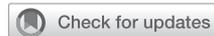


Original Article

Patients' Hopes for Advanced Cancer Treatment



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Abstract

Context. Little is known about the hopes patients with advanced (incurable) cancer have for their treatment.

Objectives. The objective of this study was to describe the treatment hopes of advanced cancer patients, factors associated with expressing specific hopes, and the persons with whom hopes are discussed.

Methods. We surveyed 265 advanced cancer patients in the U.S. about their hopes for treatment at the baseline and after three months. We developed a taxonomy of hopes for treatment, which two investigators used to independently code patient responses. We explored associations between hopes for cure and patient covariates.

Results. We developed eight categories of hopes. We were able to apply these codes reliably, and 95% of the patient's responses fit at least one hope category. The hope categories in order of descending baseline prevalence were as follows: quality of life, life extension, tumor stabilization, remission, milestone, unqualified cure, control not otherwise specified, and cure tempered by realism. Most patients reported discussing hopes with partners, family/friends, and oncologists; a minority reported discussing hopes with nurses, primary care physicians, clergy, or support groups. In logistic regression analysis, unqualified hopes for cure were more likely in younger patients and in those who did not endorse discussing their hopes with primary care physicians.

Conclusion. Advanced cancer patients harbor a range of treatment hopes. These hopes often are not discussed with key members of the health care team. Younger age and lack of discussion of hopes with primary care physicians may lead to less realistic hopes for cure. *J Pain Symptom Manage* 2019;57:57–63. *Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.*

Key Words

Hope, advanced cancer, goals, end-of-life care, communication, palliative care

Introduction

Among patients confronting serious illness such as advanced cancer, hope takes on multiple forms.^{1–5} In general, hope is the wish for—or belief in the possibility of—a better future. A hope can also be a desire

that a decision or intervention might produce a specific outcome. According to Coulehan, hopes differ from expectations in that hopes are always positive and may be improbable.²

Physicians of advanced cancer patients are faced with the challenge of maintaining or improving a

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patient's well-being in the face of an incurable illness. One way they may address this is to help patients establish or prioritize more concrete and realistic goals², such as decreasing nausea, going on a vacation, or making financial arrangements. When hopes are misaligned with what is medically realistic (e.g., when patients with incurable disease hope for a cure), patients may avoid advanced directive discussions,⁶ choose inappropriately aggressive care,⁷ and endure excessive psychological distress.^{3,8} It is important for physicians to understand their patient's hopes for treatment to facilitate informed patient-centered decision making.

Previous studies have investigated advanced cancer patients' treatment goals using both closed- and open-ended questions.^{9–17} However, these studies have been limited by small sample sizes,^{9,11,15} including patients with serious illnesses other than advanced cancer,¹¹ including only a small subset of cancer types,^{9,12,13} including only patients who expected to be offered palliative chemotherapy,¹⁶ or using cross-sectional study designs.^{9,10}

In the present study, we asked patients with advanced cancer what they were "hoping for from their cancer treatment" at two points in time to address our research questions. First, among patients with advanced cancer, what are patients' hopes for treatment and how prevalent are these hopes? Specifically, how often do patients with advanced cancer say that they hope their treatment will lead to cure? Second, with whom do patients with advanced cancer discuss their hopes? Third, what demographic, clinical, and contextual factors are associated with hopes for unqualified cure?

Methods

Overview

Our analysis was based on survey data from the Values and Options in Cancer Care cluster randomized clinical trial, which measured the effect of oncologist communication training and patient coaching on communication between oncologists and adult patients with advanced nonhematologic cancer. In the present study, we reviewed survey responses regarding patients' hopes for treatment from baseline assessment ($n = 265$) and three months after study entry ($n = 216$). The oncologist was the unit of randomization, and we used stratified randomization to balance the number of breast cancer specialists across arms. Details of the parent study have been published previously.^{18,19}

Clinician and Patient Recruitment

Medical oncologists were recruited from participating community-based clinics, hospitals, and

academic medical centers in Sacramento, California and Rochester, New York. Research assistants reviewed clinic rosters of participating physicians to recruit patients who were 21 years or older, English speaking, and diagnosed with either Stage IV nonhematologic cancer or Stage III cancer and whose oncologist "would not be surprised" if the patient died within the next year. Among cancer patients, a "no" response to this "surprise question" has been associated with a seven times greater one-year mortality.²⁰ Patients who were hospitalized or enrolled in hospice were ineligible.

