Hospice Care: What Services Do Patients and Their Families Receive?

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Objective. To determine the degree to which patients and families enrolled with hospice received services across key categories of palliative care, the extent of hospice-level variability in services delivered, and changes over time in services delivered.

Data Source. Nationally representative sample of 9,409 discharged patients from 2,066 hospices in the National Home and Hospice Care Survey.

Study Design. Observational, cross-sectional study conducted from 1992 to 2000. The primary outcome is the receipt of services across five key categories of palliative care: nursing care, physician care, medication management, psychosocial care, and caregiver support.

Data Collection. Data were obtained via interview with the hospice staff member most familiar with the patient's care, in conjunction with medical record review.

Principle Findings. In 2000, 22 percent of patients enrolled with hospice received services across five key categories of palliative care. There was marked variation across hospices in service delivery. One-third of hospices provided patients and families services in one or two of the five key categories of palliative care, whereas 14 percent of hospices provided services across five key categories of palliative care. In multivariable analysis, the odds of receiving any additional hospice service was significantly greater in later compared with earlier years (odds ratio = 1.10, 95 percent confidence interval 1.01–1.20). Nevertheless, the percentages of patients in 2000 receiving medication management (59 percent), respite care (7 percent), and physician services (30 percent) remained low.

Conclusions. Hospice care for patients and families varies substantially across hospices. Whereas some hospices provide services across the key categories of palliative care, other hospices do not provide this breadth of services. Greater understanding of the causes of variation in service delivery as well as its impact on patient and family outcomes and satisfaction with end-of-life care is a critical subject for future research. Changes in Medicare's reimbursement policies may help hospices increase the range of services provided to patients and families.

Key Words. Hospice, palliative care, Medicare Hospice Benefit

Three-quarters of individuals who die in the United States do so from chronic illnesses (Minino et al. 2002), often after suffering both physically and psychologically for months or years (The SUPPORT Principal Investigators 1995). Recent evidence (Field and Cassel 1997; Emanuel and Emanuel 1998; Singer, Martin, and Kelner 1999; Steinhauser et al. 2000) establishes the importance to patients and families coping with advanced illness of receiving services across multiple domains that address the patient's physical, psychosocial, and spiritual well-being, as well as the caregiver's well-being. However, the health care system has often failed to meet the needs of these patients and their families, who frequently experience inadequate pain and symptom management (Von Roenn et al. 1993; Bernabei et al. 1998; Morrison et al. 1998; Pritchard et al. 1998), caregiver burden and stress (Emanuel et al. 1999; Prigerson et al. 2003), limited communication (Hanson, Danis, and Garrett 1997; Hofmann et al. 1997; Teno et al. 2004; Cherlin et al. 2005), and overall dissatisfaction with care (Teno et al. 2004).

Hospice developed to address the multidimensional needs of patients suffering from advanced illness and their families, that were not being met by the medical system, and the hospice industry has experienced dramatic growth and change over time. Since 1990, approximately 1,500 new hospice agencies have emerged (General Accounting Office 2000), a 125 percent increase from 1992. Medicare spending under the Medicare Hospice Benefit increased from \$445 million in 1991 to \$3.6 billion in 2001 (Centers for Medicare and Medicaid Services 2005), and the number of Medicare hospice beneficiaries increased more than sixfold during the same period (Centers for Medicare and Medicaid Services 2005). During this time, hospice in the United States transitioned from a grassroots movement of a handful of freestanding, small hospices in the 1970s to a multimillion-dollar, national industry comprised of nonprofit and for-profit chains and freestanding agencies. Despite the recent transformation of the hospice sector, we know little about corresponding changes in the types of services delivered to patients using hospice.

Hospice is an integral component of care for patients with advanced illness. As hospice continues to grow, it is important to determine if services

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across key aspects of palliative care (National Consensus Project 2004) are being provided to patients and families and how hospice care has changed over time. Therefore, we sought to examine the types of services provided to patients and families enrolled with hospice during the last decade with attention to potential hospice-level variation in service delivery. We used the National Home and Hospice Care Survey (NHHCS), a nationally representative dataset of hospice agencies and their patients. These data provide a unique opportunity to examine changes in hospice services over time, as they were collected during the period from 1992 to 2000, paralleling the period of substantial growth in hospice use and spending.

