

END-OF-LIFE CARE: COMPARING TWO APPROACHES

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All VA institutions have been required to design end-of-life programs, but program characteristics vary widely. Here, a team of researchers takes a closer look at two hospital-based, urban programs—a consultative model and an inpatient approach.

In the past, the term end-of-life (EOL) care has been synonymous with hospice care, defined as care focused on improving the quality of dying in the last phase of a terminal illness.

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The National Hospice Study,¹ a two-year, 26-site study, demonstrated the effectiveness of hospice care, and along with the inception of Medicare reimbursement in 1982, fostered the widespread use of hospice services. Today, as the boundaries between chronic illness and terminal illness blur, EOL care has expanded to include palliative care, defined as care directed toward relieving patients' suffering and improving the quality of living as well as of dying.²

The distinction between hospice and palliative care can be somewhat artificial and, in fact, the World Health Organization uses the term palliative care to encompass all EOL care, defining palliative care as an approach that improves quality of life for patients facing life threatening illnesses and for their families "through the prevention, assessment, and treatment of pain and other physical, psychosocial,

and spiritual problems."³ Palliative care embraces a wide range of services that can be provided in a variety of settings, from the traditional home care setting to an inpatient program.⁴ Although it's used most often during the terminal phase of care, palliative care can be instituted at diagnosis and continued until death, regardless of the length of survival.⁵

The scarcity of palliative care is documented in Pan and colleagues' national assessment of hospital-based terminal care programs.⁶ Using data from the American Hospital Association survey, they reported that, of 4,797 registered hospitals responding to the 1998 survey, 2,015 (42%) reported having pain management services, EOL care, or both. In other words, more than half of the respondents identified their institutions as lacking these services. A second study by McCarthy and colleagues supports

these findings, reporting that, of patients with cancer who died between January 1, 1988 and December 31, 1998, only 260,090 (21%) received hospice services.⁷

Pan and colleagues' survey, however, also provided some encouraging news. In a follow-up questionnaire to the 2,015 hospitals reporting that they had either pain management services or EOL care, 337 (30%) of the 1,120 respondents reported having palliative care programs and another 228 (20%) had plans to establish them.⁶ The models most commonly in use or under development provided inpatient palliative care consultation (43%), hospital-based hospice care (36%), or outpatient palliative care services (32%).

Although the importance of palliative care services is now widely acknowledged, the type and quality of EOL services that originate in hospital settings is still commonly misunderstood. Among the health care systems offering EOL programs, the VA's is one of the more comprehensive.^{8,9} In response to a series of policy initiatives and mandates, all VA medical centers have been required to design EOL programs, but the specific characteristics of each have been left to the discretion of the facilities. A variety of approaches have been reported with combination programs being the most common.

A fiscal year 2001 survey of VA hospitals revealed that 80 (75%) of 107 respondents reported having inpatient programs that use existing nursing home beds to provide some form of hospice care; 79 (74%) reported having developed programs that work closely with community hospices, most of which are Medicare or Medicaid programs; and 45 (42%) reported

having hospice/palliative care consult teams.⁹ Given its diverse approach to EOL care, the VA is an ideal system in which to examine potential differences associated with various models of EOL care.

In this article, we'll describe the natural history study we conducted of two urban VA EOL programs—one that operates as a consultative and referral program and another that resides in a hospital inpatient unit. The specific aims of this study were to: 1) describe the different models of care provided by these two VA programs; 2) compare patient characteristics associated with the two distinct enrollment sites, types of care (hospice or palliative), and patient survival time; and 3) assess family satisfaction with care. After discussing our methods and findings, we'll suggest future directions for additional research.

SETTING AND SAMPLE

Both of the urban, VA EOL programs we studied offer comprehensive services. The consultative and referral program operates out of an academic medical center with 338 acute care beds and provides hospice and palliative care in a variety of settings. The inpatient program, based in a university-affiliated medical center with 159 acute care beds, provides care within a unit that has 36 nursing home beds dedicated to hospice and palliative care. Both programs provide pain control, palliative care, and hospice services.

