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Impact of Individual and Market Factors on the Timing of Initiation of Hospice Terminal Care

NICHOLAS A. CHRISTAKIS, MD, PhD, MPH,^{*} AND THEODORE J. IWASHYNA, AB[†]

CONTEXT. Hospice terminal care is now used by 10% to 15% of elderly Americans at variable points before their deaths.

OBJECTIVE. By examining the duration of patient survival after enrollment in hospice care, we sought to identify individual and market factors associated with the timing of hospice use.

DESIGN. We linked Medicare claims, census information, and Area Resource File data to form a national cohort of 151,410 hospice patients admitted in 1993 and followed up until late 1996. We examined this cohort with Cox regression and other means.

MAIN OUTCOME MEASURE. The primary outcome measure was survival after hospice enrollment.

RESULTS. The patients had a mean $\pm$ SD age of 79.0 $\pm$ 7.4 years; 10.2% were nonwhite; 51.4% were female; and 71.3% had cancer. Median survival after hospice enrollment was 30 days (interquartile range, 10–86 days). After adjustment for measured patient, provider, and market factors, several variables were as-

sociated with relatively earlier hospice enrollment, farther from death. Compared with complementary groups, nonwhites were enrolled in hospice 4 days earlier; women, 5 days earlier; older people, 1 day earlier; and those with substance abuse, psychiatric disease, or dementia, each 3 days earlier. After adjustment, income and education were not associated with the timing of enrollment. Patients residing in markets with more hospital beds, greater hospice capacity, or a higher proportion of generalists were enrolled earlier.

CONCLUSIONS. Even after adjustment for certain clinical attributes, individual social factors and local market factors were associated with survival after hospice enrollment. Certain socially disadvantaged groups were enrolled earlier, as were those residing in areas with more medical institutions. The decision to enroll patients in hospice may depend on both non-clinical and clinical factors.

Key words: hospice care; Medicare; claims; socioeconomic factors; terminal care; prognosis. (Med Care 2000;38:528–541)

Hospice is a form of terminal care that emphasizes relief of patients' physical and emotional pain and suffering more than treatment of the underlying disease. More than 80% of the time, hospice

care in the United States is provided by visiting nurses and other staff in patients' own homes. Medicare introduced a hospice benefit in 1982, and it currently pays for virtually all people ≥ 65

^{*}From the Departments of Medicine and Sociology, and the Center on Aging and Population Research Center, University of Chicago, Chicago, Illinois.

[†]From the School of Medicine, Harris Graduate School of Public Policy Studies, and the Center on Aging and Population Research Center, University of Chicago, Chicago, Illinois.

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Address correspondence to: Nicholas A. Christakis, MD, Section of General Internal Medicine, University of Chicago Medical Center, 5841 S Maryland Ave, MC 2007, Chicago, IL 60637.

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years of age who receive hospice care, spending more than \$1.5 billion annually (Health Care Financing Administration [HCFA], unpublished data). Of the 1.6 million people ≥ 65 years of age who die annually in the United States, 10% to 15% receive some hospice care, a percentage that is approximately equivalent to the percentage of Americans who die under nursing home care. Hospice is thus an important source of end-of-life care today.

In this sizable population of patients, how is this care currently being used? When in the course of illness do patients use hospice, how long before death? To what extent do social factors and local market attributes influence the timing of hospice enrollment? What is the relative importance of such attributes compared with patient diagnosis and other individual clinical factors? And how do patterns of hospice use compare to physicians' stated ideals? To answer such questions, we examined a complete enumeration of 151,410 Medicare patients newly admitted to hospice programs in 1993 and followed up until late 1996, the most recent data with such long follow-up available.

Methods

Data Sources and Cohort Development

From the HCFA, we obtained the standard analytic file regarding hospice use for all Medicare patients admitted to hospice programs during 1993. Additional HCFA data files included 1991, 1992, and 1993 Medicare Provider Analysis and Review (MEDPAR) files regarding hospitalizations; vital status files containing dates of death (with follow-up until August 20, 1996); and the 1993 provider of services (POS) file describing the hospices.¹ We also used data from the 1990 census files² and the 1996 release of the Area Resource File (ARF).³

Data were linked across HCFA sources at the individual patient level by use of patients' unique health insurance claim numbers. We linked to data from the 1990 census using patients' ZIP codes at the time of hospice enrollment; this was done to impute patient income and education on the basis of small regional levels of these features, a technique that has been partly validated with respect to these particular variables.^{4,5} In keeping with past work,⁶⁻⁸ we used the county in which the patient resided at the time of hospice admission as

a proxy for the local health care market and obtained data about this market from the ARF. For both ZIP code- and county-level data, the use of such geographic linkages is subject to certain limitations in application and interpretation that we have accommodated as much as possible.^{9,10}

There were 215,089 Medicare beneficiaries who received hospice care in 1993. However, only 185,147 were patients who were newly admitted to a hospice under the Medicare benefit in 1993, ie, were incident hospice users. We deleted 304 of these cases (0.16%) because they had inconsistent or illogical data elements, resulting in a cohort of 184,843 patients. Using the highly accurate and complete vital status files, we obtained mortality follow-up for these individuals through August 20, 1996, when all observations were censored by a fixed right mechanism (a minimum of 32 months of follow-up). On this date, only 4,815 patients (2.6% of this cohort) were still alive.