METHODS

Study Design and Sample

The NHHCS is a nationally representative sample of home health and hospice agencies and their patients conducted by the National Center for Health Statistics (NCHS) in 1992, 1994, 1996, 1998, and 2000 (NCHS 1992–2000). This study uses the NHHCS discharged patient sample. There were two sampling strategies employed during the survey period. In 1992 and 1994, the data were collected using a three-stage sampling design. The first stage consisted of the 198 Primary Sampling Units (PSUs; i.e., counties, groups of counties, county equivalents or towns, and townships) used in the 1985–1994 National Health Interview Survey (Massey et al. 1989). In the second stage, agencies were selected according to agency type (home health, hospice, or mixed), type of PSU (self-representing or non-self-representing), and metropolitan statistical area (MSA) versus non-MSA. In the third stage, an NHHCS interviewer contacted the administrator (or designee) of each sampled agency and obtained a list of the agency's patients discharged (either due to the patient's death or disenrollment from hospice) within the prior 12-month period. From this list of all patients, six discharged patients were randomly chosen from each of the selected agencies. In years 1996, 1998, and 2000, the data were collected using a two-stage sampling design. In the first stage, agencies were randomly selected, proportional to size, from 24 strata according to agency type (home health, hospice, or mixed), region (Northeast, Midwest, West, or South), and MSA versus non-MSA. In the second stage, discharged patients were chosen using the same methodology as used in 1992 and 1994. During all years of the survey, patient-level data, including demographic factors, functional impairments, diagnosis, length of stay with hospice, and use of hospice services, were

obtained via interview with the hospice staff member most familiar with the patient's care, in conjunction with a review of the patient's medical records, as needed.

Measures

The use of each hospice service was assessed using responses from the following question from the Discharged Patient Questionnaire (NCHS 2001b): "During the 30 days prior to discharge, which of these services were provided to [the patient] by your agency?" We evaluated the use of both core and noncore services as defined by federal regulations governing hospice care and participation in the Medicare program (U.S. Government Printing Office 2002a). Core services, which are defined by the Code of Federal Regulations governing hospice care as services that must be provided by hospice staff employed by the hospice, include skilled nursing services, physician services, volunteer services, counseling services (including bereavement counseling), spiritual care, dietary counseling, and social services (U.S. Government Printing Office 2002b). Noncore services, which are defined by the Code of Federal Regulations governing hospice care as services that may be outsourced by the hospice provider, include physical therapy, occupational therapy, speech-language pathology, home health care, homemaker services, administration and provision of drugs, biologicals and medical supplies, continuous home care, respite care, and other services (U.S. Government Printing Office 2002c).

To evaluate service use in the most recent survey year, 2000, we summarized services according to five general categories. These five categories represent the constellation of services that generally address the domains of quality palliative care as defined in the National Consensus Project's Clinical Practice Guidelines for Quality Palliative Care (National Consensus Project 2004): (1) nursing care (i.e., skilled nursing services and continuous home care), (2) physician care (i.e., physical evaluation or treatment by a licensed medical doctor employed by or affiliated with the hospice agency), (3) medication management (i.e., assisting with the administration of medication, dispensing the correct dosages, and establishing and following a dosage schedule), (4) psychosocial care (i.e., counseling services, dietary counseling, social services, and spiritual care), and (5) caregiver support (i.e., respite care, homemaker/household services, and personal care).

To examine trends in the provision of hospice services over time, we examined the overall range of services received by patients and the likelihood of receiving individual hospice services over time. We measured the range of

services by a count of the number of different types of services received by patients including the 12 services that were asked in each survey year. These 12 services were skilled nursing services, physician services, volunteer services, counseling, dietary counseling, social services, medication management, homemaker/household services, physical, occupational, and speech therapy, and transportation services. The count of the different types of services received by patients evaluates a critical feature of hospice care, as hospice seeks to address a broad range of physical, emotional, social, and psychological symptoms using an interdisciplinary staff.

