

Disease-Specific Patterns of Hospice and Related Healthcare Use in an Incidence Cohort of Seriously Ill Elderly Patients

THEODORE J. IWASHYNA, M.D., Ph.D.,¹ JAMES X. ZHANG, Ph.D.,²
and NICHOLAS A. CHRISTAKIS, M.D., Ph.D., M.P.H.³

ABSTRACT

There appears to be significant heterogeneity across diseases in their patterns of health care use at the end of life. We use a new, nationally representative sample of patients diagnosed in 1993 with 13 serious diseases to demonstrate this variation in rates of inpatient, outpatient, and hospice utilization. The diseases are: cancer of the lung, colon, pancreas, urinary tract, liver or biliary tract, head or neck, or central nervous system, as well as leukemia or lymphoma, stroke, congestive heart failure, hip fracture, or myocardial infarction. We present disease-specific rates of: length of stay, interhospital transfer, outpatient visits in the year before and 3 years after diagnosis, death within 4 years, and gender-specific hospice use rates among decedents. Among decedents with noncancer diagnoses, rates of hospice use vary from 5.9% to 8.7%. Among decedents with cancer diagnoses, rates vary from 15.2% to 35.2%. For the cohort overall, 14.2% of male decedents and 12.4% of female decedents used hospice. Patterns of end-of-life care vary substantially according to diagnosis.

INTRODUCTION

THERE APPEARS TO BE substantial heterogeneity in the use of hospice. Much research looking at hospice users has shown that they are more likely to be white, male, and cancer victims than a general sample of decedents. There is significant geographic heterogeneity in the fraction of decedents who die using hospice, as well.¹ Important differences in length of time in hospice—along clinical, demographic, and market structural lines—have also been found.^{2,3}

The sources of this heterogeneity are likely quite complex. Many have speculated that the

differences in predictability across diseases may explain some of the variation.⁴ Others have pointed to factors ranging from difficulties in funding to the inadequacies of physician prognostication.⁵ However, existing data sources are limited in their ability to adjudicate among the many possibilities. This is because nearly all existing data sources for the study of hospice look primarily at hospice users. As such, they lack an appropriate comparison group, i.e., similarly sick individuals who do not use hospice. Any exploration of differential hospice use must have data on both users and nonusers in order to understand the process by which some receive pallia-

¹Department of Medicine, Hospital of the University at Pennsylvania, Philadelphia, Pennsylvania.

²Department of Community and Family Medicine, School of Public Health, The Chinese University of Hong Kong, Hong Kong.

³Department of Health Care Policy, Harvard Medical School, Boston, Massachusetts.

tive care, and some die without it. In other words, a denominator-based sample of individuals at risk for hospice use needs to be examined.

In this paper, we describe initial results from a nationally representative prospective study of terminal illness. In an accompanying paper, we describe in detail the construction of the dataset, involving a cohort of over 1.2 million elderly Americans newly diagnosed with 1 of 13 serious illnesses in 1993.⁶ This cohort was followed forward through the end of 1997 to document patterns of health care use among the seriously ill. The diagnoses were intentionally chosen to be representative of causes of death in the United States and to have high mortality rates during the follow-up period. In this paper, we present the first direct demonstration of differences in rates of hospice use across diseases in a nationally representative sample of elderly patients diagnosed with serious disease and followed prospectively. The goal of this study is simply to describe basic differences in patterns of care in response to serious illness.

Among the reasons we pursue these descriptive results is the following. To the degree that hospice is felt to be beneficial, the variation in rates of hospice use among patients with serious disease can suggest those areas of medicine that have most integrated palliative care into their practice, and those diseases for which the most work needs to be done. By embedding our study of the use of hospice in a broader presentation of differences between diseases in their rates of inpatient and outpatient use following diagnosis with serious illness, we hope to spur further research and discussion about the treatment of the seriously ill.

METHODS

Data set description

The subjects analyzed here are drawn from the Care after the Onset of Serious Illness (COSI) dataset that we have built from Medicare claims.⁶ COSI contains detailed information about a cohort of patients with the new onset of a serious disease in 1993. The use of Medicare claims for such epidemiological purposes is described elsewhere.⁷ COSI contains clinical, demographic, and other information about a population-based cohort of more than 1.2 million elderly patients.

