

Outcomes and Characteristics of Patients Discharged Alive from Hospice

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OBJECTIVES: To describe outcomes and characteristics of patients discharged alive from hospice.

DESIGN: Prospective cohort study using a telephone survey.

SETTING: Hospices (n = 18) participating in the Population-Based Palliative Care Research Network during the 1-year study period.

PARTICIPANTS: English-speaking adults (n = 164) who were discharged alive from participating hospices during the 1-year study period.

MEASUREMENTS: Mortality within 6 months of hospice discharge.

RESULTS: Thirty-five percent (n = 48) of the 139 patients with known outcomes died within 6 months of hospice discharge, 15 of whom (31%) died without hospice readmission. There were no significant associations between sex ($P = .77$), length of hospice service ($P = .99$), diagnosis ($P = .73$), discharge disposition ($P = .54$), admission evidence of prognosis of less than 6 months to live ($P = .22-.95$), Karnofsky score at admission or change between admission and discharge ($P = .39, P = .38$, respectively), or duration of hospice care after stabilization ($P = .83$) and mortality within 6 months after hospice discharge. Age ($P = .11$), discharge Karnofsky score ($P = .17$), and reason for discharge being improved or stabilized condition ($P = .13$) trended toward statistical significance. The strongest predictor of mortality after hospice discharge was a report that the patient's condition had worsened (hazard ratio = 10.2, 95% confidence interval 4.5–23.4).

CONCLUSION: One-third of patients who were discharged from hospice died within 6 months of hospice discharge, indicating ongoing eligibility for hospice care even under the strictest interpretation of hospice eligibility criteria. Patients who are discharged from hospice care should be evaluated frequently, especially within the first weeks to months after discharge, for changes in status, unmet needs, and potential hospice readmission. *J Am Geriatr Soc* 52:1337–1342, 2004.

Key words: hospice; discharge; outcomes; prognosis

Congress approved the Medicare Hospice Benefit in 1982 (Public Law 97–248, s 122). Since that time, U.S. hospice care has expanded to 3,200 programs with approximately 775,000 admissions in 2001.¹ The Medicare Hospice Benefit consists of two 90-day periods and an unlimited number of 60-day periods. To be eligible for this benefit, a patient must be entitled to Medicare Part A and have a terminal disease with a prognosis of 6-month or less life expectancy that is certified by two physicians before admission and by the hospice medical director before each new benefit period. In 2001, one of every four persons who died in the United States used hospice.¹ Conflicts regarding hospice eligibility criteria have occurred between hospice care providers and fiscal intermediaries and the Office of Inspector General. Hospice agencies have been accused of fraud and have been ordered to refund payment if hospice care extends beyond a certification period for which the patient is eligible.²

Traditionally, people dying of cancer have been the primary recipients of hospice care.^{1,3} The percentage of hospice patients with a primary diagnosis of cancer has been steadily declining since 1992, from 75% in 1992 to 58% in 2000.⁴ Although hospice provides the type of care that many persons with advanced illness seek,^{5,6} the Medicare Hospice Benefit requirement of a 6-month prognosis has highlighted difficulty with prognostication at the end of life, particularly for persons with noncancer diagnoses. Physician prognostic estimates vary widely.^{7–11} It is difficult for even the most experienced clinicians to estimate a predicted time of survival for chronic, progressive illnesses.^{7–9,12–19} Persons with noncancer illnesses tend to have a dying trajectory characterized by exacerbations and remissions, with

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death occurring as an outcome of an exacerbation that is difficult to predict.¹⁸ It is thus not surprising that 6% to 8% of hospice patients are discharged alive annually, often because they no longer appear to meet the Medicare eligibility criteria.^{1,4,20,21} Anecdotally, many of these patients die shortly after discharge, which is distressing for hospice staff and families. There are no published data regarding outcomes of these patients.

To begin addressing these issues, this pilot study sought to describe the outcomes of patients who were discharged alive from hospice and, particularly, to identify those who were more likely to die shortly after discharge. Although the primary objective was descriptive, the study also tested the hypothesis that selected patient characteristics (poorer performance status, cancer diagnosis) were predictive of death within 6 months of hospice discharge. Data from this study will be important in understanding the effect of current Medicare policies and hospice practice and for informing design of more-comprehensive studies of the outcomes of discharged hospice patients.