We included the following patient-level covariates in the multivariable analyses: patient age (a categorical variable: <65, 65–74, 75–84, 85+), gender, race/ethnicity (included in the models due to reported differences in preferences for palliative care by race/ethnicity [McKinley et al. 1996; Blackhall et al. 1999; Hopp and Duffy 2000; Phipps et al. 2003]), admission diagnosis (a binary variable indicating cancer or noncancer diagnosis), residence (a binary variable indicating whether the patient lived at home or in an inpatient setting), number of activities of daily living (ADLs; i.e., bathing, dressing, eating, transferring in or out of beds or chairs, walking, and continence) (Katz et al. 1963) in which the patient required assistance from hospice staff, number of instrumental activities of daily living (IADLs; i.e., light housework, managing money, shopping, using the telephone, preparing meals, and taking medications) in which the patient required assistance from hospice staff, length of stay with hospice, the patient's primary source of payment (i.e., Medicare compared with all other sources), and year. Race/ethnicity was ascertained from the report of the survey respondent (a hospice employee) based on predetermined categories of white, black, American Indian/Eskimo/Aleut, Asian/Pacific Islander, or other and Hispanic/non-Hispanic and was coded for this analysis as a binary variable, indicating non-Hispanic white versus all others due to the low prevalence of other race/ethnicity categories. We modeled hospice length of stay as a dichotomous variable, indicating length of stay of 3 or fewer days compared with more than 3 days given that surveys of hospice staff report length of stay of at least 3 days allows for more comprehensive hospice care (Bradley et al. 2004). Further, the distribution of length of stay was right skewed and thus a categorical compared to a continuous variable was appropriate. We performed sensitivity analyses modeling length of stay as a continuous and categorical variable using alternative categories.

We also included the following organization-level covariates available in the NHHCS in the multivariable analyses: whether or not the hospice was Medicare certified (i.e., whether or not the hospice met the conditions

required in order to participate in the Medicare program), ownership (i.e., nonprofit or for-profit), whether or not the hospice was horizontally integrated (i.e., whether or not the hospice agency was a member of a group of hospice agencies operating under one corporate ownership), whether the hospice was vertically integrated (i.e., whether or not the hospice was affiliated with a hospital or home health agency), census region (i.e., Northeast, Midwest, West, and South), and whether or not the hospice was located in an MSA. The number of patients, or size of the hospice, which was available in only 2 years of the NHHCS, 1992 and 1994, was used in sensitivity analysis.

Statistical Analysis

We characterized the population of patients using standard descriptive statistics. We estimated the percentage of patients who received one through five categories of palliative care while enrolled with hospice, as well as the hospice-level variation in this measure. In addition, we report the prevalence of the receipt of each of the core and noncore services that were included in the survey. For services used by at least 5 percent of patients in at least 3 years of the study, we estimated the odds of receiving the service, adjusted for patient demographic and clinical characteristics and organization-level characteristics, for each survey year and by geographic region and urban/rural location (as measured by residing in an MSA [urban] or non-MSA [rural]). We adjusted for hospice size in sensitivity analysis using only 2 years of data, as hospice size was not available for all years of the survey. Given the high prevalence of many services, the odds of receiving the service did not approximate the probability of receiving the service (Rothman and Greenland 1998). Therefore, to facilitate interpretation of the results, we estimated the adjusted proportion receiving each hospice service by year, geographic region, and urban/rural location by calculating the average probability for a hypothetical population with a covariate distribution identical to that of the study sample. To accomplish this, we use the predicted probability of an individual receiving each type of service (i), $F_i(\mathbf{x}_j, \mathbf{b})$, where $\mathbf{x}_j$ are the independent variables for the j th individual in the sample and $\mathbf{b}$ is the estimated parameter vector (StataCorp 2001a). The means of these values over the entire dataset provide an adjusted estimate of the proportion receiving each hospice service as they are based on an identical covariate distribution.

We used multivariable-ordered logistic regression to estimate the range of services (for total services, for core services, and for noncore services) used by patients over time and by geographic region and urban/rural location. The assumption of proportionality inherent in an ordered logistic regression model

was tested using an adjusted Wald test (Hosmer and Lemeshow 2000; StataCorp 2001b) and the assumption of proportionality across the range of services used was found to be reasonable ($F = 1.25$, $p\text{-value} = .22$).

The complexity of the design of the NHHCS required the use of estimation procedures that accounted for both unequal probability selection of patients and clustering of patient observations within hospices. Patient-level data included a sampling weight proportional to the inverse of the probability of being sampled, with adjustment for over- or undersampling and nonresponse (NCHS 2001a). To obtain parameter estimates that were properly adjusted for the probability weights and to ensure robust standard errors that accounted for the clustering of observations within hospices, we used particular commands (StataCorp 2001b) in *STATA* software (StataCorp 2001c) for use with complex sample survey data.