They were initially diagnosed in 1993 with 1 of 13 leading causes of death: cancer of the lung, colon, pancreas, urinary tract, liver or biliary tract, head or neck, or central nervous system, as well as leukemia or lymphoma, stroke, congestive heart failure, hip fracture, or myocardial infarction. We have utilization and mortality follow-up for at least 4 years for all patients. The University of Chicago Institutional Review Board (IRB) approved this research.

A single patient might qualify for more than one COSI disease-specific cohort during 1993. For tabulations of longitudinal health care utilization patterns, patients are tabulated only once, by the temporally first diagnosis that they have. Greater detail is available elsewhere.⁶

Inpatient utilization

Hospitalization records were taken from the Medicare Provider Analysis Review (MedPAR) file, an enumeration of all the final claims reimbursed by the Health Care Financing Administration (HCFA, now the Centers for Medicare & Medicaid Services) during a year. Hospitals bill HCFA quarterly for the care of their patients. As such, a patient whose stay spans two (or more) billing cycles may have two (or more) separate claims filed for the same hospitalization. As others have done,⁸ we identified any patient with multiple bills on which the discharge date of one was the same as or immediately preceded the admission data of the second. If these claims were filed from the same hospital, we declared them a billing artifact that represented, in truth, a single hospitalization for the patient for purposes of tabulating length of stay.

Outpatient utilization

"Outpatient care" is funded through two distinct mechanisms in Medicare. As a result, claims for this care are located in two different files: the so-called "outpatient" files, and the "physician/supplier" files. Additional details are available elsewhere.⁸⁻¹⁴

Outpatient claims contain a number of procedure codes and a few diagnostic codes that are of unclear validity. For the present purposes, we were interested in office visits with physicians. We thus defined physician visits as a visit to a physician (as defined by the provider specialty codes) for an office visit (as defined by the CPT codes shown below) that occurred on a single

day. As others have done, Current Procedural Terminology (CPT) codes were used to define office visits as follows: Evaluation & Management—Office Visits (99201–99205 and 99211–99215), Home Visits (99341–99343 and 99351–99353), Office Consults (992414–99245), Confirmatory Consults (99271–99275), and Medical Procedures (90701–99199).¹²

Defining hospice use

All Medicare hospice admissions—regardless of whether or not a patient was in a group health organization or not—are reimbursed through a special hospice carve-out. Terminally ill Medicare beneficiaries may choose to have hospice care and so receive important and helpful services, many of which would not otherwise be covered. Any Medicare beneficiary may elect the hospice benefit if they meet the eligibility criteria.

We examined the 1993 through 1997 Standard Analytic Files for Hospice (SAF-Hospice) for any use of the Medicare hospice benefit by any members of our cohort beginning with the date of their empanelment in the cohort. Because Medicare finances the vast majority of hospice care, and Medicare-funded hospice is our object of interest, we were thus able to define the date of enrollment into hospice. The patients in COSI accounted for approximately 10% of all recipients of the Medicare Hospice Benefit in the entire period from 1993 through 1997. In order to adjust for differences in the force of mortality across diseases—and thus presumably differences in the fraction of the population for whom hospice use might have been appropriate—we present rates of hospice use only among those patients who actually died on or before December 31, 1997.

Defining death

We used HCFA's highly complete and accurate Vital Statistics File to determine the date of death of study participants.

Analytic methods

For the present descriptive study, we present simple counts and percentages of patients, tabulated by disease. Because we had no prior expectation of equivalence—and hence no appropriate “null hypothesis”—we do not present

formal statistical tests for differences between the groups. In samples of this size, differences may be statistically significant that are not meaningful from either a clinical or policy perspective.

RESULTS

Cohort description

Basic description of the COSI cohort is shown in the first column of Table 1. This tabulation represents an enumeration of all Medicare beneficiaries who met empanelment criteria, that is, who were at least age 68 at the time of their diagnosis, had complete descriptive data, and had appropriate International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) codes. Their gender, racial, geographical, and age balance thus precisely reproduces the distribution found in each disease in the United States in 1993; we have described the adequacy of our case detection algorithm elsewhere.⁶

The initial hospitalization

Table 1 presents some basic information on the initial hospitalizations of the COSI cohort members. Data are presented for the temporally first hospitalization for those with multiple empanelling diseases; it is also restricted to only those probands who lived in the 50 states or the District of Columbia. As is clear, there is substantial heterogeneity both in terms of median lengths of stay and the variability within diseases in length of stay. Patients with urinary tract cancers (which exclude prostate cancers) had the shortest median length of stay during their initial hospitalization; colorectal cancer patients had the longest stay. There was also substantial heterogeneity in the end-points of the initial hospitalization. Many myocardial infarction and central nervous system cancer patients were transferred to other acute inpatient hospitals; few of the other cancer patients were so transferred.