METHODS

Study Setting

A telephone interview-based prospective cohort study was conducted in the Population-Based Palliative Care Research Network (PoPCRN), a hospice-based research network modeled on primary care practice-based research networks. English-speaking adults (aged ≥ 18) who were consecutively discharged alive from the study hospices or their surrogates ($n = 18$, representing seven U.S. states: Colorado, Ohio, Illinois, Florida, Texas, California, and New York) and who gave consent participated in the study. On average, participating hospices enrolled 23% of patients discharged during the study period. Thirty percent of participating hospices enrolled more than 20% of their discharged patients. Enrollment commenced July 1, 2000, and continued until June 30, 2001. Subjects were followed until death or 6 months after hospice discharge. The entire study period was thus July 1, 2000, through December 31, 2001. Study subjects provided informed consent according to the requirements of the Colorado Multiple Institutional Review Board, which approved the study. A designated individual at each hospice site was responsible for systematically soliciting participation from all patients who were discharged alive during the study period.

Data Collection and Outcome Measures

After a patient or surrogate agreed to participate in the study and informed consent was obtained, the on-site study coordinators completed a discharge data collection form. Information obtained at the time of hospice discharge included sex, age, diagnosis, evidence for prognosis of 6-month or less life expectancy at the time of hospice admission (functional decline, laboratory values indicating malnutrition or progressive disease, medical director certification, met National Hospice and Palliative Care Organization (NHPCO) or Medicare eligibility guidelines, physiological criteria (e.g., vital signs), determination by referring physician or institution, weight loss), whether the patient's condition declined or stabilized during hospice

admission, length of enrollment in hospice after patient's condition stabilized, reason for discharge from hospice (condition stabilized or improved, financial reasons, pursuit of more aggressive treatment, patient decision, payment denied by fiscal intermediary), Karnofsky Performance Scale score at admission and discharge, and discharge disposition (home, assisted living, skilled nursing facility, rehabilitative facility, acute care hospital, or transferred to another hospice). For the purposes of this study, discharge was defined as disenrollment from the hospice program. Discharge does not necessarily imply a change in care setting. The study questionnaire is available upon request and via the PoPCRN Web site (www.uchsc.edu/popcrn).

The PoPCRN study coordinator or designated persons at the participating hospices placed monthly follow-up telephone calls to study participants. Interview questions included patient location, patient status (alive or dead), date and location of death if applicable, patient's current condition compared with condition at discharge (same, better, or worse), whether patient was readmitted to hospice and reason for readmission, and information source (patient or surrogate). These calls were placed to each study participant until the patient died or 6 months had elapsed since hospice discharge.

Data Analysis

The primary outcome of interest was whether the patient was alive or dead at 6 months after hospice discharge. Death within 6 months of hospice discharge is the appropriate primary outcome because eligibility for the Medicare Hospice Benefit is predicated on a 6-month life expectancy. Secondary outcomes were hospice readmission within 6 months after hospice discharge and, for those who died or were readmitted to hospice, the number of days between hospice discharge and death or between hospice discharge and hospice readmission. To measure the bivariate associations between patient characteristics and the outcomes, chi-square (categorical predictor variables) and Student *t* tests (continuous predictor variables) were performed using SAS for Windows (Version 8e, SAS Institute, Inc., Cary, NC).

Patient characteristics included in the bivariate analyses were age (scaled as a continuous variable), sex, marital status (currently married vs not), length of hospice service (scaled as a continuous variable and categorized as \leq vs > 90 days), diagnosis (cancer vs noncancer), discharge disposition (home vs other location), Karnofsky score (scaled as a continuous variable and categorized as \leq vs > 40), reason for hospice discharge (condition improved/stabilized vs other), and patient's current condition (worse vs same or better). Cox proportional hazards modeling was used for multivariate analyses because these data are right-censored. That is, a proportion of the study population was still alive at the time the data collection was stopped. Patient's current condition (worse vs same/better) was allowed to be a time-varying covariate in the proportional hazards model. The hazard was affected only forward in time. The proportional hazards assumption was tested for and was not violated, but the sample size may make detecting a proportional hazards assumption violation difficult. $P < .05$ was considered significant for the bivariate analyses. Patient characteristics that were

significant at $P < .2$ were selected for inclusion in the proportional hazards model. Results are presented for all bivariate associations for the primary outcome, mortality, and for associations with $P < .4$ for the secondary outcomes.