Elicitation and Coding of "Hopes for Treatment"

At the baseline, most surveys were administered in person and a few by telephone. At follow-up, surveys were administered in person when feasible but by telephone for patients who were not scheduled for follow-up appointments during the data collection window. Telephone surveys were completed by the same research personnel whom the patients had previously met at study entry. The focus of this study was the open-ended survey question: "What are you hoping for at this time in your cancer treatment?" This question was not further qualified, but patients answered in the context of ongoing care by their medical oncologist. Patients were allowed time to formulate hopes in their own words, which were then transcribed verbatim.

A three-person coding team (C. C., J. D., and R. L. K.) reviewed verbatim survey responses to the question regarding hopes. Using inductive reasoning, the team developed a taxonomy and codebook based on the first 25 patient responses from the baseline survey. The codebook included category names, operational definitions, instructions for code application, and illustrative quotes; these are summarized in [Table 1](#). Many patients expressed multiple hopes for treatment, so the number of hopes expressed at each time point exceeded the number of patients.

Following codebook development, C. C. and J. D. independently coded the remaining 240 baseline responses and all 216 of the three-month responses with good reliability. The mean (95% CI) of the category-specific kappa values was 0.76 (0.71–0.81) at the baseline and 0.84 (0.79–0.88) at three months. After all the responses were coded, C. C. and J. D. sought to reconcile their disagreements; based on the codebook, R. L. K. adjudicated 18 discrepancies at the baseline and seven discrepancies at three months.

Other Survey Measures

In addition to the open-ended question discussed previously, patients were asked to rate on a five-point Likert scale how thoroughly they had discussed their

Table 1
Categories of Hopes for Treatment Including Frequency, Definitions, and Examples

Category	Baseline <i>n</i> ^a (%)	Three Months <i>n</i> (%)	Definition	Examples
Unqualified cure	33 (12)	17 (8)	To be permanently free of disease	"To be cured. So I can enjoy my life with no worries"
Cure tempered by realism	14 (5)	3 (1)	To wish to be free of disease, but realizing this is unrealistic	"A cure ... I would love, but I know that is not possible"
Quality of life	110 (42)	78 (36)	To continue or improve well-being, including physical, emotional, and social functioning	"Walk strongly and feel normal when I get up"
Milestone	36 (14)	8 (4)	To survive long enough to experience a specific life event, phase of life, or significant accomplishment	"See [my] grandchildren, daughter was just married"
Life extension	84 (32)	57 (26)	To sustain life beyond what could be anticipated in the absence of treatment	"Extend my life as long as possible"
Tumor stabilization	68 (26)	66 (31)	To shrink, slow, or maintain, the tumor short of remission	"Stabilize the spread of cancer. Keep it in check"
Remission	54 (20)	34 (16)	To achieve temporary disappearance of clinically detectable cancer	"Knocking the hell out of cancer ... put it in remission"
Control not otherwise specified	25 (9)	26 (12)	To achieve control that cannot readily be classified as relating to life extension, remission, or stabilization	"Show improvement from the treatment"

^aAt the baseline, *N* = 265 patients, they expressed 424 hopes in total. At three months, *n* = 216 patients, they expressed 289 hopes in total. As some patients voiced more than one hope, the percentages of patients expressing each hope at each time point add up to more than 100%.

hopes with their 1) spouse or partner, 2) other family members or friends, 3) oncologist, 4) primary care physician, 5) nurse, 6) clergy, or 7) a support group. We dichotomized patients' responses for how thoroughly they had discussed their hopes with confidants in which not at all or a little bit was considered "not substantive" and somewhat, quite a bit, or very much was considered "substantive."

