Timing of Referral of Terminally Ill Patients to an Outpatient Hospice

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Objective: Since inordinately long or short lengths of stay at hospice can create problems for patients, providers, and payers, the author sought to identify predictors of timing of patient referral.

Methods: A retrospective cohort of 405 hospice outpatients was analyzed with Cox regression to evaluate the effect on length of stay of patient age, gender, race, diagnosis, activity level, mental status, dyspnea, insurance, income, religion, and home support, and of referring physician specialty.

Results: Median survival time at the hospice was 29 days; 15% of the patients died within seven days and 12% lived longer than 180 days. A one-unit increment in a six-unit activity-level scale was associated with a 19% reduction in the rate of death. Compared with reference groups, oriented patients and depressed patients had 57% and 35% lower death rates; patients with prostate cancer and cardiovascular disease had 50% and 58% lower death rates. There was no significant gender, race, religion, insurance, or income difference among the patient groups.

Conclusions: Inappropriately early or late referral occurs in a substantial minority of patients referred to the hospice under study. Closer attention to accurate prognostication in different types of terminally ill patients and more timely referral to hospice might help to optimize the use of this health care resource from both patient and societal perspectives.

Key words: hospice; terminal illness; survival; physician decision making; referral patterns; prognosis; social factors; religion.

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THE HOSPICE APPROACH to the care of terminally ill patients stresses relief of patients' physical, emotional, and spiritual pain rather than treatment for patients' underlying diseases. Compared with traditional hospital-based terminal care, home-based hospice care provides better pain relief,[1] fosters patient self-determination,[2] is preferred by patients,[3] and is probably more cost-effective.[4–7] According to the National Hospice Organization, 207,000 patients and families received hospice services in the United States in 1990, including one-third of all patients dying of cancer.[8] The number of patients cared for at hospices has been increasing at an annual rate of about 10% overall[8] and about 35% for Medicare beneficiaries.[9]

Current clinical and insurance standards suggest that patients who desire hospice care be referred when they have less than six months to live.[10]* While patients' attending physicians typically make this serious prognostic determination, there have been few evaluations of the accuracy of physician prognoses and referral decisions in this setting. Most studies of prognosis in the terminally ill consider patients who are hospitalized in intensive care units.[11–13] The prior studies of hospice survival that had been done—in outpatients[14, 15] and inpatients[7, 15–18]—have been limited by one or more of the following deficiencies: the exclusive focus on inpatient hospices, the use of logistic rather than Cox regression, the neglect of patient diagnoses, and the exclusion of patients with diagnoses other than cancer.

Moreover, relatively little has been written about influences on physician referral to hospice[19] or about patient characteristics that predict timing of referral. Commentators have noted, however, that physicians typically make poor judgments about intermediate-term survival in terminally ill outpatients and that unduly optimistic prognoses (with consequent late referral to hospice) and unduly pessimistic prognoses (with early referral) have adverse implications.[20, 21] One editorialist, concerned especially with the problem of late referral, remarked that "in the absence of objective criteria, the only patients referred to the hospice may be those who are so obviously close to death that the hospice's palliative care will be offered too late."[20]

Since referral that is "too early" or "too late" can create organizational, financial, clinical, and emotional problems for both caregivers and patients, a better understanding of the factors associated with duration of survival of hospice patients is warranted. Current referral patterns may be unnecessarily depriving patients of optimal access to hospice services, and, particularly if survival at hospice is short because referral is late, may be needlessly increasing the cost of care (by replacing less costly hospice care with more costly hospital care). Given the increasing prominence, cost–effectiveness, and desirability of hospice care, optimizing hospice use is thus an important goal. The objective here is therefore

*This expectation is widely held, by both referring physicians and hospice personnel, according to the qualitative research done in conjunction with this study. A six-month expected duration of survival is also the standard for "terminal" illness in most published studies on the topic of terminal illness. With respect to hospice care in particular, the six-month standard was codified in the initial legislation enacting the Medicare hospice benefit.[9]

to characterize—for a cohort of terminally ill patients referred to an outpatient hospice—the patient and physician features that are associated with the timing of physician referral.