Using a prospective design, all patients referred to hospice or palliative care services at either institution were eligible for inclusion in the study during the seven-month enrollment period. Based on clinical evaluation, two subjects were

excluded because they were not considered appropriate for EOL programs. The final sample included 262 patients—116 in the consultative and referral program and 146 in the inpatient program (Figure 1).

DATA COLLECTION

The Institutional Review Boards at both of the VA facilities approved all research protocols for the study. After being trained by the VISN 10 Geriatric Research, Education, and Clinical Center research team, staff physicians and nurses collected all patient data at their respective institutions through chart abstraction (demographic and illness-related data), phone interview (patient symptom distress and satisfaction), and mailed questionnaire (family satisfaction). Of the 262 patients who were enrolled, 59 (23%) were interviewed (55 of whom completed the interview), 91 (35%) were unable to participate in interviews due to compromised physical or mental status, 37 (14%) were inaccessible, and 75 (29%) refused. If patients consented, they completed the Memorial Symptom Assessment Scale (MSAS)¹⁰ and the patient Quality of Life Satisfaction (QOLS) scale, a clinical tool based on the World Health Organization Quality of Life-100¹¹ and adapted for use with hospice patients. We attempted to contact all patients by telephone five to 10 days after enrollment, regardless of whether they were being treated in an inpatient unit or at home.

TOOLS

Upon enrollment, in addition to demographic data, chart abstraction was used to complete the Karnofsky Performance Scale, which measures functional status.¹² The

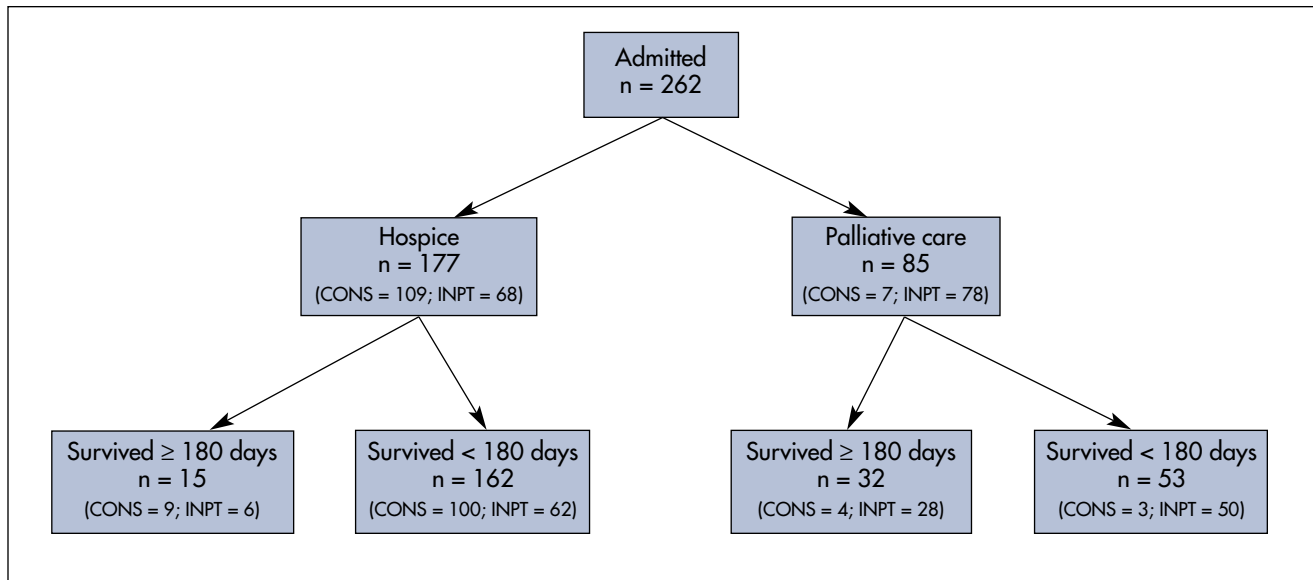


Figure 1. Classification and survival of patients admitted to the consultative (CONS) and inpatient (INPT) end-of-life programs during the study period.

hospice/palliative care teams at both sites incorporate this tool into their clinical assessment to evaluate prospective patients for hospice enrollment.