Patient-Level Covariates

We created a series of patient-level variables, dichotomized for ease of interpretation. Demographic variables included age, gender, race, education, income, relationship status, and religion. We also noted whether patients were diagnosed with "aggressive" cancers, determined prospectively in consultation with two oncologists, and including lung, gastrointestinal cancers (except colon), and genitourinary cancers (except prostate). We also constructed indicator variables for study site and trial arm.

Statistical Analysis

Analyses were conducted using STATA (Version 14.2; College Station, TX). We estimated the prevalence of the hope categories at both time points and used Pearson's chi-square test to identify statistically significant associations between patient variables and 1) hopes for unqualified cure and 2) hopes for quality of life (defining statistical significance as a two-tailed *P*-value < 0.05). We chose to focus on these two hope categories

because we hypothesized that they may be related to a life-extending versus palliative orientation near the end of life. We used mixed-effects multiple logistic regression to assess the independent association between selected patient-level variables with these two categories of hopes, adjusting for study site, study arm, and physician breast cancer subspecialty to account for the stratified randomized design. Given our lack of prior knowledge regarding predictors of hopes and the need for parsimony,²¹ we only entered the candidate covariates that were statistically significant in bivariate analysis into the multiple logistic regression. To account for the clustering of patients within physicians, we specified physician-level random intercepts.

Results

Participant Characteristics

Most patients in the study identified as white, identified as Christian, and had at least some college education (Table 2). Half had cancers classified as aggressive.

Categories of Hopes for Treatment

Of the 265 patients who responded to baseline surveys, 45 patients died and four dropped out of the study in the intervening three months; survey responses at three months were available from 216 patients. Using the taxonomy described in the Methods section, our team identified eight categories

Table 2
Characteristics of Participants (N = 265)

Characteristic	n	% (Mean)
Patient age		64.3 (SD = 11.4)
Gender		
Male	119	45
Female	146	55
Race		
Nonwhite	30	11
White	235	89
Patient education		
HS or less	73	28
Some college or more	192	72
Income		
\$50,000 or less	123	54
Over \$50,000	106	46
Relationship status		
Committed/married	176	66
Separated/widowed/never married	89	34
Patient religion		
Christianity	191	72
Other/no religion	74	28
Cancer type ^a		
Aggressive	133	50
Nonaggressive	132	50
Location		
Sacramento, California	94	35
Rochester, New York	171	65

^aAggressive tumors were prospectively determined by two oncologists and included lung cancer, GI cancers (except colon), and GU cancers (except prostate) while less aggressive cancers included breast, prostate, and colon.

of hopes into which 95% of patients' responses could be categorized at both the baseline and three months: 1) unqualified cure, 2) cure tempered by realism (in which the patient hopes for cure but acknowledges this is unrealistic), 3) quality of life, 4) milestone, 5) life extension, 6) tumor stabilization, 7) remission, and 8) control not otherwise specified. The distribution of hopes by category at each time, category definitions, and examples is shown in Table 1.

Patients expressed an average of 1.6 (SD = .77) hopes for treatment at the baseline and 1.3 (SD = .66) hopes at three months. At both time points, the most frequently expressed hope was for improved or maintained quality of life, while patients infrequently expressed unqualified hopes for cure and cure tempered by realism.

Discussions of Hopes With Members of Care Team

As shown in Figure 1, most patients reported having substantive discussions about their hopes for treatment with spouses/partners, other family or friends, or oncologists. A minority reported having substantive discussions with nurses or nurse practitioners, primary care physicians, clergy, or members of support groups or online communities.