The cohort examined here, consisting of 151,410 individuals, had 2 additional, intentional restrictions imposed on it. From the 184,843 individuals, we eliminated 6,396 people who resided outside of the continental United States and 20,192 people who were not ≥ 67 years old; the latter restriction was necessary so that we would be able to look back in the Medicare hospital claims for a full 2-year period for all individuals (for example, a 66-year-old person would generally have been enrolled in Medicare for 1 year at most, thus preventing a full 2-year look back). After these 2 restrictions, there were 158,255 such incident hospice enrollees. We imposed an exclusion on this group dictated by data constraints, eliminating 6,845 individuals (4.3%) who were missing data from the POS, census, or ARF files; however, the results presented here are not sensitive to this exclusion (data not shown).

Patient-Level Variables

We obtained the patients' gender, age, and race from the vital status file. For race, HCFA data from the years we are examining do not support examination beyond a "white" versus "nonwhite" dichotomy.¹¹ Because of an evident nonlinear relationship between age and hospice survival, we modeled this variable with a quadratic term in addition to a linear one. Other variables did not show any meaningful nonlinearity that suggested alternative modeling approaches. The condition

reported in the standard analytic file to be the cause of the patient's hospice admission, using ICD-9 codes, was defined to be the patient's "principal diagnosis." We grouped principal diagnoses into 26 categories; our taxonomy reflected clinical considerations about the similarity of the diseases, statistical considerations to ensure that no one category was too large or small, and consistency with previous work. We used patient ZIP code of residence on hospice admission to impute patients' income and education levels. The average years of education completed was constructed from a weighted average of the number of people in each of 7 education categories.

For each individual, we obtained several measures of in-patient hospital use and comorbidity by using MEDPAR information about hospitalizations during the 730 days preceding hospice admission. For example, we counted the number of hospitalizations in the previous 730-day period and the total number of hospital and intensive care unit days in the previous 730- and 30-day periods. Using the discharge diagnoses and the procedure codes available on any and all hospitalizations occurring during the 730-day look-back period, we developed measures of psychiatric illness, substance abuse, and dementia (a list of codes is available from the authors).

We used the MEDPAR data and a modification of the Deyo et al¹² and the Romano et al¹³ methods to develop a Charlson comorbidity score¹⁴ for every patient, a technique not without limitations.^{15,16} This comorbidity score ranges from 0 to a theoretical maximum of 29 and is based on the presence of certain diseases with assigned point values. For example, dementia contributed 1 point; severe diabetes, 2 points. There were 26,828 patients in the cohort (17.7%) who did not experience hospitalization in the 730 days before hospice admission (a reliable period for developing this score¹⁶); it was thus not possible to assign them a Charlson score. We defined a variable called "severe comorbidity" as representing cases wherein the Charlson score was ≥ 6 , and we assigned people without any hospitalizations to the lower category. Our findings were not sensitive to a number of alternative specifications, however, including using Charlson scores as a continuous measure or incorporating various adjustments for cases in which the Charlson score was unavailable because of a lack of hospitalizations (data not shown).

Provider-Level Variables

We developed 4 variables regarding each patient's hospice provider by using data in the POS file: (1) the number of years in operation under Medicare as of 1993, which we dichotomized at 5 years to indicate "new" hospices; (2) an indicator of type of provider with the following 4 categories: free-standing hospice, home health agency, nursing home-operated hospice, and hospital-operated hospice; (3) an indicator of for-profit versus not-for-profit status; and (4) an indicator of whether the hospice had ever changed ownership since becoming Medicare certified. We also developed an indicator of size based on the number of new patients admitted in 1993 ("small" hospices were those admitting < 200 new patients) as observed in our data. Our interest in the impact of these variables is only incidental here, but they are included in the regression model as controls.