The MSAS is a multidimensional tool developed to assess the frequency, severity, and distress associated with 32 symptoms commonly experienced by patients with cancer. It has three validated subscales and test-retest reliability.^{10,13} Its Global Distress Index (MSAS-GDI) is calculated by obtaining the mean of the frequency scores associated with four psychological symptoms (feeling sad, worrying, feeling irritable, and feeling nervous) and the distress scores associated with six physical symptoms (lack of appetite, lack of energy, pain, feeling drowsy, constipation, and dry mouth). Its Physical Symptom Subscale (MSAS-PHYS) is the mean of the frequency, severity, and distress associated with 12 physical symptoms (lack of appetite, lack of

energy, pain, drowsiness, constipation, dry mouth, nausea, vomiting, change in taste, weight loss, feeling bloated, and dizziness). Finally, its Psychological Symptom Subscale (MSAS-PSYCH) is the mean of the frequency, severity, and distress associated with six psychological symptoms (worrying, feeling sad, feeling nervous, difficulty sleeping, feeling irritable, and difficulty concentrating). Scoring is in increments of one with a score of 0 representing no symptom and a score of 4 indicating that the symptom is almost constant. In comparison to Portenoy and colleagues' sample,¹⁰ out of the 55 subjects who completed the MSAS for our study, six (11%) had noncancer diagnoses. Internal consistency reliability for the three scales was adequate: MSAS-GDI was 0.78, MSAS-PHYS was 0.92, and MSAS-PSYCH was 0.94.

The QOLS scale is used routinely at the inpatient site. It contains 32 items to be rated on a

five-point Likert-type scale, ranging from "strongly disagree" to "strongly agree." The instrument's items can be categorized broadly into issues related to quality of life (for example, "I am disappointed that I cannot do many of the things I used to do") and satisfaction (for example, "I am satisfied with the medical treatment that I am receiving"). In addition, it contains one item related to pain intensity, which is rated on a 10-point scale with 0 representing "no pain" and 10 representing "excruciating pain." The QOLS scale is comprehensive and cohesive, uses straightforward language, and poses a minimal burden for patients. The tool's internal reliability for this sample was 0.9.

Family satisfaction data were collected through a mail survey sent out three months after the patients' death. The questionnaire included an explanatory letter; a reminder postcard was sent one week later. Questionnaires were

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identified by site (the consultative or the inpatient program) but not by patient name, care status (hospice or palliative care), or length of time in care.

The eight-item questionnaire asked family members to evaluate their satisfaction with patient comfort (two items) and communication between the family and the health care team (six items).¹⁴ Items were scored “agree,” “disagree,” or “not applicable,” with higher scores indicating more agreement.

When Baker and colleagues used this tool in face-to-face interviews with family members and other surrogate respondents for 767 seriously ill hospitalized adults who died, they reported fewer than 5.5% “don’t know” or missing responses and a Cronbach’s alpha coefficient of 0.8 for the comfort score and 0.71 for the communication score.¹⁴ In our study, we had a smaller sample (81 responses from family members) and more “not applicable” or missing responses (20%), but the internal consistency statistics were adequate with a Chronbach’s alpha of 0.94 for comfort and 0.74 for communication.

PROGRAM DIFFERENCES

To compare the two models of care, the consultative and referral program versus the inpatient program, we considered infrastructure, personnel, and care processes.

In the consultative model of care, the hospice/palliative care team (advanced practice nurse, physician, social worker, and chaplain) receives consult requests from physicians and nurses. Most patients are enrolled from the hospital’s inpatient acute care services (69%), while less than one third (28%) come from home, and

a very few (3%) come from nursing homes. A team member evaluates and counsels the patient and family members about EOL issues and makes recommendations to the care team concerning comfort measures and symptom management. All recommendations are documented in the patient record, but members of the referring medical service—not consultation team members—write treatment orders. In a typical referral, the hospice team from the consult service follows the patient through the inpatient stay and arranges for posthospital care through placement in a community hospice program or in a nursing home, with or without a hospice program.