Individual Changes, Time Point Prevalence, and Cumulative Incidence of Hopes

Among the 216 patients who provided responses at both the baseline and three months, 185 (86%) expressed at least one change in the categories of hopes they expressed from the baseline to three months. The largest change in the prevalence of hope types from the baseline to three months (Fig. 2) was in hopes for milestone (from 14% at the baseline to 3% at three months) and hopes for cure tempered by realism (5% to 1%). However, the most common at both the baseline and three months were hopes for quality of life (41% vs. 36%).

Associations With Hopes for Unqualified Cure and Quality of Life

In bivariate analysis, we identified two patient variables that were significantly associated with hopes for

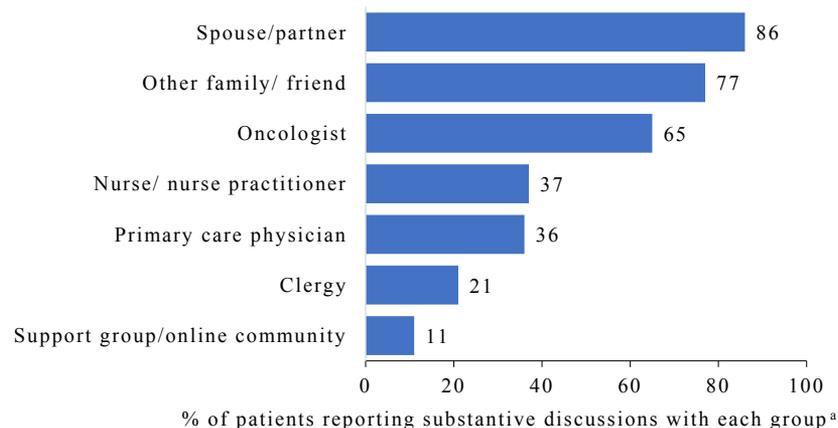


Fig. 1. Frequency of hopes discussion with members of care team at the baseline. ^aHope discussion quality was rated by patients on a five-point scale and dichotomized for analysis. "Not substantive" included those who responded they discussed hopes not at all or a little bit, whereas "substantive" included those who responded they discussed hopes somewhat, quite a bit, or very much.

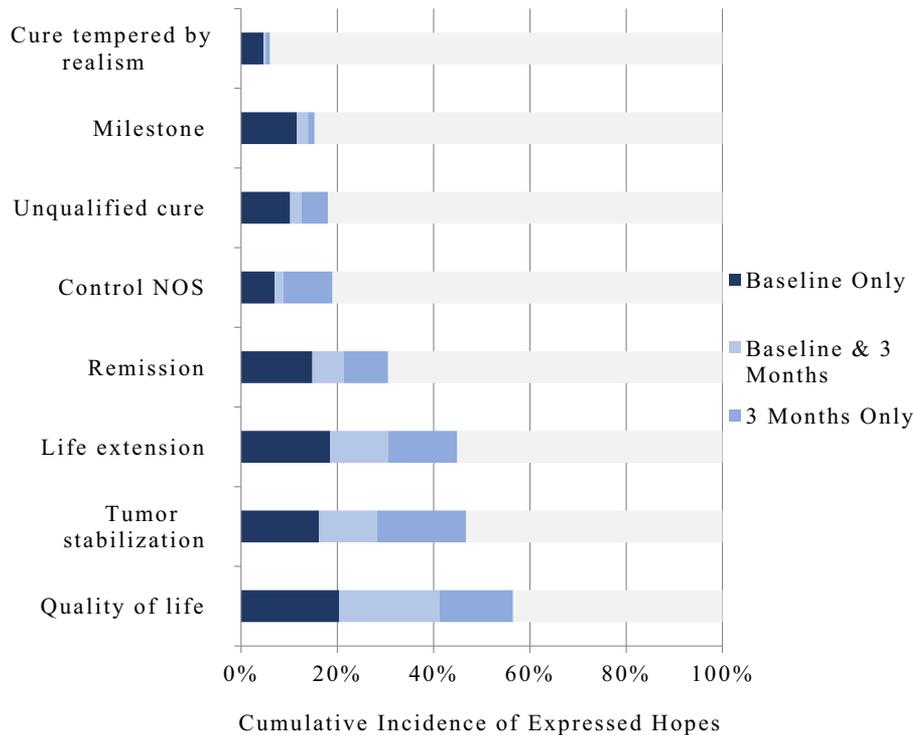


Fig. 2. Prevalence and cumulative incidence of hopes ($N = 216$). NOS = not otherwise specified.