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METHODS

Site

Data were collected at Wissahickon Hospice, a large, independent, nonprofit, Medicare-certified outpatient hospice located in a suburb of Philadelphia. It has a daily census of 40–50 patients and admits about 400 new patients per year, all of whom are cared for at their own homes. It is the only hospice in a catchment area of 400,000 people, encompassing Philadelphia Health District 9 and some adjoining areas of Montgomery County. In this area, approximately 20% of all adults dying of all nonaccidental causes, and 43% of all those dying of cancer, receive their terminal care at this hospice.[22] Wissahickon Hospice was chosen for this study because it maintains a computerized patient database and because its patients are typical of hospices in Pennsylvania and the nation.[8, 23] In-depth interviews were conducted with ten physicians who refer patients to this hospice and with several hospice personnel. These interviews, along with a review of the literature, formed the basis for a number of the hypothesized associations evaluated quantitatively. This research was approved by the Wissahickon Hospice Human Studies Committee.

Variables

Data for all 405 patients newly admitted to the hospice between November 1, 1990, and November 21, 1991, were retrospectively obtained from the hospice computer database. The dependent variable was the duration of hospice stay until death or discharge. During the study period, 256 patients died and 114 were discharged; 35 were still enrolled on the last day of the study period. The independent variables, chosen because of their availability in the hospice computer system, were determined at the time of admission.

The nonclinical independent variables included age, gender, race, insurance type, income, religion, home support, and referring physician specialty. Home support was considered to be high when a family member lived in the patient's home and cared for the patient on a full-time basis.

The clinical independent variables were the patient's diagnosis, mental status, activity level, and presence of dyspnea. Fifty-six different ICD-9 diagnoses were represented in the sample; each patient had only one. These diagnoses were grouped into 14 categories, based on the affected organ system, and were analyzed as dummy variables. Information about cognitive and psychological status was available in the following, non–mutually exclusive categories, which were coded as dummy varia-

bles: oriented to self, place, and time; comatose; depressed; and agitated. The data describing activity were in the form of an ordinal activity-level scale with values of 1 through 6, corresponding to the following categories: confined to bed; needs assistance to transfer from bed to chair; bedrest with bathroom privileges; up as tolerated; independent at home; and no restrictions.

Statistical Analysis

The data were analyzed using Cox proportional hazards regression.[24] Having a higher "hazard rate," or "risk," of death implies a shorter survival time or shorter length of stay, and vice versa. In the context of this study, such models delineate those variables that put patients at risk for longer or shorter hospice stays, with early or late referral, respectively. The coefficients in the models may be interpreted as "risk ratios," similar to odds ratios, or translated into percentage changes in the hazard rate.[25]

Cox regression models are able to include data from cases that are removed from the set at risk for death ("censored") by some means other than death, for example, cessation of follow-up or discharge. Discharge is common in patients referred to hospices; for example, a national study of Medicare hospice patients documented that patients had their stays interrupted through discharge approximately 30% of the time,[26] and figures for discharge in other settings are also comparable.[27] Patients in this cohort were discharged from the hospice for one of four reasons: 1) transfer to noninstitutional, nonhospice care (47%); 2) unsuitability to the hospice approach (e.g., lack of a suitable caregiver at home) (40%); 3) transfer to a hospital (11%); and 4) transfer to a different hospice (2%). Hence, some patients with relatively *low* and others with relatively *high* risks of imminent death were in the pool of discharged patients; unfortunately, as is typical for survival analysis, it is not possible to determine their relative proportions. Given the possibility that such nonrandom, "informative" censoring might be present, I conducted sensitivity analysis involving the extreme assumptions that patients who were censored were at the very highest or very lowest risk of death.[28] This analysis did not change the major conclusions of this study, so only the main analyses are detailed below.

Tests of significance employed two-tailed t-tests at the 0.05 level. The explanatory power of the models was evaluated by means of an R^2 based on the score statistic.[29] The survival function was generated with the Kaplan-Meier method.[30]

RESULTS

The patients in this cohort ranged in age from 22 to 102 years; the mean age was 71.2 years. The patients had the following diseases: lung cancer, 106 (26.2%); gastrointestinal cancer, 52 (12.8%); liver or pancreas