If the patient is transferred to an inpatient hospice facility, VA involvement is terminated. If the patient is discharged to a home hospice program, the VA physician and hospice team continue to participate in care through consultation with the community-based hospice team.

During the enrollment period, 116 patients were signed up for the consultative program. Similar to other hospice studies, we found that the patients in this program used more than one service during their enrollment: 24% used inpatient hospice or palliative care services, 56% used home hospice, and 34% used both hospital-based and external long-term care services.

The inpatient program has an integrated model of care that includes 36 dedicated nursing home beds: 16 for hospice and 20 for palliative care. All care is managed by a hospice/palliative care team—consisting of a clinical nurse specialist, an advanced practice nurse, a physician, a social worker, and a chaplain—dedicated to providing

comprehensive inpatient clinical services. Both community and VA institutions provided referrals to the inpatient program. During the period studied, the majority of referrals came from the hospital’s acute care inpatient services (54%), but patients also were referred to the program from outpatient community sources (33%), nursing homes (11%), or community inpatient hospices (2%). Although more than 95% of the patients were admitted to the inpatient unit at the time of enrollment, outpatient services (which are coordinated with community hospice programs) remained an option for all patients. In a few instances, patients were discharged and readmitted to the inpatient unit a number of times over the course of their illness.

Compared to the consultative program, the inpatient program had a much smaller proportion of the patients that used services outside of the VA: Of the 146 patients enrolled in this program during the study period, 100% were admitted to the inpatient hospice/palliative care unit, 7% used home hospice services, and 4% used hospital-based or external long-term care services.

The two programs differ in how they designate patients to receive “hospice” or “palliative care.” In the consultative model, the designation is made on a case-by-case basis with the primary criterion for differentiation being advanced, progressive, incurable disease. Symptom management is the treatment goal for all hospice patients. Patients receiving palliative care, however, also are monitored for response to aggressive therapy and hemodynamic improvement. The distinction between hospice and palliative care is not based on “do

not resuscitate" (DNR) orders (B. McIver, oral communication, 2002).

In the inpatient model, the classification system is more formalized. All patients with serious, incurable disease are eligible for admission into one of two contiguous units: hospice or palliative care. Patients must have a DNR order to be admitted for hospice care. The enrollment criteria for palliative care do not include a DNR order and patients may continue to receive aggressive treatment. All patients with noncurative cancer are eligible for admission to palliative care, as are patients who have been admitted to an acute care institution three times in the past six months with the same medical diagnosis (for example, chronic obstructive pulmonary disease or heart failure), or who have one or more intensive care unit admissions over the past six months for the same medical diagnosis.¹⁵

PATIENT CHARACTERISTICS

We compared patient characteristics associated with the two program sites, care status, and survival time.

Subjects at both sites were similar in age, gender, diagnosis, and the availability of a support network (Table 1). The consultative site, however, had a higher proportion of blacks (37% versus 17%) and of patients whose highest educational level was grade school (28% versus 9%). A larger proportion of patients in the inpatient model had enrollment Karnofsky scores of 40 or below (65% versus 49%; $\chi^2 = 6.4$, $P = .011$). For the total population, enrollment Karnofsky scores correlated with overall survival (Kendall's tau-B = 0.4, $P < .001$). More patients with cancer than patients without cancer

had Karnofsky scores of 50 or higher upon entry (49% versus 16%; $\chi^2 = 19$; $P < .001$), but there were no significant differences in length of stay between these two groups.

There were differences between the two programs in terms of the proportion of patients designated for hospice or palliative care. In the inpatient program, 90% of the patients were designated to receive palliative care, while in the consultative program, 61% of patients were assigned to hospice. There were significant differences in Karnofsky scores upon enrollment between patients receiving hospice and palliative care, with patients assigned to hospice having decreased function and increased symptom scores ($\chi^2 = 8.9$, $P = .003$). As expected, the percentage of patients with DNR orders was lower in the group designated to receive palliative care.