Market-Level Variables

We used patient county of residence to define several variables regarding the local health care market. Our choice of variables was guided by prior work on health care variation at the market level.^{6,17-19} Using ARF data, we quantified the number of hospital beds, nursing home beds, and skilled nursing facility beds per 1,000 people ≥ 65 years of age in the patient's county of residence. We measured the number of doctors per 1,000 people ≥ 65 years of age, as well as the proportion of physicians who were primary care practitioners. We were especially interested in the possible influence of physician specialty given past work in this area.²⁰ We quantified the percentage of all people in HMOs as a measure of HMO market penetration, and we considered markets to have "high" HMO penetration if $\geq 25\%$ of the inhabitants were HMO members. As a measure of urbanization, we observed whether the county had a high ($> 1,000$ people per square mile) population density. Finally, using our data as a numerator, we quantified the number of hospice patients per 1,000 people ≥ 65 years of age admitted in each county and established the percentage of these patients who were admitted to for-profit hospices (as a county-level measure of for-profit hospice market penetration).

Statistical Analysis

We estimated the cohort survival function using the Kaplan-Meier method, and we used Cox regression to assess the association between duration of survival after hospice enrollment and various patient and market attributes.²¹ The dependent variable was survival from hospice enrollment until death in days. In Cox regression, the association between a variable and survival is expressed as a "hazard rate" or "risk ratio," which is interpreted similarly to an odds ratio. In the present context, a risk ratio greater than unity is associated with a higher risk of death and therefore a shorter survival time after hospice enrollment, which can be interpreted as later enrollment, closer to death, and vice-versa. The model was evaluated for important violations of the proportionality assumption. We also used the model to assess the baseline hazard function and therefore to obtain median survival for variables after adjusting for all other measured covariates, quantities that are sometimes more understandable than risk ratios. To control for the natural clustering of hospice patients within markets, we used the method of White²² as implemented by Allison.²³ This algorithm corrects the standard errors of the coefficients to take into account pseudoreplication and produces accurate confidence intervals and probability values, thus partially adjusting for one of the limitations of ecological data of the type we used for certain of our variables.^{9,10}

Results

Characteristics of Medicare Hospice Patients

A summary of the attributes of members of the cohort, their hospice providers, and their local health care markets is provided in Table 1. These patients were cared for in a total of 1,366 hospice programs and resided in a total of 2,649 counties. The mean $\pm$ SD age of the 151,410 patients in the study cohort was 79.0 ± 7.4 years, and 51.4% were female. Of the patients in the cohort, 71.3% had cancer of some type, with lung cancer, colorectal cancer, and prostate cancer being the leading cancer diagnoses (Table 1). Leading noncancer diagnoses include congestive heart failure and chronic obstructive pulmonary disease. A history

of substance abuse was noted in 4.0% of patients, of psychiatric disease in 7.8%, and of dementia as a comorbid condition (distinct from those with a principal diagnosis of dementia) in 4.9%.

The median survival after hospice enrollment was 30 days (interquartile range, 10 to 86 days). A substantial minority of patients, 19.2%, died within 7 days of enrollment; at the other extreme, 13.7% lived > 180 days, and 7.2% lived > 1 year.

Factors Associated With the Timing of Hospice Enrollment Before Death

Table 2 shows the results of a multivariate Cox model of survival after hospice enrollment involving patient, hospice, and market characteristics. The sample was large, so the effects of variables could be measured well and reach statistical significance at the customary level, but more important, many of the variables of interest had effects of meaningful size. The patient's principal diagnosis was an important determinant of survival after enrollment. Moreover, measures of illness burden and health care use were associated with shorter survival after hospice enrollment; specifically, having a Charlson comorbidity score of ≥ 6 was associated with a 20.4% increase in the hazard of death and thus shorter survival after enrollment, and each 1-day increment in the number of hospital days used in the 30 days preceding hospice admission was associated with a 0.9% increase in the hazard of death.

After adjustment for the foregoing clinical attributes and for other provider and market factors, several demographic and clinical variables were associated with the duration between enrollment and death. As before, Table 2 gives estimates of these effects in terms of the hazard of death. Table 3 gives the adjusted median survival in terms of days, according to certain patient attributes of more specific interest here. At the median, non-white patients were enrolled in hospice 4 days (13%) earlier before death compared with whites; women were enrolled in hospice 5 days (17%) earlier before death compared with men; older people were enrolled 1 day (3%) earlier before death than younger people (comparing 84 and 73 year olds); and those with substance abuse, psychiatric disease, or dementia were, on average and after adjustment for all other factors, enrolled 3 days (10%) earlier before death. After adjustment for the other covariates, income and education