RESULTS

Study Population

One hundred sixty-four patients who were discharged from 18 participating PoPCRN hospices during the study period consented to participate. Twenty patients were lost to follow-up despite efforts to obtain mortality information from

the participating hospices, and five patients withdrew consent; follow-up data are available on 139 (85%). There were few differences between those for whom complete follow-up data were available ($n = 139$) and those who were lost to follow-up or withdrew consent ($n = 25$). Those who were lost to follow-up were more likely to have a cancer diagnosis (56% vs 25%, $P = .002$), were more likely to have been discharged because of patient or family decision (28% vs 9%, $P = .01$), and had a shorter average length of hospice service (70 vs 136 days, $P = .002$). Of the initial total study population ($n = 164$), 67% were female, and 29% had a hospice admitting diagnosis of cancer. Noncancer

Table 1. Characteristics of Study Population with Stratification by Mortality Status at 6 Months After Hospice Discharge

Patient Characteristic	Total Study Population N = 164*	Stratified by Mortality Status 6 Months After Hospice Discharge		P-value†
		Alive n = 91	Dead n = 48	
Age, mean ± SD	76 ± 16	76 ± 17	80 ± 12	.11
Female, n (%)	109 (67)	59 (66)	32 (68)	.77
Length of hospice service, total days, mean ± SD	127 ± 116	136 ± 101	136 ± 152	.99
Diagnosis, cancer, n (%)	48 (29)	23 (26)	11 (23)	.73
Discharge disposition, n (%)‡				
Home	75 (46)	41 (46)	17 (36)	
Nursing home or skilled nursing facility	63 (39)	37 (41)	24 (51)	
Assisted living	9 (6)	6 (7)	2 (4)	
Acute care hospital	3 (2)	1 (1)	2 (4)	
Other (hospice, rehabilitation)	12 (7)	5 (6)	2 (4)	.54
Admission evidence of prognosis ≤ 6 months, n (%)				
Referring physician or institution	127 (78)	70 (78)	34 (71)	.37
Medical director certification	114 (70)	62 (69)	31 (65)	.61
Functional decline	108 (66)	65 (72)	33 (69)	.67
Met National Hospice and Palliative Care Organization/Medicare, n (%)				
Eligibility guidelines	98 (60)	53 (59)	28 (58)	.95
Weight loss	68 (42)	37 (41)	20 (42)	.95
Lab values	38 (23)	21 (23)	7 (15)	.22
Vital signs	11 (7)	8 (9)	2 (4)	.31
Karnofsky score, mean ± SD				
Admission	37 ± 13	36 ± 14	34 ± 11	.39
Discharge	45 ± 15	46 ± 14	42 ± 14	.17
Difference from admission to discharge	8 ± 14	10 ± 3	7 ± 17	.38
Days received hospice care after stabilization, n (%)				
0–6	2 (2)	1 (1)	1 (3)	
7–14	14 (11)	10 (13)	2 (6)	
15–21	16 (13)	9 (12)	3 (9)	
22–30	29 (23)	16 (21)	9 (27)	
31–60	41 (33)	25 (33)	12 (36)	
> 60	22 (18)	14 (19)	6 (18)	.83
Reason for discharge, n (%)§				
Improved or stabilized	128 (79)	76 (85)	36 (75)	.13
Patient/family decision	19 (12)	7 (8)	5 (10)	.61
Pursuit of more-aggressive treatment	12 (7)	6 (7)	4 (8)	.73

* Because of missing data, $n = 153$ for Karnofsky score data, and $n = 124$ for days received hospice care after stabilization data.

† P-value for comparison by mortality status at 6 months after hospice discharge.

‡ For the purposes of this study, “discharge” was defined as disenrollment from the hospice program. It does not necessarily imply a change in care setting. Data reflect patient care setting immediately after cessation of hospice services.

§ $n = 159$; remaining responses were “other.”

SD = standard deviation.

diagnoses included heart disease (17%); dementia (17%); global geriatric decline, debility, or failure to thrive (15%); neurological disorder, stroke, or coma (10%); lung disease (5%); and other (6%). The study population had more women (67% vs 56%) and fewer subjects with a diagnosis of cancer (29% vs 54%) than the national hospice population. The study population also had a longer average (127 days vs 48 days) and median (91 days vs 21 days) length of service than the national hospice population.²² Characteristics of the study population are shown in Table 1.

