

Understanding their Options: Determinants of Hospice Discussion for Older Persons with Advanced Illness

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BACKGROUND: Clinicians' discussions about hospice with patients and families are important as a means of communicating end-of-life options.

OBJECTIVE: To identify determinants of clinicians' hospice discussions and the impact of such discussions on hospice use.

DESIGN: We interviewed 215 patients age ≥ 60 years with advanced cancer, chronic obstructive pulmonary disease (COPD), or heart failure (HF) at least every 4 months for up to 2 years. Participants provided information about their health status and treatment preferences. Clinicians completed a questionnaire every 6 months about their estimates of patient life expectancy and their communication with the patient and family about hospice.

RESULTS: In their final survey, clinicians reported discussing hospice with 46% of patients with cancer, compared to 10% with COPD and 7% with HF. Apart from diagnosis of cancer, the factors most strongly associated with hospice discussion were clinicians' estimate of and certainty about patient life expectancy ($P < 0.001$). However, clinicians were unable to anticipate the deaths of a considerable portion of patients (40%). Although patient unwillingness to undergo minor medical interventions was associated with hospice discussion ($P < 0.05$), a sizeable portion of clinicians (40%) whose patients reported this characteristic did not have the discussion. Clinicians' discussion of hospice independently increased the likelihood of hospice use (OR=5.3, 95% CI=2.3–13).

CONCLUSIONS: Clinicians' discussion of hospice for patients with advanced illness, and, ultimately, patients' use of hospice, relies largely on clinician estimates of patient life expectancy and the predictability of disease course. Many clinicians whose patients might benefit from learning about hospice are not having these discussions.

KEY WORDS: hospice; discussion; end-of-life; communication; prognosis.

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INTRODUCTION

Hospice currently serves well over one-third of the people who die in the United States.¹ Studies have shown that hospice provides quality care for patients at the end of life, with a high satisfaction rate for patients and families.^{2–4} Nevertheless, this service is underutilized, and many of those who enroll do not subsequently live long enough to fully benefit from hospice care.^{2,5–7} Lack of clinicians' discussion about hospice with the patient and family has been identified as a barrier to hospice use,^{8,9} supported by retrospective studies, in which caregivers, asked to recall their conversations with clinicians, frequently report an absence of communication about hospice or treatment options.^{4,10,11} Although one small study retrospectively estimated that the majority of persons offered hospice by their clinicians utilized this service, there has been no prospective evaluation of the relationship between hospice discussion and use.

Regardless of its effects on utilization, the discussion about the availability of hospice services itself is important as a means of communicating end-of-life options and guiding the patient's transition from being seriously ill to dying.¹² Although several studies have assessed factors associated with referral of patients to hospice,^{13–15} no prospective study has examined the factors associated with discussions about hospice, regardless of whether the clinician makes a hospice referral or the patient chooses to enroll in hospice.

The goals of this study were to identify patient and clinician factors associated with individual hospice discussions, and to determine the relationship between hospice discussion and patient utilization of facility-based or community-based hospice services.

METHODS

Participants

Study participants were 60 years or older and had a primary diagnosis of cancer, chronic pulmonary obstructive disease (COPD), or heart failure (HF). Patients screened for the study were being cared for as inpatients in a university teaching

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hospital, a community hospital, and a Veterans Affairs hospital; in six cardiology, four oncology, and three pulmonary practices in the greater New Haven area; and as outpatients in two Veterans Affairs hospitals. The human investigations committee of each of the participating hospitals approved the study protocol. All patients provided written informed consent.

Sequential medical records were screened for the primary eligibility criterion of advanced illness, as defined by clinical criteria used by the Connecticut Hospice¹⁶ or those used in the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment.^{17,18} Another eligibility criterion, determined by telephone screening and selected to improve the identification of patients with advanced illness,¹⁹ was the need for assistance with at least one instrumental activity of daily living (IADL).²⁰ Patients were required to be full-time residents of Connecticut and cognitively unimpaired, as measured by a test of executive functioning²¹ and the Short Portable Mental Status Questionnaire.²² In order to obtain an equal number of participants with a diagnosis of cancer, COPD, and HF, screening and enrollment were stratified according to diagnosis.