TABLE 1. Characteristics of the 1993 Medicare Hospice Patient Study Cohort*

Patient attributes	
Demographics	
Mean age, y	79.0 ± 7.4
Female gender, %	51.4
Nonwhite race, %	10.2
Mean annual income, \$	31,540 ± 11,580
Mean education, y	12.8 ± 1.0
Health care use measures	
Had >0 hospitalizations in 365 days preceding hospice, %	76.0
Had >0 hospitalizations in 730 days preceding hospice, %	82.3
Mean days spent in hospital in 730 days preceding hospice	27.4 ± 36.3
Mean hospitalizations in 730 days preceding hospice, n	2.5 ± 2.4
Mean days spent in hospital in 30 days preceding hospice	6.0 ± 8.3
Mean days spent in ICU care in 730 days preceding hospice	2.3 ± 6.3
Spent >0 days in ICU care in 730 days preceding hospice, %	32.7
Mean DRG expenditures in the 730 days preceding hospice, \$	14,860 ± 16,280
Health measures	
Mean Charlson comorbidity score [†]	4.8 ± 2.7
Charlson score ≥6, %	41.6
History of substance abuse, %	3.96
History of psychiatric problem, %	7.80
History of dementia as a comorbid condition, [‡] %	4.85
Diagnosis at enrollment into hospice, %	
Neoplasms	
Head and neck	1.64
Upper gastrointestinal tract	3.24
Colon and rectum	8.99
Hepatobiliary system	2.84
Pancreas	4.30
Lung	19.38
Skin	0.81
Breast	4.80
Female genital tract	2.97
Prostate	7.00
Urinary tract	3.26
CNS	1.98
Lymphoma	1.90
Leukemia	2.63
All others	5.59
Nonneoplasms	
Dementia	2.33
Parkinson's disease	0.73
Stroke	3.12
Other neurological diseases	0.77
Congestive heart failure	5.51
Other cardiovascular diseases	4.40
COPD	4.22
Liver disease/failure	0.86
Renal disease/failure	1.96
Infections	0.71
All others	4.07
Market attributes [§]	
Mean hospital beds/1,000 people ≥65 y, n	27.1 ± 15.8
Mean nursing home beds/1,000 people ≥65 y, n	46.5 ± 21.8
Mean SNF beds/1,000 people ≥65 y, n	1.9 ± 4.1

(Continues)

TABLE 1. (Continued)

Mean new hospice patients/1,000 people ≥ 65 y, n	7.6 $\pm$ 11.5
Mean new hospice patients at for-profit hospices, %	18.1 $\pm$ 26.8
Mean doctors/1,000 people ≥ 65 y, n	20.5 $\pm$ 13.9
Mean physicians who are generalists, %	30.7 $\pm$ 14.2
$\geq 25\%$ of people in HMOs, %	25.8
Population density >1,000 people/sq mile, %	37.7
Hospice attributes, ^S %	
Small size (<200 admissions/y)	41.4
New hospice (<5 y since Medicare certification)	31.1
Change in ownership since certification	9.0
For profit	18.3
Operated by hospital	18.6
Operated by SNF	2.1
Operated by home health agency	30.3
Operated by free-standing hospice program	49.0

CNS indicates central nervous system; COPD, chronic obstructive pulmonary disease; and SNF, skilled nursing facility.

*Descriptive statistics regarding patients and, on a patient level, markets in which these patients reside are provided for the 151,410 members of the study cohort.

[†]The Charlson score here is based only on those 124,582 patients who had ≥ 1 hospitalization in the 730-day look-back period and for whom, as a result, the score was determinable.

[‡]This variable characterizes the presence of dementia as a comorbidity in those 97.7% of patients for whom dementia is not the principal diagnosis.

^SThese variables are expressed at the patient level.

were not associated with the duration between hospice enrollment and death (Table 2). The even greater impact of some of these variables in combination is illustrated in the Figure. For example, after adjustment for all other measured factors, the median time before death that patients were referred to hospice was 26 days for white men versus 37 days for black women, and it was 31 days for patients without substance abuse or psychiatric disease versus 36 days for those with both of these traits.

Certain market factors were meaningfully associated with the time between hospice enrollment and death among patients who were enrolled (Table 2). An increase in the number of hospital beds (but not of nursing home beds) per 1,000 people ≥ 65 years of age was associated with a decrease in the hazard of death and thus relatively earlier enrollment. An increase in the number of hospice patients per 1,000 people ≥ 65 years of age newly admitted to hospice in the local county was also associated with earlier enrollment. An increase in population density or in for-profit hospice market penetration (but not in HMO market penetration) was associated with later enrollment. The number of physicians per capita was not associated with timing of hospice enrollment, but an increase in the percentage of generalist physi-

cians was associated with earlier enrollment. If a market with a structure conducive to late enrollment (eg, hospital beds per capita of 17.2 per 1,000 people ≥ 65 years of age, nursing home beds of 30.1, and hospice patients of 5.1, all values at about the 25th percentile for each variable) was compared with a market with values of these variables conducive to early enrollment (eg, hospital beds of 34.6, nursing home beds of 56.8, and hospice patients of 9.4, all values at about the 75th percentile for each variable), then the difference in median survival, even with individual and hospice provider attributes and other market traits held constant, would be 29 compared with 32 days.