For most study participants, evidence of a prognosis of a 6-month or shorter life expectancy was documentation by the referring physician (78%) or hospice medical director (70%), functional decline (66%), or meeting NHPCO/Medicare hospice eligibility guidelines (60%). The mean Karnofsky score was 37 on admission and 45 on discharge, with a mean improvement of 8 points from admission to discharge. Seventy-nine percent of subjects were discharged from hospice because of stabilization of their condition. Fifty-one percent received hospice care for more than 30 days after stabilization of their condition. Forty-six percent of study participants were discharged to home, 39% to a nursing home or skilled nursing facility, 6% to assisted living, 2% to an acute care hospital, and 1% to a rehabilitation center. Six percent were transferred to another hospice.

Outcomes of Live Hospice Discharge

Of the 139 patients for whom follow-up data are available, 48 died within 6 months of hospice discharge (35%) (Figure 1). Of these 48 patients, 31% ($n = 15$) were not readmitted to hospice and therefore did not receive hospice care immediately before death. Participants who died within the 6-month study period were more likely to have been readmitted to hospice than those who remained alive. Sixty-nine percent of those who died, versus 11% of those who survived more than 6 months ($P < .001$), were readmitted to hospice within 6 months of hospice discharge.

For those who died, the mean number of days between hospice discharge and death was 86 days (range 3–188 days). Forty-three patients (31%) were readmitted to hospice at an average of 56 days (range 0–174 days) after hospice discharge. Five of the six patients who were readmitted to hospice within 0 to 1 days of hospice discharge were direct transfers to other hospice programs. Of those who were readmitted to hospice ($n = 43$) and for whom data are available ($n = 33$), 82% ($n = 27$) were readmitted for a decline in condition. Within this group of patients readmitted to hospice, 33 (77%) died in an average of 35 days (range 0–178 days) after hospice readmission.

Predictors of 6-Month Outcomes After Hospice Discharge

There were no significant associations between sex ($P = .77$), length of hospice service ($P = .99$), diagnosis ($P = .73$), discharge disposition ($P = .54$), admission evidence of prognosis of 6-month or less life expectancy ($P = .22-.95$), Karnofsky score at admission or change between admission and discharge ($P = .39$, $P = .38$, respectively), or duration of hospice care after stabilization ($P = .83$) and mortality within 6 months after hospice discharge (Table 1). Age ($P = .11$), discharge Karnofsky score

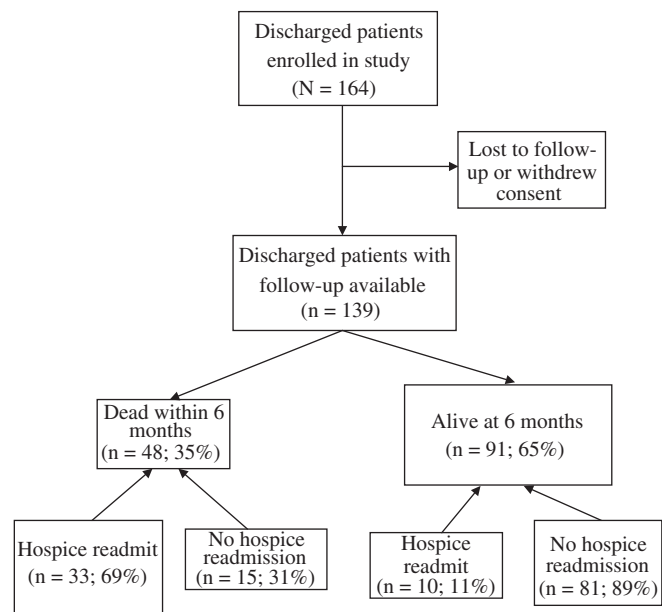


Figure 1. Outcomes 6 months after hospice discharge.

($P = .17$), and reason for discharge being improved or stabilized condition ($P = .13$), although not attaining generally accepted levels of statistical significance, demonstrated trends toward being associated with mortality.

Of patients who died within 6 months of hospice discharge, those with a cancer diagnosis appeared to have a shorter mean number of days between discharge and death (70 vs 90 days) than those with noncancer diagnoses. Of patients readmitted to hospice, those with cancer were readmitted sooner (40 vs 60 days) than those with noncancer diagnoses. These differences trended towards statistical significance ($P = .25$ and $P = .19$, respectively). Those with a lower discharge Karnofsky score (≤ 40 vs > 40) appeared to experience a higher average number of days between hospice discharge and death (90 vs 75 days) and between discharge from and readmission to hospice (61 vs 44 days). These findings also trended toward statistical significance ($P = .37$ and $P = .25$, respectively).