Of the 548 patients identified by medical record review, 30 were not contacted because their clinicians refused permission, 24 died before telephone screening, 19 refused screening, and 6 could not be reached. Of patients screened, 108 were excluded because they did not need assistance with one IADL, 77 because of cognitive impairment, and 6 because they were not full-time residents of Connecticut. Of the 279 eligible patients, 51 refused participation and 2 died before enrollment. A total of 226 patients were included in the final sample, with 82% participation of eligible patients. Participants did not differ from nonparticipants according to age, sex, or Charlson comorbidity index score.²³ Of eligible patients with HF, 8% refused participation, as opposed to 19% with cancer and 25% with COPD ($P=0.02$). Eight (4%) of the 226 participants withdrew after the initial interview, 26 (12%) died before a follow-up interview, and 3 (1%) were unable to complete follow-up interviews. Of the 124 participants surviving at the end of the first year of the study, 98 (79%) consented to participate for a second year.

The patients identified the clinician chiefly responsible for the care of their primary diagnosis. Of 105 identified clinicians, 96 (91%) agreed to participate and completed interviews for 215 patients. Participants with a clinician in the study did not differ from patients without a clinician according to age, sex, ethnicity, education, or income; however, none of the clinicians of patients with cancer declined to participate, compared to 2% of clinicians for patients with COPD and 15% of clinicians for patients with HF ($P<0.001$). This study includes only the 215 patients whose clinicians participated.

Data Collection

Patients were interviewed in their homes. Interviews were conducted every four months for up to two years, and immediately after any decline in status, designated by one of the following: need for assistance with an additional activity of daily living,²⁴ hospitalization for at least seven days or resulting in discharge to a rehabilitation center or nursing home, or enrollment in hospice. Clinicians completed a mail survey every six months. The last completed clinician survey was used for data in this study, while the last patient interview that

preceded the clinician survey was used to ensure correspondence of information.

The outcome variables were whether hospice was discussed and whether the patient received hospice services. Hospice discussion was determined by clinicians' response to the question of whether they had discussed hospice with the patient and/or family. They were also asked to choose from a list of reasons if they had not discussed hospice. Receipt of hospice services was determined by patient self-report, supplemented by surrogate report if the patient was too ill to participate in an interview or died during the study.

Descriptive and analytic variables obtained from patient interviews included measures of sociodemographic, health, and psychosocial status. Ordinal variables were dichotomized at clinically meaningful cut points. Sociodemographic variables included age, education, sex, ethnicity, marital status, living arrangement, and sufficiency of monthly income.²⁵ Health status variables included self-rated health ("excellent," "very good," "good," "fair," or "poor") and symptom assessment, using the Edmonton symptom assessment scale.²⁶ Psychosocial variables included overall quality of life ("best possible," "good," "fair," "poor," or "worst possible"),²⁷ perceived prognosis (patients were asked, "If you had to take a guess, how long do you think that you might have to live?," with responses of "<1 month," "1–6 months," "7–12 months," "13–23 months," "2–5 years," "6–10 years," or ">10 years"), willingness to undergo major or minor therapies if they would return the patient to his/her current state of health (major therapies were described as "being in the intensive care unit, receiving surgery, or having a breathing machine" and requiring a hospital stay of "at least a month," while minor therapies were described as "[having] intravenous antibiotics and oxygen," and requiring "a few days to a week" in the hospital), and knowledge about alternatives to hospitalization (patients were asked a series of questions: "If your illness should become worse than it is now, what, if anything, has your doctor told you about how you could be treated?," followed by, "If you were sick enough that you potentially would need the hospital, do you think that you would have any choices other than being hospitalized?," and if so, "What is/are the choices?," followed by, "If you wanted to stay out of the hospital, do you know of any services that could help you?," and if so, "What are they?"). Health status and psychosocial variables were obtained at every interview.

Descriptive and analytic variables obtained from clinician questionnaires included the following: best estimate of the patient's life expectancy (<1 month, 1–6 months, 7–12 months, 13–23 months, 2–5 years, 6–10 years, or more than 10 years), and level of certainty about it ($\geq 99\%$, $>90\%$ certain, 50–90%, 10–49%, <10%, or <1% certain); whether they had informed the patient that he or she could die as a result of the disease; and whether they had discussed life expectancy with the patient.