Patients with myocardial infarction stroke, lymphoma, or malignancies of the liver and biliary tract, lung, or pancreas all had a greater than 1 in 10 chance of dying during their initial hospitalization. In contrast, patients with urinary tract cancer and hip fracture had less than a 1 in 20 chance of dying.

TABLE 1. CHARACTERISTICS OF INITIAL HOSPITALIZATION

Disease	Number	Length of stay (days)			End of stay ^a	
		Median	25th percentile	75th percentile	Transfer	Death
Noncancer Diagnoses						
MI	218,946	7	4	10	15.3%	15.8%
CHF	253,093	7	4	11	3.8%	10.1%
Hip fracture	210,493	8	6	11	5.6%	4.0%
Stroke	244,259	7	4	10	5.9%	9.7%
Cancer Diagnoses						
CNS	5,536	8	4	14	8.2%	7.7%
Colon	80,209	10	7	15	1.2%	6.3%
Head & neck	10,565	6	3	12	1.7%	5.9%
Liver & biliary tract	8,504	9	5	15	3.7%	15.7%
Leukemia	20,489	6	4	11	3.9%	14.9%
Lung	83,888	8	4	13	2.4%	13.4%
Lymphoma	31,630	7	4	13	2.8%	9.0%
Pancreas	14,993	9	5	16	2.9%	15.7%
Urinary Tract	38,548	5	3	9	1.2%	3.4%

^aPatients not transferred to another hospital, nor dead, were either discharged to home or to a long-term care facility.

MI, myocardial infarction; CHF, congestive heart failure; CNS, central nervous system.

Use of outpatient physician care

The mean number of outpatient physician visits is shown for each of the COSI diagnoses in Table 2. Several patterns are worthy of comment. The substantial cross-disease heterogeneity is again present, at least at these whole-year tabulations. Lymphoma patients had an average of 18.9 outpatient office visit days in the year after their diagnosis, whereas pancreatic cancer patients had only 7.9. Cardiac patients had the most claims for procedure-oriented office visits after diagnosis; liver, biliary tract, and pancreatic cancer patients had less than half as many. Typically more than 85% of patients had at least one outpatient visit identified in the claims. For 6 of the 13 conditions, the total number of outpatient visits declined in the year of diagnosis relative to the year before diagnosis. (Note that these numbers do not adjust for the fact that some patients may die immediately after diagnosis, limiting the length of time for which they could receive outpatient procedures; in contrast, by construction, all patients are alive for the entire year preceding diagnosis.)

Use of hospice among decedents

As shown in Table 3, there was substantial heterogeneity across diagnoses in the rate of

hospice use, with an overall use rate of 13%. Patients with cancer use hospice at much higher rates than patients with noncancer diagnoses. Specifically, 7.8% of male decedents with noncancer diagnoses in COSI used hospice; 26.3% of men with cancer diagnoses used hospice. Similarly, 7.7% of women with noncancer diagnoses used hospice; 28.6% of women with cancer diagnoses used hospice. In general, hospice rates seem higher among decedents of conditions with higher rates of short-term mortality. Thus, nearly 1 in 3 patients who dies after diagnosis of pancreatic or CNS cancer uses hospice; in contrast, barely 1 in 15 patients who dies after a myocardial infarction uses hospice. But differences persist even among diseases with equivalent rates of short-term mortality; rates of hospice use are ten percentage points higher among decedents with head and neck cancers than with leukemia.