Discussion

Duration of patient survival after hospice enrollment, as an indicator of the timing of enrollment, is an important outcome to observe in end-of-life care because it is relevant to the quality and cost of terminal care that patients receive.^{20,24,25} Previous work describing hospice care has focused on clinical attributes of patients associated with their survival after enrollment, and it has found, as have we, that clinical factors, such as

TABLE 2. Attributes Associated With Survival After Enrollment in Hospice Terminal Care*

Variable	Hazard Ratio (95% CI)
Patient demographics	
Age, per year	0.97 (0.96–0.98) [‡]
Age squared, per 100 y squared	1.02 (1.01–1.03) [‡]
Female gender	0.84 (0.83–0.85) [‡]
Nonwhite race	0.91 (0.89–0.94) [‡]
Annual income, per \$10,000	1.00 (0.99–1.02)
Education, per year	1.01 (0.99–1.03)
Patient health measures and health care use	
History of substance abuse	0.95 (0.92–0.97) [‡]
History of psychiatric problem	0.94 (0.91–0.96) [‡]
History of dementia as a comorbid condition	0.93 (0.90–0.96) [‡]
Days spent in hospital in 30 days preceding hospice, per day	1.01 (1.01–1.01) [‡]
High comorbidity (Charlson score ≥ 6)	1.20 (1.19–1.22) [‡]
Patient diagnosis	
Neoplasms	
Head and neck	0.90 (0.87–0.93) [‡]
Upper gastrointestinal tract	0.98 (0.95–1.01)
Colon and rectum	0.88 (0.87–0.90) [‡]
Hepatobiliary system	1.20 (1.16–1.24) [‡]
Pancreas	1.03 (1.01–1.06) [‡]
Skin	1.02 (0.97–1.08)
Breast	0.83 (0.81–0.85) [‡]
Lung	1.00
Female genital tract	0.98 (0.95–1.01)
Prostate	0.74 (0.73–0.76) [‡]
Urinary tract	0.94 (0.91–0.96) [‡]
CNS	0.90 (0.87–0.93) [‡]
Lymphoma	1.15 (1.10–1.20) [‡]
Leukemia	1.05 (1.01–1.09) [†]
All others	0.97 (0.95–0.99) [†]
Nonneoplasms	
Dementia	0.59 (0.56–0.63) [‡]
Parkinson's disease	0.63 (0.59–0.68) [‡]
Stroke	0.92 (0.86–0.98) [†]
Other neurological diseases	0.73 (0.68–0.78) [‡]
Congestive heart failure	0.75 (0.72–0.78) [‡]
Other cardiovascular diseases	0.71 (0.67–0.76) [‡]
COPD	0.67 (0.64–0.69) [‡]
Liver disease/failure	1.02 (0.95–1.09)
Renal disease/failure	1.30 (1.22–1.38) [‡]
Infections	1.06 (0.97–1.14)
All others	0.82 (0.79–0.85) [‡]

(Continues)

TABLE 2. (Continued)

Variable	Hazard Ratio (95% CI)
Market attributes	
Number of hospital beds/1,000 people >65 y, per 10 beds	0.99 (0.98–0.99) [†]
Number of nursing home beds/1,000 people >65 y, per 10 beds	1.00 (0.99–1.00)
Number of SNF beds/1,000 people >65 y, per 10 beds	1.01 (0.99–1.04)
Number of hospice patients/1,000 people >65 y, per 10 patients	0.96 (0.94–0.97) [‡]
For-profit hospice patient market share, per 10% >25% of people in HMOs	1.01 (1.01–1.02) [‡] 1.03 (0.99–1.08)
Number of doctors/1,000 people >65 y, per 10 doctors	1.00 (0.99–1.02)
Percentage of physicians who are generalists, per 10%	0.98 (0.98–0.99) [‡]
Population density >1,000 people/sq mile	1.05 (1.01–1.11) [†]
Hospice provider attributes	
Operated by a hospital	1.00
Operated by SNF	1.20 (1.11–1.31) [‡]
Operated by home health agency	1.02 (0.99–1.05)
Operated by free-standing hospice program	0.95 (0.92–0.98) [‡]
Small size (<200 admissions/y)	0.98 (0.96–1.01)
Change in ownership since certification	1.04 (0.96–1.13)
New hospice (<5 y since certification)	0.93 (0.91–0.96) [‡]
For profit	0.97 (0.92–1.02)

Definitions as in Table 1.

