that addressing hospice disenrollment may be an effective means of reducing Medicare expenditures for hospice users without restricting access to the MHB. Options include better understanding of why some hospices have substantially higher disenrollment rates than

others,⁴ requiring hospices to track disenrollment rates and the reasons for hospice disenrollment, and interventions to support patients and families who have disenrolled.

Although there are a number of strengths of this study, including the longitudinal nature of the data, the large sample size, and innovative approach of evaluating both hospice and nonhospice use and Medicare expenditures from hospice enrollment to death, there are also limitations. With our data we are unable to identify the reasons for hospice disenrollment. The short time from hospice disenrollment to death suggests that ineligibility for the MHB was not a likely factor in disenrollment in this sample. Future studies that include patient and caregiver interviews are needed to understand the factors that motivate hospice disenrollment. Our sample includes individuals with cancer who used hospice and died between 1998 and 2002 and thus may not be generalizable to individuals with cancer who used hospice and did not die within the period 1998 to 2002. However, using existing data,¹⁹ we estimate that approximately 94% of individuals with cancer who used hospice during 1998 to 2002 would have also died within the period 1998 to 2002. In addition, by restricting our sample to decedents, it is likely that hospice care was clinically appropriate for the individuals in the study, and thus our results are informative for understanding the use of hospice care at the end of life. Our results differ from a previous study²⁰ that found no difference in costs per day for hospice disenrollees compared with those for individuals who remained with hospice until death. However, that study compared only unadjusted average expenditures and used a substantially smaller sample size. Finally, our sample does not include individuals who were enrolled in a Medicare managed care organization before hospice enrollment, and thus our findings may not be generalizable to this group.

Our findings have implications for both clinical practice and policy. Oncologists should view hospice disenrollment by their patients as a marker for patient complexity and be aware of the increased probability that such patients will be hospitalized, perhaps multiple

times, and often in their last few weeks of life. Strategies to support patients who have disenrolled from hospice and their families, including the use of a palliative care consultation at the time of hospice disenrollment, may be beneficial and should be explored. From a policy perspective, proposals aimed at decreasing access to hospice as a means to control costs may be detrimental to oncologists who rely on the support and assistance that hospice teams provide in the care of their patients with terminal cancer. A more targeted approach to decreasing Medicare expenditures for hospice users may be to better understand the processes of care and patient and family decision making related to hospice disenrollment and to develop strategies to better manage the patient's care and support the family following hospice disenrollment.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

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