DISCUSSION

In this paper, we have presented basic differences between diseases in their trajectory of health care use after diagnosis with 1 of 13 serious illnesses. Our primary goal here was to provide raw material to facilitate discussion of our

TABLE 2. PHYSICIAN OFFICE VISITS BY DIAGNOSIS AND TIME SINCE DIAGNOSIS

<i>Disease</i>	<i>Visit type</i>	<i>Year prior</i>	<i>Year of diagnosis</i>	<i>Year after diagnosis</i>	<i>2 years after</i>
Noncancer					
MI	Procedures	3.23	8.25	5.57	5.32
	E&M	7.18	7.31	7.45	7.13
	Total	10.79	15.96	13.44	12.87
	% w/1 or more visits	90%	92%	92%	90%
CHF	Procedures	3.42	6.32	6.05	6.00
	E&M	7.80	6.85	7.15	6.81
	Total	11.70	13.61	13.66	13.26
	% w/1 or more visits	91%	90%	91%	90%
Hip fracture	Procedures	2.94	3.81	3.89	3.93
	E&M	6.09	4.48	4.52	4.22
	Total	9.44	8.72	8.82	8.55
	% w/1 or more visits	88%	87%	85%	84%
Stroke	Procedures	3.29	5.60	4.93	4.83
	E&M	7.04	5.56	5.75	5.39
	Total	10.75	11.60	11.13	10.66
	% w/1 or more visits	90%	88%	89%	87%
Cancer					
CNS	Procedures	3.57	3.26	3.62	4.31
	E&M	7.98	4.44	5.47	5.79
	Total	12.36	8.51	9.58	10.65
	% w/1 or more visits	93%	83%	77%	83%
Colon	Procedures	2.76	5.05	4.18	4.02
	E&M	7.42	10.98	8.76	7.63
	Total	10.97	16.67	13.40	12.09
	% w/1 or more visits	92%	89%	90%	89%
Head & neck	Procedures	3.27	4.52	4.49	4.40
	E&M	9.15	9.79	9.77	8.58
	Total	13.74	15.26	14.86	13.52
	% w/1 or more visits	94%	89%	91%	89%
Liver & biliary tract	Procedures	2.85	2.64	3.66	3.68
	E&M	8.47	5.03	7.51	7.55
	Total	12.02	8.15	11.64	11.70
	% w/1 or more visits	92%	75%	84%	86%
Leukemia	Procedures	3.13	4.27	4.99	5.09
	E&M	11.26	9.09	11.13	10.94
	Total	15.05	13.82	16.64	16.55
	% w/1 or more visits	92%	84%	91%	91%
Lung	Procedures	3.59	3.79	4.36	4.60
	E&M	9.00	6.75	8.63	8.46
	Total	13.61	11.15	13.52	13.59
	% w/1 or more visits	92%	81%	87%	87%
Lymphoma	Procedures	3.77	5.78	5.60	5.49
	E&M	12.03	12.45	12.52	11.67
	Total	16.75	18.90	18.70	17.73
	% w/1 or more visits	94%	88%	92%	91%
Pancreas	Procedures	2.99	2.38	3.57	4.26
	E&M	8.93	5.00	7.84	7.51
	Total	12.67	7.86	11.79	12.16
	% w/1 or more visits	93%	74%	82%	83%
Urinary Tract	Procedures	3.20	4.57	4.80	4.93
	E&M	8.59	8.79	8.39	7.96
	Total	12.60	14.00	13.70	13.39
	% w/1 or more visits	93%	91%	91%	90%

Diagnosis: Patients are tabulated by their empaneling diagnosis. That is, for patients diagnosed with, for example, lung cancer by COSI criteria in 1993, we then retrospectively examine their utilization for the 365 days prior to their index admission. Mean number of visits are reported.

Total: Procedures, E&M, home visits, confirmatory consults, and office consults.

E&M, evaluation and management; MI, myocardial infarction; CHF, congestive heart failure; CNS, central nervous system; COSI, Care After Onset of Serious Illness.

TABLE 3. DEATH BY END OF FOLLOW-UP AND USE OF HOSPICE AMONG DECEDENTS

	<i>Of cohort members, what percentage died by December 31, 1997?</i>		<i>Of these decedents, what percentage used hospice?</i>	
	<i>Men</i>	<i>Women</i>	<i>Men</i>	<i>Women</i>
Noncancer				
MI	53.9%	57.0%	7.0%	5.9%
CHF	71.9%	65.8%	8.3%	7.9%
Hip fracture	70.8%	54.6%	8.1%	8.7%
Stroke	64.2%	62.6%	7.9%	7.6%
Cancers				
CNS	95.1%	90.6%	33.4%	35.2%
Colon	61.6%	57.6%	28.4%	29.5%
Head & neck	72.7%	67.8%	25.1%	26.6%
Liver & biliary tract	94.6%	93.0%	28.6%	31.3%
Leukemia	81.4%	75.9%	15.2%	16.0%
Lung	92.4%	87.6%	27.8%	31.5%
Lymphoma	80.4%	75.7%	20.1%	21.7%
Pancreas	96.4%	95.0%	34.1%	34.5%
Urinary tract	57.7%	58.4%	24.7%	28.9%
Overall	68.0%	62.6%	14.2%	12.4%
Total cases	514,732	706,421	350,217	442,152