TABLE 1

Cohort Description

Gender	
Female	222 (54.8%)
Male	183 (45.2%)
Race	
White	302 (74.6%)
Nonwhite	103 (25.4%)
Insurance status	
Medicare	312 (77.0%)
Medicaid	19 (4.7%)
Private	74 (18.3%)
Annual income	
$0–15,000	138 (34.1%)
$15,001–35,000	236 (58.3%)
> $35,000	31 (7.6%)
Religion	
Protestant	198 (48.9%)
Catholic	161 (39.8%)
Jewish	30 (7.4%)
Other	16 (3.9%)
Referring physician specialty	
Internist	209 (51.6%)
Family practitioner	104 (25.7%)
General practitioner	35 (8.6%)
Surgeon	10 (2.5%)
All others	47 (11.6%)

cancer, 31 (7.7%); prostate cancer, 26 (6.4%); hematologic cancer, 25 (6.2%); gynecologic cancer, 24 (5.9%); breast cancer, 18 (4.4%); urinary tract cancer, 17 (4.2%); head and neck cancer, 16 (4.0%); some other cancer, 24 (5.9%); neurologic disease, nine (2.2%); AIDS, 11 (2.7%); cardiovascular disease, 33 (8.2%); and some other noncancer disease (mostly emphysema), 13 (3.2%). Thus, 84% of the patients had cancer of some type. The mean activity level of the sample was 3.2 ± 1.1; 11.6% of the patients in the sample were depressed, 72.7% were oriented, and 87.3% had high home support. Further description of the cohort is given in Table 1.

Two models of survival, and hence of timing of referral, are given in Table 2. Model 2 differs from model 1 only in that the variables coding for diagnosis have been added. A likelihood ratio χ^2 test showed that the difference between models 1 and 2 was significant (p = 0.03), demonstrating the importance of diagnosis in determining timing of referral. In model 2, age, gender, and race were not statistically significant. Orientation, activity, and depression were all significantly associated with lower risks of death—that is, longer stays until death and *earlier* referral. In this model, the oriented patients had a 57% lower risk of death than did the disoriented patients (p < 0.001). Each one-unit increment in activity level resulted in a 19% lower risk of death (p < 0.001). The depressed patients had a 35% lower risk of death than did the nondepressed patients (p = 0.05). Prostate cancer, cardiovascular disease, and

"other diseases" (mostly emphysema) were associated with lower risks of death and longer stays, compared with the reference category of lung cancer; the patients with these conditions had 50% (p = 0.02), 58% (p = 0.003), and 60% (p = 0.03) reductions in their risks, of death, respectively. Compared with lung cancer, no disease category was significantly associated with shorter stays and late referral. The R^2 of model 2 was 0.23. In model 1, each additional year of age decreased the risk of death by 1.2% (p = 0.02), but this finding did not remain significant after controlling for diagnosis.

The relationship between activity level and length of stay for the 256 patients whose deaths were observed can also be illustrated as follows: mean length of stay (unadjusted for covariates) increased from 19 days for those with activity levels of 1 or 2, to 38 days for those

TABLE 2

Risk Ratios (95% Confidence Intervals) for Two Models of Hazard Rates of Death*

	Model 1	Model 2
Age	0.98 (0.97–0.99)†	0.99 (0.98–1.00)
Gender—male	1.16 (0.90–1.50)	1.18 (0.88–1.59)
Race—white	1.21 (0.90–1.64)	1.26 (0.91–1.75)
Orientation	0.45 (0.32–0.61)†	0.43 (0.31–0.60)†
Activity	0.84 (0.75–0.95)†	0.81 (0.71–0.92)†
Depression	0.69 (0.45–1.06)	0.65 (0.42–0.99)†
Gastrointestinal cancer		0.75 (0.48–1.15)
Head and neck cancer		1.09 (0.53–2.23)
Liver or pancreas cancer		1.23 (0.70–2.16)
Breast cancer		1.08 (0.56–2.08)
Gynecologic cancer		0.67 (0.37–1.23)
Prostate cancer		0.50 (0.28–0.92)†
Urinary tract cancer		0.72 (0.38–1.36)
Hematologic cancer		1.28 (0.73–2.23)
AIDS		1.07 (0.42–2.76)
Neurologic disease		0.70 (0.29–1.71)
Cardiovascular disease		0.42 (0.24–0.75)†
Other cancers		0.88 (0.48–1.61)
Other diseases		0.40 (0.17–0.91)†
Likelihood ratio χ^2	73.6	98.8
df	6	19
p	< 0.001	< 0.001

*All variables except age and activity were coded as 1 = present, 0 = absent; lung cancer is the reference category for the diagnoses. Analogous to odds ratios, risk ratios greater than unity imply a correspondingly increased risk of death, and vice versa.
†p < 0.05.