MSAS-PSYCH and MSAS-GDI scores indicated similar symptom burden between patients assigned to hospice and palliative care (Figure 2). Lack of energy and pain were the dominant symptoms in both hospice and palliative care groups, with more than 75% of the patients who completed the MSAS reporting the presence of these two symptoms. Patients receiving palliative care reported drowsiness, dry mouth, and worrying more than patients assigned to hospice care, while weight loss was more common in the latter group. The QOLS scale scores and the pain scores were similar for both care groups at both sites—though the mean pain score of 3.9 in the palliative care group indicated a moderate amount of unrelieved pain (Table 2).

We evaluated patients' survival, comparing characteristics of those

who survived fewer than 180 days with those who survived 180 days or more (Table 3). Of the 86 patients assigned to receive palliative care, 32 (37%) survived 180 days or more. Of the 177 patients assigned to hospice care, only 15 (8%) survived more than 180 days. Those surviving 180 days or more had greater function, less disease burden, and a higher median Karnofsky score (50 versus 40) on enrollment. The overall scores for the QOLS scale were similar between the two survival groups. The MSAS survey data, however, showed no significant differences in level of distress between those who survived 180 days or more and those who did not.

FAMILY SATISFACTION

Three months after the patients' death, surveys were mailed to 191 (73%) of the families. The sample size was decreased primarily because addresses were either incorrect or unknown or there were no known family contacts. Ultimately, 81 (42%) of the surveys were returned, with both sites returning a similar number (consultative, 38; inpatient, 43). Mean family satisfaction scores for the two sites were nearly identical. For the consultative and inpatient programs, respectively, the mean scores were 1.7 for both sites (standard deviation, ± 0.67 and 0.69) on the comfort subscale (possible range, 1 to 2) and 4.9 (± 1.4) and 5.2 (± 1.5) on the communication subscale (possible range, 1 to 6). Notably, 78% of the respondents wrote additional comments—68% of which were overwhelmingly positive, primarily expressing appreciation for the attention that family members received from the hospice team.

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Table 1. Demographics of patient populations admitted to the consultative and inpatient end-of-life programs during the study period

Characteristic	Consultative,* no. (%)	Inpatient,† no. (%)
Initial program		
Hospice	109 (94)	68 (47)
Palliative care	7 (6)	78 (53)
Age		
< 65	34 (29)	40 (27)
65–79	65 (56)	80 (55)
80+	17 (15)	26 (18)
Male gender	113 (97)	144 (99)
Married	38 (33)	61 (42)
Race		
White	71 (61)	120 (82)
Black	43 (37)	25 (17)
Hispanic	1 (1)	0 (0)
Unknown	1 (1)	1 (1)
Presence of support person	66 (57)	83 (57)
Highest educational level		
Grade school	33 (28)	13 (9)
High school	42 (36)	105 (72)
College or above	2 (2)	23 (16)
Missing	39 (34)	5 (3)
Karnofsky performance scale‡		
Least functional (10–40)	57 (49)	94 (64)
Most functional (≥ 50)	58 (50)	50 (34)
Diagnosis category		
Cancer	94 (81)	112 (77)
Dementia	7 (6)	5 (3)
Respiratory disease	3 (3)	12 (8)
Liver disease	2 (2)	1 (1)
Cardiac disease	4 (3)	3 (2)
Renal disease	0 (0)	7 (5)
Other	6 (5)	6 (4)
DNR§ orders on admission	67 (58)	112 (76)
*n = 116. †n = 146. ‡Data were unavailable for one patient from the consultative group and two patients from the inpatient group.		
§DNR = do not resuscitate.		

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SIMILARITIES AND DIFFERENCES

The two EOL programs we studied (both of which operate out of urban, tertiary, VA medical centers) take very different approaches to patient care. One model follows a traditional inpatient hospice/palliative care model with a dedicated team working on a dedicated EOL hospital unit; the other uses a traditional consultative approach in which the referring medical team continues to care for the patient until he or she is transferred to a formal hospice program or another site of care. The two patient populations differed in terms of education and race, but were remarkably similar in terms of age, presence of a caregiver, proportion of patients with cancer, disease severity, symptom burden and control, and family satisfaction.