This requires that the probands lived in the 50 states or Washington, D.C. Probands are tabulated only once, by their temporally first diagnosis if they were multiply empanelled.

MI, myocardial infarction; CHF, congestive heart failure; CNS, central nervous system.

system of terminal care. We leave the more complex task of integrating hospice use patterns with patterns of inpatient and outpatient care for future work.

In these tabulations, we find similar lengths of stay for initial hospitalizations across diagnoses; but there are important differences in the variability of length of stay, the use of transfers, and the frequency of inpatient death. There are also differences in their patterns of outpatient care, and large differences in their patterns of hospice use. There are no very obvious correlations between patterns of outpatient use and patterns of hospice use. The dominant picture is one of heterogeneity across diseases in their patterns of terminal care. There remains one common denominator: despite the clearly high forces of mortality in all of these populations, a minority died with hospice.

Turning more specifically to palliative care, the roots of this heterogeneity in patterns of hospice and related health care use are quite complex, with variation on both clinical and social axes. Patterns of care often have strong geographical components, that is, people are treated more like their neighbors than one would expect if practice

patterns were randomly distributed.^{15,16} However, explaining these patterns has proven quite difficult. In the particular case of hospice, it has been shown that people in the same county have similar rates of hospice use.¹⁷ However, these patterns of intracounty similarity in hospice use could not be explained by either demographic factors or by the structure of the local market. It appears that they are the result of local culture in which physicians and patients in the context of the local community establish norms about hospice referrals.

The striking variation between diseases in rates of hospice use shown here suggests a similar conclusion. Diseases with similar natural histories show divergent rates of hospice use. This suggests—but assuredly does not prove—that the communities of specialists treating particularly diseases may each have evolved their own norms of referral rates. In some cases, these differences may be related to differences in the interaction of the intrinsic pathology of the disease with our conventions for treatment; for example, it has been suggested that the treatment of leukemias and lymphomas relies more heavily on blood products, and hospices are less comfortable adminis-

tering this form of therapy even to palliative ends. It is less clear, however, the degree to which these tumor-specific differences truly represent barriers to hospice care in some intrinsic sense. Rather, the striking differences in hospice rates seem to be a mandate for local studies, both quantitative and qualitative, that seek to understand the barriers to hospice as perceived by relevant patients and care providers.

These initial tabulations were not designed to test specific hypotheses. Moreover, these data are rooted in Medicare claims, and so have all the well-known limitation of claims research.⁷ These limitations include that the claims do not include information on: patients in certain Medicare health management organizations (HMOs) and individuals not covered by Medicare or who choose for some reason to pay for their care out-of-pocket. Indeed, we found that about 10% of patients in all the disease groups ostensibly did not see a doctor for an outpatient visit in the year prior to diagnosis—a rate which is consistent with the rates of Medicare HMO penetration.¹⁸ Also, claims cannot be used to directly explore nursing home use, visits at which a physician was not seen, or follow-up visits for surgical patients (which are typically reimbursed bundled with the surgery). Finally, claims lack all but the most basic of socioeconomic data. Clearly, sophisticated understandings of the nature of end-of-life care require triangulations from multiple data sources.

In summary, then, these results demonstrate substantial clinical heterogeneity in the patterns of care after diagnosis with serious illness among the American elderly. A close study of these patterns is important to an informed effort to understand the way Americans care for the dying—and such understanding may be essential to the developing effective interventions to improve the care of the terminally ill.

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Address reprint requests to:
Nicholas A. Christakis, M.D., Ph.D., MPH
Department of Health Care Policy
Harvard Medical School
180 Longwood Avenue
Boston, MA 02115

E-mail: christakis@hcp.med.harvard.edu

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