RESULTS

Sample Characteristics

There were 9,409 discharged patients from 2,066 hospices surveyed between 1992 and 2000, representing a national estimate of approximately 2,000,000 hospice patients after applying the sample weights (Table 1). The sample was evenly distributed by gender and the average patient age was 72 years. Approximately 80 percent of patients were white non-Hispanic and 67 percent had cancer. Most patients resided in a private residence (72 percent) and had Medicare as the primary source of payment for hospice care (71 percent). The mean number of ADL dependencies that the hospice provided assistance with was 3.5, and the mean number of IADL dependencies that the hospice provided assistance with was 1.6. Almost all patients (92 percent) received care from a Medicare-certified hospice and the majority of patients received care from a nonprofit hospice (84 percent). Slightly more than one-third of patients (39 percent) received care from a hospice that was horizontally integrated and most patients received care from a hospice affiliated with either a hospital (34 percent) or a home health agency (30 percent). Patients were fairly evenly distributed across regions of the country and the majority of patients (83 percent) received care from a hospice in an MSA.

Use of Hospice Services

In 2000, 22 percent of hospice patients received services across five key palliative care categories (i.e., nursing care, physician care, medication

Table 1: Characteristics of Hospice Patients and the Agencies from Which They Received Care

<i>Characteristics of Patients</i>	<i>Percentage of Patients</i>						<i>Total Number of Patients</i>	
	<i>1992</i>	<i>1994</i>	<i>1996</i>	<i>1998</i>	<i>2000</i>	<i>Total</i>	<i>Weighted (N=2,057,569)</i>	<i>Unweighted (N=9,481)</i>
Gender								
Female	49	48	50	52	50	50	1,029,098	4,742
Male	51	52	50	48	50	50	1,028,471	4,739
Age group								
<65	28	27	32	24	21	26	524,690	2,541
65-74	31	28	23	26	25	26	530,759	2,547
75-84	27	28	28	32	29	29	599,487	2,729
85+	14	17	17	18	26	20	402,633	1,669
Race/ethnicity								
White non-Hispanic	85	77	76	76	82	79	1,623,179	7,789
White Hispanic	1	2	3	4	2	3	53,200	200
Black	6	7	11	9	8	9	170,433	773
Other	3	1	1	1	2	2	32,330	163
Unknown	6	13	9	11	6	9	178,427	556
Admission diagnosis								
Cancer	76	71	71	66	59	67	1,365,466	6,611
Disease of the circulatory system	12	14	10	11	12	12	238,193	1,111
Disease of the respiratory system	4	2	5	6	7	5	110,313	428
Mental disorder	0	0	1	1	4	2	37,912	158
Other	7	13	13	15	19	15	305,685	1,173
Where living								
Private residence	85	82	73	74	61	72	1,482,539	7,150
Inpatient	11	11	15	24	35	22	451,987	1,858
Assisted living facility	2	5	4	2	3	3	66,340	283
Other	2	1	9	1	1	3	56,703	190
Primary source of payment								
Medicare	64	65	65	72	79	71	1,456,445	6,416
Private insurance	15	16	15	14	12	14	285,218	1,314
Medicaid	6	4	12	5	5	6	128,931	536
Out of pocket	4	2	1	0	1	1	27,283	67
Other	12	13	7	8	2	7	159,692	1,148
Characteristics of agencies from which patients received care								
Medicare certification status								
Medicare certified	88	88	91	92	97	92	1,898,810	8,621
Not Medicare certified	12	12	9	7	3	8	155,741	842
Unknown	0	0	0	1	0.1	0.1	3,018	18

Continued

Table 1. *Continued*

<i>Characteristics of Patients</i>	<i>Percentage of Patients</i>						<i>Total Number of Patients</i>	
	1992	1994	1996	1998	2000	Total	<i>Weighted</i> (N=2,057,569)	<i>Unweighted</i> (N=9,481)
Ownership								
Nonprofit	91	90	87	73	84	84	1,721,553	8,021
For-profit	6	10	13	27	16	16	328,949	1,380
Unknown	3	0	0	0	0.1	0.3	7,067	80
Horizontal integration								
Horizontally integrated	33	47	34	37	42	39	805,060	3,728
Not horizontally integrated	67	53	66	58	56	59	1,210,654	5,630
Unknown	0	0	0.3	4	3	2	41,855	123
Vertical integrated								
Affiliated with hospital	34	29	36	35	35	34	695,158	2,693
Affiliated with home health agency	36	40	29	25	29	30	624,611	1,641
Not affiliated	30	31	32	36	37	34	695,960	4,973
Unknown	0	1	4	4	0.4	2	41,840	174
Census region								
South	29	30	38	33	34	33	686,819	3,689
Midwest	21	22	25	23	26	24	492,637	2,394
Northeast	30	33	18	19	20	23	464,708	1,599
West	20	14	18	25	21	20	413,405	1,799
Metropolitan statistical area								
Yes	78	83	84	81	87	83	1,714,632	6,904
No	22	17	16	19	13	17	342,937	2,577