FIGURE 1. Survival of terminally ill patients referred to an outpatient hospice. The curve illustrates the relatively short median survival time of 29 days. The dashed lines show arbitrary cutoffs for late referral (less than seven-day survival) and early referral (more than 180-day survival).
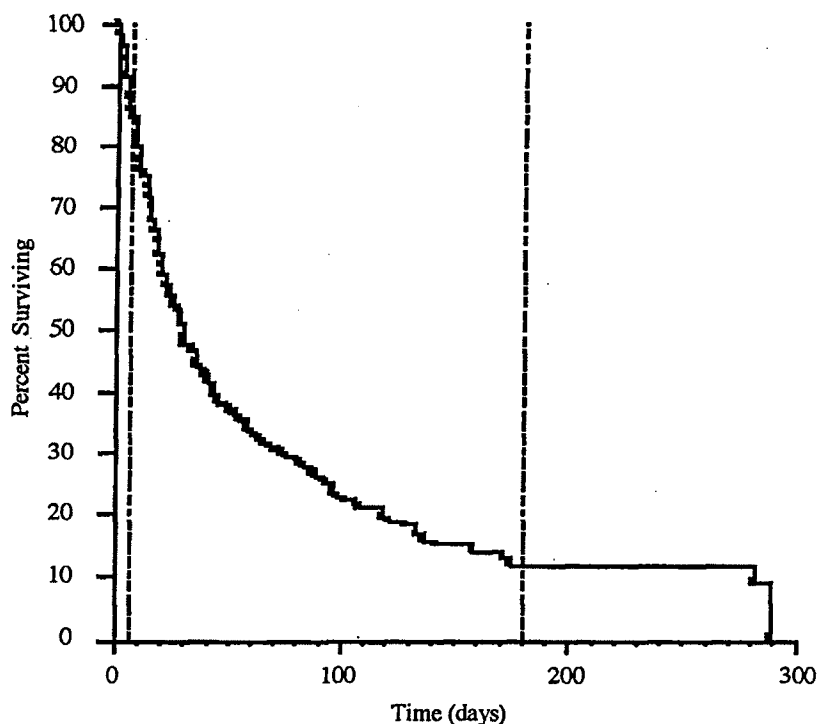
with levels of 3 or 4, to 54 days for those with levels of 5 or 6. Of patients with an activity scale value of 1, 69% died within seven days of referral; at the other extreme, no patient with a value of 6 died within seven days.

Of the 57 patients whose deaths were observed to have occurred within seven days of referral, 22 (38.6%) died of lung cancer; eight (14.0%) of gastrointestinal cancer; five (8.8%) of hematologic cancer; four (7.0%) of liver or pancreas cancer; three each (5.8%) of breast cancer, urinary tract cancer, and all other cancers; two each (3.5%) of prostate cancer, AIDS, and cardiovascular disease; and one each (1.7%) of head and neck cancer, gynecologic cancer, and neurologic disease.

Dyspnea and agitation were not associated with referral in a statistically significant fashion (data not shown). Coma was highly associated with death and hence with late referral; ten patients were comatose on admission; five died within two days and all ten died within eight days.

Models 1 and 2 were used as baseline models for the evaluation of the nonclinical variables: income, private insurance, religion, home support, and referring physician specialty. None of these variables significantly affected the timing of referral (data not shown).

The Kaplan-Meier estimate of median survival time after referral was 29 days. The survival function is shown in Figure 1. For illustration, 15% of the patients died within an arbitrary cutoff of seven days after referral, 30% died within 14 days, and 12% lived longer than 180 days. Indeed, of the 12% who outlived the prediction upon admission to the hospice of less than 180 days of survival, all outlived it by at least 90 days.

DISCUSSION

The findings in this pilot project regarding both the observed survival and the predictors of early and late referral may reflect the situation at other Medicare-certified outpatient hospices, though further research with national samples of hospice patients will be necessary. This hospice was larger than the national average; but the study cohort was comparable to the national hospice patient population in terms of patient age, gender, percentage with diagnoses of cancer or AIDS, and percentage covered by Medicare.[8]

An explicit assumption in this research is that the main determinant of length of stay at a hospice is the timing of the patient's referral, as opposed, for example, to the aggressiveness of the therapy the patient receives after arrival at the hospice. That is, timing of referral is considered to be the determinative factor in duration of survival at hospice: on average, patients referred to hospice early in their illnesses will have longer stays and those referred late will have shorter stays. This assumption is especially likely to obtain under circumstances such as those found at this hospice, namely, where survival time was relatively short. Moreover, the findings of this study must be restricted to the factors that influence timing of referral of patients who are actually referred to hospice; other, potentially different factors might influence the decision of *whether* to refer patients at all.