*The table shows a Cox proportional hazards regression model giving the “hazard” or risk ratios and 95% CIs of survival after referral to hospice depending on patient, hospice provider, and local market attributes in a sample of 151,410 Medicare beneficiaries. Analogous to odds ratios, risk ratios greater than unity imply a correspondingly increased risk of death and hence shorter survival time after hospice enrollment and vice versa. All dichotomous variables were coded as 1=present and 0=absent. Lung cancer is the reference category for diagnosis, and “operated by a hospital” is the reference category for hospice type. Confidence intervals have been adjusted to account for the natural clustering of patients into hospice markets (see text).

[†] $P < 0.05$; [‡] $P < 0.001$.

more severe illness (eg, our measures of hospital use or comorbidity), are associated with shorter survival.^{26–28} Here, using a virtually complete national enumeration of Medicare hospice patients and measuring a broad set of variables drawn from Medicare claims and other sources, we focused on socioeconomic and market factors that are associated with timing of hospice enrollment and found important effects for certain of these factors.

Our major finding is that several variables ordinarily associated with shorter survival or worse health outcomes,^{29–34} including, eg, nonwhite race, lower education, lower income, psychiatric history, substance abuse history, dementia history, and advanced age, were associated with longer survival after hospice enrollment. For most of these variables,

this held true after adjustment for each other and for other clinical, provider, and market factors. As shown in Table 3 and the Figure, these factors, even taken individually, are of a potentially clinically significant magnitude (up to a 30% impact on the median survival, depending on the variable, and more if variables are taken in combination). The existence of a pattern in the results, wherein the impact of being within any disadvantaged group had a similar effect, supports the supposition that such factors are associated with an earlier hospice enrollment rather than with some beneficial effect of these factors on survival after enrollment.

There are other possible explanations for short or long survival durations after hospice enrollment that our study and all other studies of hospice

TABLE 3. Adjusted Median Survival After Enrollment in Hospice (in Days) According to Certain Patient Attributes*

Attribute	Absent	Present
Nonwhite	30	34
Female	29	34
Advanced age [†]	30	31
Low income [†]	30	31
Low education [†]	30	31
History of substance abuse	30	33
History of psychiatric disorders	30	33
History of dementia	30	33

*All figures represent the effects of the variable in question, holding all other variables constant at their mean and adjusting for all of the variables presented in the Cox regression in Table 2. Except for income and education, all of these differences are statistically significant at $P = 0.05$ level.

[†]This is a continuous variable for which median adjusted survival was computed for the 25th percentile ("absent") and 75th percentile ("present") for age and vice versa for income and education.

patients (which have involved solely patients enrolled in hospice observed only from the time of enrollment) cannot exclude. For instance, it is conceivable that hospices have differential effects on mortality after enrollment; eg, hospice care might somehow shorten life in patients without a history of comorbid dementia but not shorten it in those with such a history. Although such an effect would explain the results and cannot be ruled out with the data at hand, it does not seem credible. Moreover, 2 small, randomized, controlled trials of hospicelike care did not suggest any effect of hospice care in shortening survival in general.^{35,36} Alternatively, possibly the only people referred to hospice are those members of the subgroups defined by these variables who, even in the absence of hospice, would have survived unusually long (ie, there might be selection into hospice). However, such differential referral would need to be taking place on the basis of things other than attributes we measured, ie, based on factors other than the patient's primary diagnosis, comorbidities, age, race, gender, prior hospital utilization, income, or education. Overall, we believe that a more parsimonious explanation is the differences in the timing of enrollment along the characteristics we describe. That is, we believe it is more likely that nonwhite patients, for example, are enrolled

in hospice relatively early than that nonwhite race is conferring a survival advantage to patients after enrollment.

If certain groups are being enrolled in hospice earlier than others, why might this be occurring? Our data do not permit definitive conclusions, but there are at least 4 possible explanations. First, predictions of death or evaluation of symptoms may be more difficult in some patients (eg, in those with dementia or psychiatric disturbance), thereby complicating decisions about when to switch from traditional medical care to hospice care and leading to earlier referral. Faced with prognostic or clinical indeterminacy near the end of life, for example, physicians may choose to refer such patients relatively early. However, most research suggests that, if anything, prognostic uncertainty results in postponement of hospice referral.³⁷⁻⁴¹ Second, outside help may be brought in more quickly by family members, physicians, or other concerned parties for those patients likely to be difficult to care for at the end of life (eg, those with dementia, psychiatric disorders, or substance abuse problems) or those who usually fill the caregiving role and therefore possibly lack a caregiver themselves (eg, women). That is, the preferences of the members of the groups defined by our variables may be to favor earlier use of hospice care. However, some prior work examining the relevance of patients' social support for the timing of hospice enrollment has tended to show that, if anything, lack of social support delays enrollment in home-based hospice care.⁴²⁻⁴⁴ Lack of social support (eg, being a widow) may indeed preclude hospice care altogether, a contention suggested by the fact that women in our sample are less numerous (51.4%) than in the underlying Medicare population as a whole (59%). A third possibility is that physicians who make referrals to hospice may be less willing, for psychological reasons, to accept the nearness of death in people resembling themselves (eg, those who are educated, young, and without dementia, substance abuse, or psychiatric illness) and so underestimate its nearness in such people and delay referral. Fourth and finally, socially stigmatized groups may possibly be seen as less appropriate for the costly, aggressive, "curative" care that is ordinarily offered in the period preceding the use of hospice and so might be referred to hospice relatively early, in a form of "turfing."⁴⁵⁻⁴⁸ Disquieting support for some role for the fourth explanation comes from previous examinations of the role of race,^{7,48-52} gender,⁴⁸