SITE OF CARE PREFERENCES

This study is limited by the fact that all data were collected from patients and family members over the same seven-month period. Additionally, information on preferences for site of care would have been informative.

Previous studies have documented a preference for home care, but patients frequently move among settings, depending on patient and caregiver needs.¹⁶⁻¹⁸ Although our data suggest that certain patients may choose inpatient EOL care and report high levels of satisfaction with such care, this finding is speculative. Further research is necessary to determine when and why patients choose inpatient care and whether patients with terminal illnesses who are admitted to an inpatient hospice would prefer to be transferred home after admission.

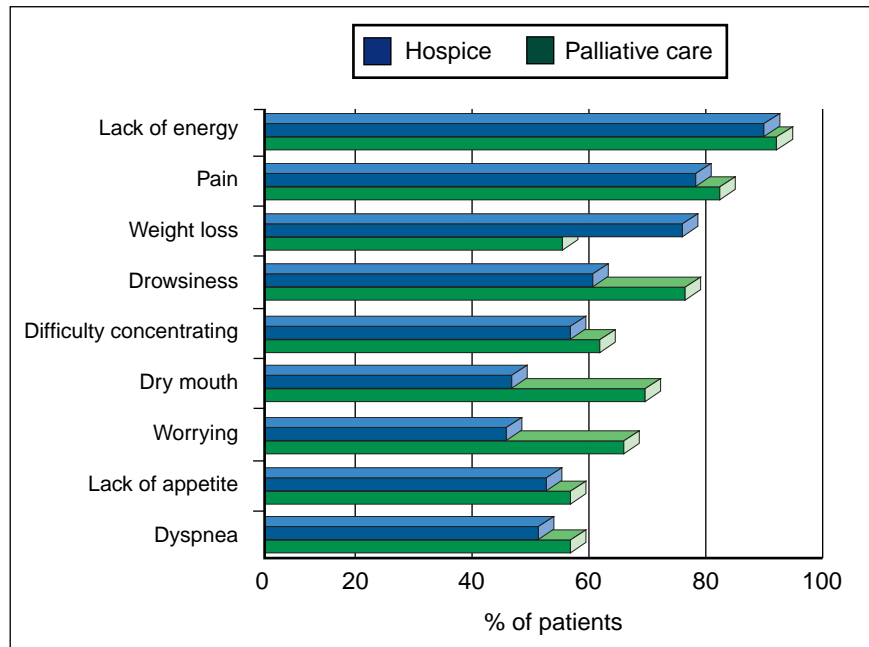


Figure 2. Prevalence of the nine most common signs and symptoms reported by study patients completing the Memorial Symptom Assessment Scale (n = 55).

CARE DESIGNATION

We attempted to understand the discrepancies between the two programs in terms of the proportion of patients assigned to receive hospice or palliative care. Given the wide variation in patient health status and the different definitions used for hospice and palliative care, we were unsure whether the distinction was based on semantics or objective criteria.

First, we investigated whether more patients in the consultative program should have been assigned to receive palliative rather than hospice care. Since there was no uniform definition of palliative care in this study, we evaluated all patients according to six-month survival, a decision based on previous Medicare regulations. Using this criterion, one would anticipate more long-term survivors in the

palliative care group, an expectation supported by our data. Of patients entering the inpatient palliative care program, roughly two thirds survived more than 180 days. In both the consultative and inpatient hospice programs, a similar proportion of patients survived more than 180 days (8% and 7%, respectively). Using the 180-day criterion, therefore, most patients entering the consultative program were appropriately classified as hospice patients.