A further explicit assumption in this research is that physicians differ in the timing of their referrals of terminally ill patients to hospice and that these differences are partly contingent on the uncertainty inherent in

medicine, partially contingent on patient attitudes toward death and terminal care, but also partly contingent on patient and physician attributes that are independent of the patient's postulated prognosis. Indeed, if physicians could make perfect predictions about when death would occur and if they agreed to refer patients at a uniform time before death, none of the invariant patient variables examined in this study (such as diagnosis) would have been statistically significant. While physicians are not the sole decision makers in hospice referral, they are an essential part of the process and, at least theoretically, are capable of modifying their practice styles to minimize early or late referral.

This study has two limitations in addition to the foregoing assumptions. First, only a limited range of variables potentially related to timing of referral was considered. And second, the findings of this study will need to be evaluated in an independent data set, preferably a national sample of hospice patients.

Generally speaking, in a population of terminally ill people, those with good mental status or high activity level or both may be expected to have longer durations of survival compared with those without.[31,32] Thus, as expected, higher activity levels and orientation were associated with longer lengths of stay at this hospice. Conversely, compromised activity level and mental status were associated with shorter lengths of stay.

Compared with nondepressed patients, those who are depressed should have shorter survivals.[33-36] Yet depression was associated with relatively long survival at this hospice. There are several possible explanations for the relatively early referral of such patients. Depressed patients with terminal illness might be considered more unmanageable by their physicians and so be referred earlier. The persistence of this finding when controlling for physician specialty suggests that, if present, such physician behavior occurs across many specialties. Alternatively, depressed patients might feel their symptoms to be more severe than do similarly situated nondepressed patients; hence, a depressed patient might actually be less sick than a nondepressed patient. Finally, depression typically occurs relatively early in the stages through which terminally ill patients pass as they cope with their diseases[37]; thus, depression may simply be a marker for earlier disease stage or more recent diagnosis, and hence, perhaps, less severe pathology.

Model 1 suggests that advanced age is negatively associated with death. This finding, similar to that for depression, might arise from the fact that old patients are referred earlier to hospice than are young patients. Young terminally ill patients might undergo longer courses of aggressive care before being referred to hospice—at which point they would be relatively late in the course of their illnesses and more physically compromised. This is consonant with the practice patterns of several of the physicians who were interviewed: elderly terminally ill

patients, they claimed, were much more likely to be promptly referred to hospice for palliative care than were similarly situated young patients. However, the effect of age disappeared when diagnosis was controlled for, which suggests that older patients had different, and less severe, diagnoses than did younger patients.

The relationship identified here between duration of hospice stay and certain primary diagnoses has not been described in prior analysis of hospice survival.[15] Analysis of the data for specific disease categories suggests that patients with prostate cancer, cardiovascular disease, and certain other diseases (e.g., emphysema) have significantly longer stays and are being referred to hospice sooner in the course of their diseases. In the case of prostate cancer, this is consonant with the fact that this disease frequently is associated with early painful metastases to bone (which necessitate pain management), and this, according to respondents in interviews, fosters early referral.

Other clinical (e.g., age, weight loss, dyspnea[15,38]) and nonclinical (e.g., religion,[39,40] social support[41]) features may also affect the survival of terminally ill patients. In this study, however, unlike previous studies,[15,38] dyspnea was *not* found to be significantly associated with shorter survival, perhaps because the present study controlled for diagnosis. Nor, in the present study, did religion, income, insurance type, race, or social support have a significant effect on length of stay at hospice. The findings regarding insurance and income suggest that financial factors may be irrelevant to timing of referral; specifically, there was no difference in timings of referral of patients with Medicare versus private insurance in this cohort.

The length of stay at hospice does not appear to be influenced by whether the referring physician was a subspecialist. Some internists, particularly oncologists, who refer patients to hospices stated in interviews that they continued to treat a patient aggressively until they felt that the patient had less than *one* month to live. On the other hand, family practitioners and general internists tended to endorse the hospice approach and described their practice style as one of earlier referral. This hypothesis about different lengths of hospice stay according to physician specialty was not supported by the quantitative data.