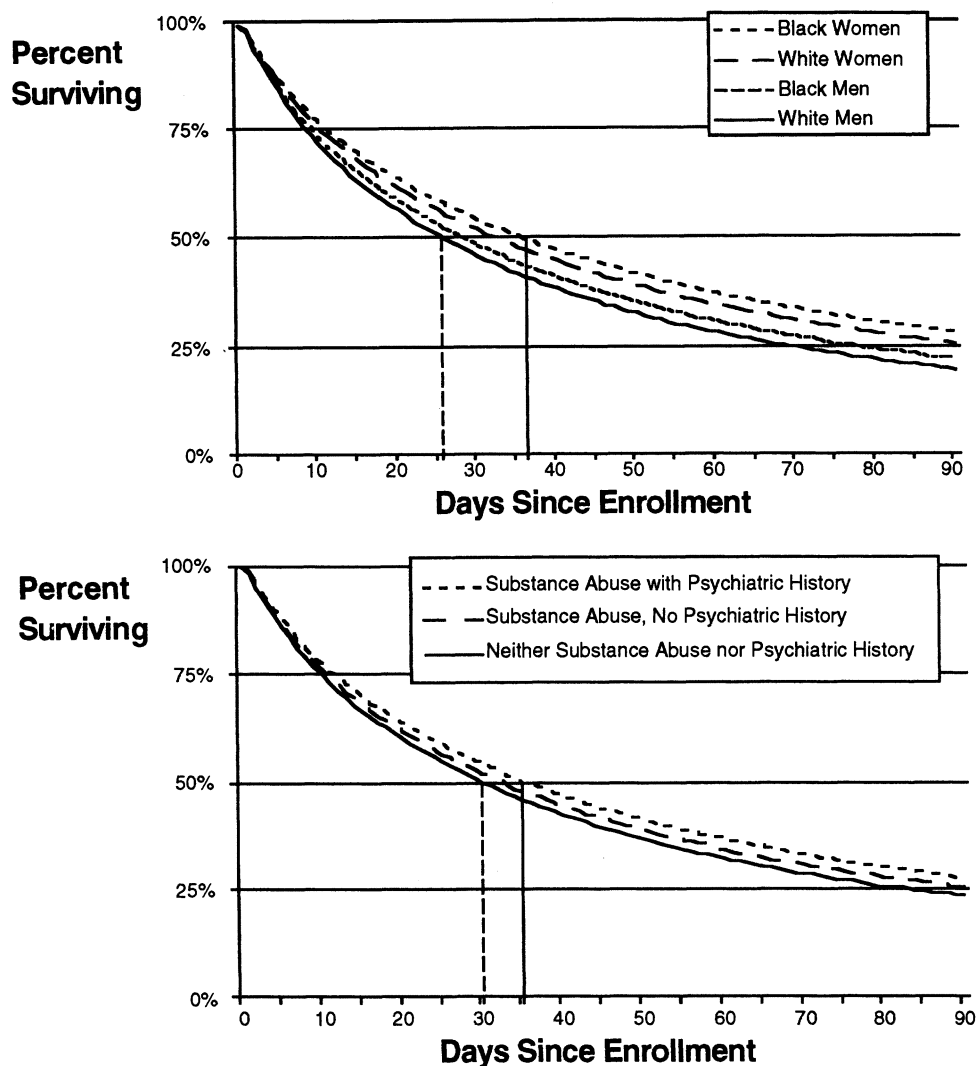


FIG. Adjusted 90-day survival after hospice enrollment as estimated in selected subpopulations. These curves show differences in survival profiles after hospice enrollment. Curves adjust for all factors considered in Table 2; ie, these curves remove any differences in survival between groups resulting from primary diagnosis, type of hospice chosen, market in which patient resided, and other measured individual-level characteristics, such as age, income, and Charlson comorbidity score. Bottom, Curve that would have been displayed for those patients with psychiatric history but no history of substance abuse almost exactly coincides with displayed line for those with history of substance abuse but not of psychiatric history and so is suppressed.