Second, we investigated whether the patients enrolled in the inpatient palliative care program were appropriately classified. There were formal criteria for admission to the palliative care unit, and the Karnofsky, pain, and MSAS scores suggested considerable disease burden in these patients, indicating that they were good candidates for

Table 2. Survival, symptom burden, quality of life, and pain of patients assigned to receive hospice or palliative care

Measure	Hospice	Palliative care	t value	P value
Length of stay (days)				
Mean (SD*)	52 (89)	168 (178)	-5.6	< .001
Median	18	87		
Range	0-616	2-616		
No. of patients	177	85		
Memorial Symptom Assessment Scale				
Mean global distress score (SD)	1.2 (0.5)	1.4 (0.6)	-0.9	.3
Mean physical distress score (SD)	1.2 (0.5)	1.3 (0.6)	-0.4	.7
Mean psychological distress score (SD)	1.2 (0.8)	1.5 (1.0)	-1.4	.16
No. of patients	32	23		
Quality of Life Satisfaction scale				
Mean score (SD)	112 (14)	105 (20)	1.6	.11
No. of patients	34	25		
Pain scale				
Mean score (SD)	2.9 (2.7)	3.9 (2.5)	-1.4	.16
No. of patients	34	25		
*SD = standard deviation.				

an EOL program. We speculated that each program's organizational structure determined the patient mix—that is, that the inpatient program received a disproportionate number of palliative care referrals (53%) compared to the consultative program (7%) because of its recognition as a separate programmatic unit. This seems likely since there is a clinical need in busy hospitals to free acute beds with early transfers.

By the same token, the low number of palliative care referrals to the consultative program may not reflect the lack of patients who need the service but rather, the unavailability of an inpatient unit that would provide palliative care services. Aside from helping larger numbers of patients, an additional benefit of having an inpatient palliative care unit is that it provides EOL care to patients even though the patient, family, or provider is

undecided or reluctant to accept the hospice patient designation.

Health care providers, patients, and families usually consider EOL services only when there is an expectation of imminent death. While there will always be a degree of uncertainty in determining the trajectory of dying—and there are no known clinical criteria—dying generally is thought to be associated with functional decline, which is determined in part by disease

Table 3. Survival, symptom burden, quality of life, and pain of patients surviving less than 180 days versus 180 days or more

Measure	Length of stay		t value	P value
	< 180 days	≥ 180 days		
Length of stay (days)				
Mean (SD*)	34 (38)	350 (129)		
Median	18	320		
Range	0–178	193–616		
No. of patients	218	46		
Memorial Symptom Assessment Scale				
Mean global distress score (SD)	1.4 (0.6)	1.4 (0.6)	–0.11	.9
Mean physical distress score (SD)	1.3 (0.6)	1.3 (0.6)	0.03	.9
Mean psychological distress score (SD)	1.4 (0.8)	1.2 (1.0)	–0.6	.5
No. of patients	41	16		
Quality of Life Satisfaction scale				
Mean score (SD)	109 (15)	110 (21)	0.36	.72
No. of patients	42	17		
Pain scale				
Mean score (SD)	3.1 (2.6)	3.9 (2.8)	1.1	.28
No. of patients	42	17		
*SD = standard deviation.				

state.¹⁹ The difficulty lies in coming to grips with one of the central questions in EOL care: Who should be considered to be dying?²⁰

Although no longer a Medicare requirement, a life expectancy of less than six months or the willingness to accept a DNR designation remains an implicit assumption for admission to many hospice programs. As in other studies, our data support the unreliability of

this criterion. Furthermore, because the boundary between hospice and palliative care is blurred and seems to have as much to do with patient, family, and provider preference as with life expectancy, patients who continue more aggressive therapy may be excluded from hospice care, even though they may need extensive help with pain management, and with physical and psychological symptoms.

RECOMMENDATIONS FOR FURTHER STUDY

This study provided insight into current models of EOL care in the VHA. Further investigations are needed to collect such data as the number of patients who are considered appropriate for hospice versus the number who receive hospice care, patient preferences for site of care (home versus institutional setting), and an economic

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evaluation of the two models of care. Additionally, research that investigates ways of extending the hospice philosophy to greater numbers of patients has the potential to expand the EOL process into more of a continuum. ●

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