Statistical Analysis

Frequencies and proportions were used to describe patient-reported and clinician-reported variables, in total and stratified according to diagnosis. The association between these variables and clinician report of hospice discussion was first examined in bivariate analysis, utilizing the chi-square test or, when cell sizes were small, the Fisher exact test. Those variables found to be associated in bivariate analysis with

$P < .15$ were entered into a logistic regression model (gender was included in the model regardless of bivariate association). The association between clinician discussion and hospice enrollment was examined in a logistic regression model, adjusting for covariates known to be associated with hospice enrollment.²⁸ Because of the strong association between clinicians' estimates of life expectancy and hospice discussion, the accuracy of these estimates was explored by examining the frequency of these estimates according to whether the patient died during the course of the study.

RESULTS

Patient Population

Characteristics of patient participants are shown in Table 1. Although most (71%) reported their health to be fair or poor, only a small number (12%) reported their quality of life to be poor. Patients' perceptions of their life expectancy were much more optimistic than their clinicians' estimates. While only 10% of patients believed they had one year or less to live, nearly half of clinicians estimated their patients' life expectancy to be one year or less. Of the patients whose clinicians made this estimate, a larger proportion had a diagnosis of cancer (76%) than COPD (22%) or HF (19%). Only 14% cited hospice as an alternative to hospitalization, and of these patients, approximately one-half (52%) had clinicians who reported discussing hospice, suggesting that a small number of patients had knowledge of hospice outside of communication with their clinician.

Table 1. Characteristics of Older Persons with Advanced Illness

Characteristic	Total (N=215)	Cancer (n=79)	COPD* (n=79)	HF* (n=57)
Age, %				
60–69	35	42	37	25
70–79	45	46	43	47
80+	20	13	20	28
Education \leq 12 years, %	68	63	75	67
Female, %	42	43	49	30
White [†] , %	91	92	92	86
Married, %	57	62	53	56
Lives alone, %	25	16	27	33
Health perception fair to poor [‡] , %	71	68	71	75
Quality of life poor to worst possible [§] , %	12	13	13	11
Selected moderate to severe symptoms, %				
Pain	29	38	19	29
Decreased activity level [§]	63	56	73	60
Depression [§]	13	11	15	13
Shortness of breath	42	20	71	32
Unwilling to undergo therapies for return to current health, %				
Major therapies [‡]	11	9	14	9
Minor therapies [§]	2	3	1	4
Clinicians' estimate of patient life expectancy \leq 1 year, %	41	76	22	19
Clinician reported informing patient of life expectancy, %	30	62	10	14
Patients' self-perceived life expectancy \leq 1 year [¶] , %	10	10	13	7

*COPD = Chronic obstructive pulmonary disease; HF = heart failure
[†]N=214; [‡]N=211; [§]N=212; ^{||}N=213; [¶]N=210

Hospice Discussion and Associated Factors

Overall, clinicians for 22% of patients reported discussing hospice. The most frequently cited reasons for not discussing hospice were that the patient was "not terminally ill" (50%) and "prognosis too uncertain" (37%); patient-centered reasons, such as "would take away patient's hope" (10%) and "patient wants life-sustaining therapies" (9%), were less frequently cited (Table 2).

Selected patient and clinician characteristics and their association with hospice discussion are shown in Table 3. Clinicians of patients with cancer were significantly more likely to report a discussion (46%) than were clinicians of patients with COPD (10%) or with HF (7%) ($P < .001$). Among patients whose clinicians estimated their life expectancy to be \leq 1 year, 49% had a clinician who reported a hospice discussion, compared to only 4% among patients whose clinicians estimated a longer life expectancy ($P < .001$). Within the subset of patients whose clinicians estimated their life expectancy to be \leq 1 year, hospice discussion was reported significantly more frequently by clinicians who were $>90\%$ certain about their estimate than by clinicians who were less certain (93% versus 40%, $P < .001$). Patients with poorer quality of life, who had moderate to severe pain, whose self-reported life expectancy was \leq 1 year, who were unwilling to undergo minor therapies for a return to current health, and whose clinicians reported informing them of their life expectancy were more likely to have clinicians who reported having a hospice discussion. Nonetheless, sizeable portions of patients with these characteristics had a clinician who did not report a hospice discussion. Patients' self-rated health and unwillingness to undergo major therapies for a return to current health were not associated with hospice discussion.