age,^{53,54} education,⁵⁴ and psychiatric illness⁵⁵ in access to and use of medical technology in general. To sort out which of these 4 explanations, if any, explain the patterns we observe requires further research. It is worth noting, however, that even if referral to hospice is occurring earlier in some patients than in others for reasons that are possibly inappropriate, this might not actually be

harming such patients if hospice referral is occurring too late for patients in general. Indeed, hospice care appears to be used later in the course of illness than most physicians prefer.²⁰

Our second main finding is that certain features of local health care markets are associated with duration of survival after hospice enrollment, even after adjustment for individual patient attributes.

Patients residing in counties with more medical infrastructure of certain types were enrolled in hospice earlier, farther from death. In the case of hospital beds specifically, this may have resulted because, at the individual patient level, discharge from a hospital to a hospice may be a way to decrease costs for a hospital caring for a seriously ill patient. This specific finding is perplexing, however, and appears to run counter to work on the impact of hospital bed capacity on home death.⁵⁶ It is possible that hospital bed capacity is associated with a low likelihood of using hospice but also with an earlier enrollment of patients when they are actually enrolled; more research is required to sort out such complex effects. Although the number of doctors per capita was not associated with timing of referral, a higher proportion of generalists was associated with earlier referral, a finding in keeping with past work that suggests that, compared with specialists, generalists favor earlier hospice referral, perhaps because they are more willing to cease aggressively curative efforts.²⁰ The effect of for-profit hospice market penetration, while appreciable and associated with later enrollment, is somewhat harder to account for. One possible explanation is that markets with higher for-profit hospice penetration are more competitive, driving all hospices to accept "marginal" patients with what might prove to be short survivals.

In keeping with some past work on market variation in health care use,¹⁸ we generally found that the measured role of market factors was smaller than the role of individual factors. Although market-to-market variation in survival after enrollment remains meaningful even after adjustment for multiple patient and hospice provider attributes, it seems quantitatively less important than each of the several individual-level patient traits we have considered. However, market-to-market variation in timing of hospice use was not negligible either. Recent work has shown substantial geographic variation in other forms of health care at the end of life and has suggested that local health resources, such as the availability of hospital or ICU beds, may partly explain this variation.¹⁷ In our analysis, these effects persisted after adjustment for important covariates at the individual patient and hospice provider level.

Our work has several limitations. First and most important, only patients actually enrolled in hospice programs were studied; hence, only timing of enrollment for such patients was examined. Sec-

ond, our analysis is restricted to (elderly) Medicare patients; however, Medicare beneficiaries account for ~80% of all hospice patients (elderly and nonelderly). Third, the performance status and certain other clinical details of patients were not available; however, we did adjust for comorbidity and hospital resource use. Moreover, the absence of performance status would only subvert the direction of our results if performance status were substantially better in the older, nonwhite, demented, etc., subgroups, which seems unlikely. Fourth, duration of illness before hospice enrollment was not examined; however, 2 years of prior health information was extracted. And fifth, no information was available about the referring physicians, patient preferences, or possibly important market factors (eg, home health agency availability).

Health care decisions at the end of life are made at a time when patients are at their most vulnerable. In general, patients get only one chance to elect hospice care, and if the care is inadequate for any reason, it is unlikely that they will have an opportunity to switch or improve on their choice. For these reasons, parties who contribute to the hospice enrollment process should act with the greatest probity. Because patients in general are, regardless of their attributes, enrolling in hospice late in the course of their illness, thought might be given to addressing some of the barriers to more timely referral. The apparent role of certain social and market factors in the timing of hospice enrollment suggests that it is not merely the patient's clinical status, but other factors as well, that influences this important end-of-life transition in care. This in turn suggests that it may be possible to change the way hospice is used.

Physicians recommend that hospice be used for ~3 months before death.²⁰ However, as we have seen, patients typically receive hospice care for about a third of this amount of time. To the extent, therefore, that changes in the timing of hospice enrollment are considered desirable, thought might be given to improving the timing of enrollment of patients with certain attributes. As individual physicians contemplate hospice referral for individual patients, there is likely to be an important influence on their decisions of historical patterns of hospice use or of the way colleagues treat similar patients. An explicit understanding of the factors that shape conventional practice thus allows practicing doctors to consciously choose how to optimize such practice. Because hospice care is

cost-effective^{57,58} and preferred by most patients,^{59–62} modifications in practice might help to rationalize care at the end of life from both patient and societal perspectives.

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