Because of rounding, percentages may not sum to 100%.

management, psychosocial care, and caregiver support). However, substantial variation across hospices existed (Figure 1). An estimated 14 percent of hospices provided services on average across five key palliative care categories, whereas 33 percent of hospices provided services on average in one (12 percent of hospices) or two (21 percent of hospices) categories of care.

In addition to this hospice-level variability, we found evidence of substantial change over time in the range of services received by patients and their families enrolled with hospice. In multivariable analysis, the odds of receiving any additional service within hospice was significantly greater in later compared with earlier years (OR = 1.10, 95 percent CI 1.01–1.20). The increase in the range of services received by patients during the study period was similar for core (OR = 1.08, 95 percent CI 0.98–1.18) and for noncore (OR = 1.12, 95 percent CI 1.02–1.23) services.

Figure 1: Variability by Hospice Agency in the Average Number of Categories of Palliative Care^a Provided to Patients

^aCategories of palliative care are nursing care, physician care, medication management, psychosocial care, and caregiver support.

A number of specific services increased substantially from lower use in the early 1990s (Table 2). The largest changes during the study period were in the percentages of patients receiving medication management services (21 percentage point increase, from 39 percent in 1992 to 59 percent in 2000) and the percentage of patients receiving spiritual care (20 percentage point increase, from 39 percent in 1994 to 59 percent in 2000). There were also increases in durable medical equipment and supplies (DMES; 16 percentage point increase, from 29 percent in 1994 to 45 percent in 2000) and social services (12 percentage point increase, from 59 percent in 1992 to 71 percent in 2000).

The multivariable analyses indicated that there was a significant increase by year in the probability of receiving spiritual care (OR = 1.23, 95 percent CI 1.05–1.43), dietary counseling (OR = 1.29, 95 percent CI 1.06–1.58), social services (OR = 1.15, 95 percent CI 1.03–1.29), medication management (OR = 1.31, 95 percent CI 1.17–1.46), DMES (OR = 1.19, 95 percent CI 1.03–1.37), and high-tech care (including intravenous and enterostomal therapy, enteral nutrition, and dialysis; OR = 1.18, 95 percent CI 1.03–1.35). The predicted probabilities of patients receiving individual hospice services by year, accounting for patient and organization-level characteristics, are shown in Figure 2.

Variation in Service Use by Geographic Region and Urban/Rural Location

Adjusting for patient demographic and clinical characteristics and organization-level characteristics, the odds of receiving an additional hospice service

Table 2: Prevalence of the Use of Individual Hospice Services, 1992–2000

	1992	1994	1996	1998	2000	Change*
Core services						
Skilled nursing services	95	88	96	88	92	– 4
Physician services	24	17	25	29	30	6
Volunteer services	30	36	44	32	33	3
Counseling	36	31	47	44	31	– 5
Spiritual care	N/A	39	N/A	52	59	20
Dietary counseling	9	10	5	15	17	8
Social services	59	60	76	71	71	12
Noncore services						
Medication management	39	36	50	62	59	21
Durable medical equipment and supplies	N/A	29	N/A	55	45	16
High-tech care	6	8	N/A	8	10	3
Referral services	4	9	N/A	7	4	– 0.3
Transportation services	3	4	4	3	2	– 0.4
Meals on wheels	0.5	0.2	N/A	0.4	0.5	0.0
Personal care	51	59	N/A	64	59	7
Homemaker/household services	8	17	26	10	13	4
Continuous home care	N/A	7	12	8	4	– 4
Respite care	11	7	N/A	4	7	– 4
Physical therapy	2	2	3	4	5	2
Occupational therapy	1	1	1	1	2	0.3
Speech therapy	0.2	1	0.5	1	1	1
Respiratory therapy	N/A	N/A	N/A	12	13	1
Vocational therapy	N/A	1	N/A	0.2	0.1	– 1
Oral care	N/A	5	N/A	8	N/A	3

N/A indicates that the services type was not asked in that survey year.