Previous research has documented that hospice care is often superior to other forms of terminal care, such as family or hospital care, based on factors such as pain control,[1] patient preference,[3] and monetary expenditures.[5] Thus, a terminally ill patient would probably be better served by spending, say, the last three months of his or her life under hospice care rather than two months in a hospital and then only the last month in a hospice. Such a patient, in other words, would benefit from earlier referral. In general, needlessly early and late referrals— "late" and "early" death, respectively—may result in the use of substantial hospice resources without the

achievement of commensurate benefits. A late death[10] may be provisionally and arbitrarily defined as one that occurs more than 180 days after referral, and an early death[20] as one that occurs within seven days of referral.

"Late" death at hospice provides several reasons for concern. In some situations where death does not result within 180 days, the patient may have derived greater benefit from rehabilitative care than from hospice care. In addition, such an extended stay in a constant state of anticipation of death may be demoralizing and financially costly to the patient. Such extended stays may also be financially costly for hospices[42] and, finally, may oblige hospice nurses to deliver a type of nursing care that is inconsistent with their specialized training.

"Early" death also provides several reasons for concern. For patients, early death may result in inadequate use of a mode of care they consider desirable; a longer stay in hospice might make their experience of terminal illness more humane and more clinically appropriate. Moreover, early death often means that hospice professionals have inadequate time to develop and implement a comprehensive care plan. In addition, late transfer of a patient to hospice results in a discontinuity at a particularly critical point in the patient's illness: when the patient is facing virtually immediate death, transfer to an entirely new set of caregivers may be inappropriate because death might have been managed just as well by the referring hospital or physician—without the need to establish new caregiver–patient relationships. And when death is very rapid because referral is very late, hospice nurses may be called upon to deliver hyperacute death care rather than true hospice care. Finally, the extensive work typically necessary at the beginning of the care of a new patient is organizationally disruptive and possibly financially burdensome to a hospice working under daily fee schedules. In sum, patients who are avoidably referred late are needlessly deprived of the benefits of hospice.

Some early deaths at hospice may be unavoidable, however. For example, a patient might become terminally ill suddenly, be immediately referred to hospice, and then die rapidly (or "early"). In such a situation, the physician would not have had an opportunity to refer earlier and hospice care may nevertheless be completely appropriate. However, such cases probably account for a small minority of early deaths at this hospice, given the pattern of diagnoses in the sample of patients dying within seven days. That is, as described, only 5.2% of such patients had either "neurologic disease" or "cardiovascular disease" as their diagnosis; the remainder had diagnoses of cancer of some type, diagnoses generally not consistent with an acute, fulminant presentation. Moreover, cardiovascular disease was associated in a statistically significant fashion with *long* stays at this hospice. Nevertheless, further research will be needed to clarify exactly how long before referral to hospice a given diagnosis is actually made.

This study thus demonstrates that a substantial minority of patients referred to an outpatient hospice die at what may be considered to be an inopportune time; for example, 15% of the patients died within seven days and 12% died after 180 days. Presuming that hospice care is indeed preferable to other forms of terminal care, such patients would benefit more fully from hospice if physicians would refer them in a more timely fashion. All of the physicians and hospice personnel interviewed for this study identified two objectives in order to optimize hospice use. First, median duration of survival should be increased from 29 days to 60–90 days so that patients might receive the best terminal care possible; moreover, outliers with inordinately short stays should be minimized. Second, this should be done as much as possible without increasing the number of outliers with inordinately long hospice stays.

Insofar as these objectives are endorsed by other clinicians caring for terminally ill patients, the findings of this pilot project suggest some strategies to achieve these objectives that warrant investigation. The findings about the effect of orientation and activity level suggest that consideration should be given to referral while patients are still able to ambulate independently and are still oriented; in this way, median survival for all referred patients would increase. By the time patients are neither ambulatory nor oriented—or are comatose—their expected survival is very likely to be significantly less than 29 days. However, the findings about specific conditions, namely, prostate cancer, cardiovascular disease, certain other diseases, and depression, suggest that patients with such illnesses in particular might benefit from later referral in order to minimize long-stay outliers. In addition to the clinical and emotional benefits for patients and caregivers, more appropriate timing of referral to hospice might result in more cost-effective terminal care from a societal perspective.

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