Of the explanatory variables considered, the strongest predictor of death within 6 months after hospice discharge, assuming a proportional hazards model, was the patient's (or surrogate's) assessment that the patient's condition had worsened (hazard ratio = 10.2, 95% confidence interval = 4.5–23.4) (Table 2). Specifically, respondents were asked monthly: "How does his/her status compare with that at discharge (same, better, worse)?" None of the other potential predictors (age, reason for hospice discharge, discharge Karnofsky score) contributed significantly to hazard of death.

DISCUSSION

This prospective study of persons discharged from hospice care showed that 35% died within 6 months of discharge and that, of those who died, 31% did so without having been readmitted to hospice care. The strongest predictor of death after hospice discharge was a report from the patient or surrogate that the patient's condition had worsened,

Table 2. Hazard Ratios for Death After Hospice Discharge (n = 117*)

Variable	Hazard Ratio for Death	95% Confidence Limit	P-value
Patient or surrogate stated that patient condition had worsened (vs same/better)	10.2	4.5–23.4	<.0001
Age (per decade)	1.14	0.83–1.58	.41
Improvement in condition (vs other reasons for hospice discharge)	0.57	0.24–1.32	.19
Discharge Karnofsky score (per 10 points)	0.88	0.66–1.16	.35

*Mortality status was available on n = 139. The proportional hazards model n = 117 because of missing data on the patient's condition (same/better/worse).

consistent with other studies that have shown that patient self-report is a reliable predictor of survival.^{23–25}

Most patients discharged alive from hospice have noncancer diagnoses.²¹ Although the NHPCO noncancer guidelines have been used to determine patient eligibility and appropriateness for hospice admission, they have been shown to be ineffective when used as a predictor of survival of less than 6 months in patients with end-stage chronic disease.¹⁷ Thus, identifying predictors of likely outcome in patients discharged from hospice may aid in making hospice discharge decisions. Other studies have shown that certain patient characteristics, such as Karnofsky scale score, age, physiological parameters, weight loss, cognitive status, nutritional status, and functional status, can aid in prognosis in patients with cancer and acquired immune deficiency syndrome,^{15,26–30} but these attributes have not been shown to be predictive of survival in all patient populations. Physicians' estimates of patient prognosis are inconsistently accurate in predicting patient survival.^{7–9,13,19}

The strengths of this study are its longitudinal nature and inclusion of data from a number of geographically diverse hospices, but it does have several limitations. It may not have had sufficient sample size to detect statistically significant differences in all parameters evaluated. For example, the number of days between discharge and readmission to hospice and death were greater in the noncancer than the cancer groups and for those with lower (≤ 40 vs > 40) discharge Karnofsky scores, but these differences were not statistically significant using a *P*-value of .05. Given the primarily descriptive purpose of this study and the small sample size, a *P*-value of .05 may have been too rigorous a standard. Potential selection bias limited the generalizability of the study data. Given that, on average, only 23% of discharged patients participated in the study, it is possible that nonparticipants may have systematically differed from participants. For example, the sickest or frailest patients may have not participated in the study. This study may thus have underestimated mortality after hospice discharge. Additional limitations relate to the actual data collected in this study. Mortality is not the only important outcome. In retrospect, it would have been useful to inquire about the experience of hospice discharge and its effect on the patient and family.

The finding that a patient's or proxy's assessment of worsening condition was the strongest predictor of death within 6 months of hospice discharge has important implications for providing better end-of-life care and for future study of hospice discharge outcomes. Although this study did not identify any patient characteristics or demographics

that predicted patient outcome after hospice discharge, it also found that current criteria being used to determine appropriateness of hospice discharge did not consistently predict mortality. Close follow-up of patients discharged alive from hospice, perhaps with telephone calls inquiring how the patient (or surrogate) feels he or she is doing, could lead to discovery of unmet needs and potentially more timely hospice readmission. Based on these data, follow-up should occur with the greatest frequency within the first 30 to 90 days after discharge, because the highest risk of death after hospice discharge occurs in these first weeks to months after discharge. These data provide preliminary insight into outcomes after hospice discharge and demonstrate the need for further study of the hospice discharge process itself, including patient, family, and hospice staff perspectives on the effect of the discharge on quality of care and on the experience of serious advanced illness.

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