*Because of rounding, the year 2000 percentage minus the year 1992 percentage may not exactly equal the change percentage.

were higher for patients in the Midwest (OR = 1.70, 95 percent CI 1.16–2.50), West (OR = 1.74, 95 percent CI 1.11–2.74), and South (OR = 2.20, 95 percent CI 1.49–3.27) compared with patients in the Northeast. Specifically, patients served by hospices in the Northeast had significantly lower odds of receiving physician services, social services, medication management, DMES, and high-tech care.

There was no significant difference in the range of services received by patients in urban compared with rural hospices (OR = 1.03, 95 percent CI 0.77–1.37). There were, nonetheless, differences in the receipt of individual services by rural/urban location. In multivariable analysis, patients receiving care from urban hospices had a lower odds of receiving volunteer services (OR = 0.68, 95 percent CI 0.51–0.93) and respite care (OR = 0.43, 95 percent

Figure 2: Predicted Probability of Service Use, by Year

Note: *Significant ($p < .05$) trend by year.

Models are adjusted for patient age, gender, race, diagnosis, number of dependencies in activities of daily living and independent activities of daily living, residence, primary source of payment, length of stay, and hospice certification status, ownership, horizontal and vertical integration, census region, and rural/urban location.

SNS, skilled nursing services; DMES, durable medical equipment and supplies; HHS, home-maker/household services; CHC, continuous home care.

CI 0.25–0.74) but higher odds of receiving skilled nursing services (OR = 1.99, 95 percent CI 1.00–3.97) and continuous home care (OR = 1.85, 95 percent CI 1.15–2.98) compared with patients receiving care from rural hospices.

DISCUSSION

In 2000, 22 percent of patients and families enrolled with hospice received services across five key palliative care categories. We found that this percentage varied markedly across hospices. One-third of hospices provided patients and families services in one or two of the five key categories of palliative care, whereas other hospices provided patients and their families services across five key categories of palliative care. This marked variability across hospices

underscores the importance of recent efforts by hospices and other health care stakeholders to develop and adopt national quality practices for the delivery of hospice care (National Quality Forum 2005).

The overall range of services received by patients enrolled with hospice increased during the 1990s; however, the percentage of patients receiving some services, specifically medication management, respite care, and physician services, remained remarkably low as recently as the year 2000. Only 59 percent of patients who were enrolled with hospice in 2000 received medication management services (i.e., assisting with the administration of medication, dispensing the correct dosages, and establishing and following a dosage schedule) from their hospice agency. Given the often complex and dynamic nature of managing a patient's pain and symptoms with medication, particularly while the patient is actively dying, the fact that many patients in 2000 did not receive medication management services from their hospice is striking. The percentage in 2000, however, represents a sharp increase from the percentage of patients receiving this service in 1992 (39 percent). The increasing trend may reflect the increasing number and complexity of medications used among individuals with serious illness and hence an awareness of greater medication management needs. To the extent that this trend continues, as it is likely to do, medication management services is likely to become an even more critical component of hospice care for patients and their caregivers, especially for those patients who remain at home.

The limited use of respite care (only 7 percent in 2000) is consistent with suggestions in the literature that Medicare's reimbursement policies for respite care create barriers to its provision (Huskamp et al. 2001). In order for a hospice to be reimbursed for respite care, Medicare requires that the patient be transferred to an inpatient facility. The potential complications and stress of transferring a terminal patient between home and inpatient settings may impede the use of respite services substantially. Further, a recent GAO report (General Accounting Office 2004) found the per diem reimbursement rate for respite care was 61 percent lower than the average per diem cost of respite care, and clinicians have cited difficulty finding inpatient facilities that are willing to accept the respite per diem rate (Huskamp et al. 2001). As suggested by others (Jeon, Brodaty, and Chesterson 2005), revising the reimbursement policy to allow for respite care in the home and increasing reimbursement rates for respite care may increase the use of this service and potentially benefit both patients and caregivers of the terminally ill.