In multivariable analysis, clinicians' estimate of the patient's life expectancy \leq 1 year was the variable most strongly associated with hospice discussion (odds ratio (OR) = 13, 95% confidence interval (CI) = 4.3–39) (Table 4). A diagnosis of cancer remained independently associated with hospice discussion; other factors associated with hospice discussion in bivariate analysis did not retain their significance. One variable, "clinician informed patient of life expectancy," was not included in the model due to its high correlation with "clinician-estimated life expectancy \leq 1 year" (Pearson correlation coefficient, >0.3). A second variable, "clinician certainty about life expectancy," was not included in the model because it was measured only among the group of clinicians who estimated their patients' life expectancy to be \leq 1 year.

Hospice Use and Its Relationship to Discussion

Hospice was utilized by a total of 31% of patients, including 63% of patients with cancer, 11% of patients with COPD, and 14% of patients with HF. Hospice discussion was associated with greater hospice utilization in bivariate analysis; of the 48 patients whose clinician reported a hospice discussion, 73% utilized hospice, compared to only 19% of patients whose clinician did not report a discussion ($P < 0.001$). In multivariable analysis, including diagnosis, self-rated quality of life, willingness to undergo minor therapies, and site of care as co-variables, hospice use remained independently associated with hospice discussion (OR=5.3, 95% CI=2.3–13).

Table 2. Clinician Reports of Hospice Discussion and Reasons for Not Discussing Hospice

Characteristic	Total (N=215)	Cancer (n=79)	COPD* (n=79)	HF* (n=57)
Clinician discussed hospice with patient or family [†] , %	22	46	10	7
Reasons for not discussing hospice [†] , %				
Not terminally ill	50	32	66	55
Prognosis too uncertain	37	29	48	34
Patient would not handle this discussion well	5	0	10	4
Patient wants life-sustaining therapies	9	15	6	5
Would take away patient's hope	10	8	19	2
Services would not benefit patient	9	11	5	13

*COPD = Chronic obstructive pulmonary disease; HF = heart failure
[†]N=214

Accuracy of Clinician Prognosis

During the course of the study, a total of 56% of the participants died, which included 77% of patients with cancer, 42% of patients with COPD, and 47% of patients with HF. A sizeable portion of these patients (40%) had clinicians who

Table 3. Association of Selected Patient and Clinician Characteristics with Hospice Discussion

Characteristic (N=215)	Discussion of Hospice (n=48)	No Discussion of Hospice (n=167)	P - value
Diagnosis, %			
Cancer	46	54	
Chronic Obstructive Pulmonary Disease	10	90	
Heart Failure	7	93	<.001
Pain*, %			
Moderate to severe	31	69	
None to mild	19	81	.057
Activity level reduction [†] , %			
Moderate to severe	26	74	
None to mild	17	83	.113
Quality of life [‡] , %			
Poor or worst possible	42	58	
Best possible, good, or fair	20	80	.011
Patient unwilling to undergo minor therapies for return to current health [†] , %			
Yes	60	40	
No	22	78	.043
Patients' self-perceived life expectancy [‡] , %			
≤1 year	41	59	
>1 year	20	80	.028
Clinicians' estimate of patient life expectancy, %			
≤1 year	49	51	
>1 year	4	96	<.001
Clinicians' level of certainty about patient life expectancy when estimate is ≤1 year, %			
>90%	93	7	
≤90%	40	60	<.001
Clinician reported informing patient of life expectancy, %			
Yes	57	43	
No	7	93	<.001

*N=213; [†]N=212; [‡]N=210

Table 4. Multivariable Model for Characteristics Associated with Hospice Discussion

Variable	Odds ratio (95% confidence interval)
Cancer diagnosis	3.4 (1.3–8.9)
Male	1.9 (0.8–4.5)
Moderate to severe pain	1.0 (0.4–2.5)
Moderate to severe reduction in activity level	1.6 (0.7–4.0)
Fair/poor self-rated quality of life	2.1 (0.6–7.6)
Patient self-perceived life expectancy ≤ 1 year	1.7 (0.5–5.8)
Clinicians' estimate of patient life expectancy ≤ 1 year	13 (4.3–39)
Patient unwilling to undergo minor therapies for return to current health	5.2 (0.2–131)

provided a life expectancy estimate of >1 year, within six months prior to patient death. Stratified by patient diagnosis, this overestimate occurred for 11% of patients with cancer and 68% of patients with COPD or HF.