Another troubling finding was the low rate of physician services and the lack of a significant increase in physician services over time. Physician services in

the NHHCS referred to the physical evaluation or treatment by a licensed medical doctor employed by or affiliated with the hospice agency. Although hospice physicians may have been involved in patient care through participation in care planning meetings, there was relatively little hands-on hospice physician involvement in patient care. Further, although the percentage of patients receiving physician services from their hospice agency increased by 6 percentage points from 1992 to 2000, this increase was not significant. The fact that fewer than one-third of patients received hands-on physician services may be considered consistent with the nonmedical model of hospice care. However, given increases in disease complexity, diversity of diagnoses, and symptom burden of patients enrolled with hospice (American Academy of Hospice and Palliative Medicine 2006), we may have expected a greater percentage of patients with direct physician care. It is possible that the patient's primary care physician might have continued to provide ongoing medical care for the patient once enrolled with hospice; however, these physicians may not have possessed the palliative care education, knowledge, and skills of a trained hospice physician.

We also found differences in the range of hospice services provided to patients in different regions of the country. Extending work by Wennberg et al. that documents geographic variation in hospice use (Wennberg, Fisher, and Skinner 2002; Wennberg et al. 2004) and Medicare hospice spending (Wennberg 2003) in the last 6 months of life, our findings indicate that the types of services received by patients enrolled with hospice varied by geographic region. Patients enrolled with hospice in the Northeast received a significantly narrower range of services than patients enrolled with hospice in other regions of the country. It may be that in the Northeast, alternative forms of palliative care at the end of life are more commonplace, as evidenced by the more recent rapid growth of hospital-based palliative care programs in the Northeast compared with other regions (Morrison et al. 2005). The existence of alternative forms of palliative care may influence the role and scope of hospice care in these areas.

The fairly limited differences in the range and types of services in rural compared with urban hospices is reassuring given recent studies citing concern regarding access to hospice care for rural elders (Virnig et al. 2004). The results of the current study suggest that once in hospice, the range of services is comparable for patients served by rural and urban hospices. However, the lower probability of rural patients receiving skilled nursing and continuous home care could potentially be addressed by increasing reimbursement to hospices in rural areas to cover travel expenses and to help attract skilled nursing professionals to rural areas.

The data used in this study are unique in providing greater detail than other longitudinal databases regarding the specific hospice services received by patients over time. However, important limitations of these data exist. First, while the number of categories of care and the range of services received by patients may provide insight into the quality of care received by patients, not all services are of equal value to a patient, and the NHHCS data lack information regarding the quantity of each service provided, the overall quality of particular services provided, and patient preferences for services, which are important for interpreting the full implications of our findings. Nonetheless, given the breadth of services that hospice is intended to address, the range of services provided to patients and families is an important feature. Second, although we included numerous organization-level covariates in our analyses, we were not able to control for hospice size, which may be relevant to understanding service delivery. The NHHCS does not have consistent data on hospice size in the Discharge Patient File, or that can be linked to the Discharge Patient File, over all survey years. Specifically, data on size are obtainable for years 1992 and 1994 but not years 1996, 1998, or 2000. However, the size distribution of hospices did not change substantially during the 1990s (General Accounting Office 2000) and thus is unlikely to have impacted longitudinal trends. Further, analyses of the 1992 and 1994 NHHCS data, which include information on hospice size, did not reveal significant associations between hospice size and the range of services patients received. Third, the NHHCS data do not include information on the market in which a hospice is located and thus the potential impact of competition on service delivery cannot be examined. Although the assessment of competition would not change the results of the current study, increasing competition over time may help explain the increase in the range of services received by patients of hospice during the study period. Finally, we were not able to evaluate patient and family outcomes, as these data were not collected in the NHHCS. Establishing substantial variation across hospices in the delivery of key components of palliative care, however, provides an important basis for future work linking the provision of hospice services to such outcomes.

Multiple factors potentially influence the delivery of services within hospice, including the regulatory and reimbursement environment faced by hospices and their internal processes and management. Some factors, including Medicare's reimbursement rates and payment policies, may contribute to low use of important hospice services such as medication management and respite care. Recent proposals to change Medicare's hospice payment policies (Medicare Payment Advisory Commission 2002; General Accounting Office

2004) have the potential to alleviate possible barriers to service delivery within hospice. The determinants of hospice-level variability in service delivery, however, remain unexplained. As efforts to apply clinical guidelines and develop quality indicators (National Consensus Project 2004; National Quality Forum 2005) for hospice and palliative care continue to gain momentum, it is critical to understand variation in hospice clinical practice with the goal of promoting the best possible experiences for patients with serious advanced illness and their families.

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