DISCUSSION

This study involving older adults with advanced cancer, COPD, and HF demonstrated that clinicians reported hospice discussion for nearly one-half of patients with cancer but only a small proportion of patients with COPD or HF. Although several characteristics suggesting that patients might benefit from hospice were associated with a greater likelihood of discussion, such as moderate to severe symptoms, unwillingness to undergo minor medical interventions, and poorer quality of life, a substantial number of patients with these characteristics did not have the discussion. Other such characteristics, including poorer self-rated health and unwillingness to undergo major medical interventions, were not associated with hospice discussion. The single factor most strongly associated with discussion was clinicians' estimate of and level of certainty regarding patient life expectancy. However, clinicians failed to identify a sizeable portion of patients who subsequently died within six months. Ultimately, clinicians' discussion of hospice significantly increased the likelihood of hospice use.

These results are consistent with a previous study in which clinicians cited the difficulty in prognostication to be the greatest barrier to the clinician offering hospice.²⁹ However, in contrast to this earlier study, clinicians did not cite patient preferences for treatment and readiness to handle the discussion as major barriers to discussion. One possible explanation for this difference is that in the current study clinicians were referring to specific patients at specific times rather than citing general barriers to discussion. The 73% of patients who utilized hospice following a discussion with their clinician compares to a previous study asking clinicians to recall the number of hospice offers they had made over a two-year period and also the number of patients that used hospice, resulting in an estimate of a 63% enrollment rate.²⁹

Regardless of patients' decision to use hospice, the discussion itself is important for patients with advanced illness so they know the options available as their disease progresses. Through conversations about services that may be available to the patient in the future, the clinician may help the patient come to terms with the illness and aid the patient's transition

from being seriously ill to dying.¹² The results of this study, showing that patients are largely unaware of alternatives to standard treatment and that clinicians' discussion of hospice is determined largely by their perceptions and level of certainty regarding patient life expectancy, suggest that many patients who could benefit from such a discussion are not receiving it.

The close relationship in this study between level of prognostic certainty and hospice discussion appears to suggest that improved prognostic information would enhance clinician-patient communication regarding hospice. However, various lines of evidence demonstrate the limited value of focusing on prognostic data. First, clinical prediction criteria based on National Hospice Organization guidelines for patients with COPD and HF have been shown ineffective in identifying persons with a life expectancy of six months or less.³⁰ Second, the provision of such prognostic information to clinicians in the SUPPORT study did not improve clinician-patient communication.³¹ In order to better identify patients who would benefit from hospice, modifications to the Medicare Hospice Benefit eligibility criteria have been proposed to include factors such as functional status, quality of life, and symptom burden.³² Such an approach would address the many patients in this study whose health status and/or preferences indicated that they might benefit from hospice care but with whom their clinicians did not discuss hospice. The association between life expectancy and hospice discussion in this study suggests that clinicians would need clear guidelines about what should prompt a discussion about hospice care.

One limitation of this study is that clinicians were not asked to describe the nature of discussions that occurred, such as whether they made a recommendation or simply provided information; however, considering the high proportion of participants in this study who enrolled in hospice subsequent to the discussion, one might argue that discussions were largely characterized by the former. Another limitation is data collection by self-report, without independent confirmation that the discussions as reported by clinicians actually occurred. Clinicians, who completed a survey every six months, may have been required at times to recall discussions that took place several months prior. Furthermore, the responses may have been subject to desirability bias. It is also possible that clinicians were more likely to have discussions as a result of their participation in the study.

This study suggests that clinicians' decisions to discuss hospice for patients with advanced illness are primarily determined by their estimates of life expectancy and the predictability of disease course. Such discussions between clinicians and patients with advanced illness are important so that patients can understand their options and make informed decisions about their care. Given the limitations of prognostication for patients with non-cancer diagnoses, hospice discussions occur primarily for patients with cancer near the end of life. Many patients whose health status and treatment preferences suggest that they might benefit from hospice are not having a discussion with their clinicians about hospice as a treatment option.

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