cure (Supplemental Table 1). Patients in the youngest quartile (<57 years) were statistically significantly more likely to express hopes for cure than patients aged 58 years or greater. In addition, patients who did not substantively discuss hopes with their primary care physician were more likely to express unqualified hopes for cure. Only one variable, study site, was found to have a significant association with hopes for quality of life (Supplemental Table 2). Patients from Rochester, New York, were more likely than patients in Sacramento, California, to express hopes for quality of life (47% vs. 32%, $P = 0.02$).

In the multiple logistic regression (Table 3), the adjusted odds of expressing hopes for an unqualified cure were higher in patients younger than 57 years and patients who did not discuss hopes with primary care physicians. Physician effects (as measured by the between-physician variance component) were not significantly different from 0.

Discussion

In this longitudinal study of a clinically diverse sample of patients with advanced cancer, investigators reliably classified patient's responses to an open-ended question about their hopes for treatment into eight categories. Although the presence of specific hope categories often changed in individual participants over three months, the relative prevalence of these

categories did not change substantially. We also found that while the majority of patients discuss their hopes with spouses, family and friends, and oncologists, a minority are discussing them with other individuals who could have important roles in health and well-being including primary care physicians, nurses, clergy and support groups.

The eight categories in our study expand upon the six treatment goals found in the structured literature review by Kaldjian et al.¹⁷ In both our study and the literature review,¹⁷ the two most common hopes were for good quality of life and life extension. These two treatment goals are consistent with the aims of both palliative cancer-directed therapy and of palliative care more generally²² and therefore could be construed as realistic in this setting of advanced cancer.^{23,24} By contrast, a small, but a nontrivial minority of patients in our study harbored hopes for cure from their treatments, which were arguably unrealistic hopes given that patients were recruited based on limited life expectancy and the incurability of their cancers.

Patients were less likely to hope for cure if they reported discussing their hopes with primary care physicians. By contrast, patients who discussed hopes with oncologists were just as likely to hope for cure as patients who did not discuss hopes with oncologists. While we cannot assume causation from these associations, primary care physicians may play a role in helping patients reframe what is important and realistic.

Table 3
Adjusted Associations Between Baseline Characteristics and Hopes for Unqualified Cure

Variable	Adjusted Odds Ratio (95% CI) ^a	P-Value
Age		
<57 yrs	3.92 (1.63–9.40)	0.002
≥58 yrs	1.0 (ref)	
Hope discussions with primary care physicians ^b		
Not substantive	3.21 (1.13–9.14)	0.029
Substantive	1.0 (ref)	

^aFrom multiple logistic regression model that adjusted for listed variables as well as site, study arm, and breast cancer subspecialty among the 38 physician clusters. Unmeasured physician factors (as measured by the estimated variance component for the distribution of physician random effects) were not significant.

^bHope discussion quality was rated by patients on a five-point scale and dichotomized for analysis. “Not substantive” included those who responded they discussed hopes not at all or a little bit, whereas “substantive” included those who responded they discussed hopes somewhat, quite a bit, or very much.

These practitioners may also be less likely to stoke hopes for cure than oncologists, as they are not directly vested in cancer-directed treatment. In some studies, oncologists have been observed to skirt discussions of prognosis to focus on treatment options,²⁵ a process of mutual avoidance that some have termed “collusion.” This process of avoidance may be well intentioned to protect patients from despair, leaving important topics unexplored. Alternatively, patients with more unrealistic expectations may be less likely to seek, remember, or seriously consider counsel from a primary care physician. It is also possible that cancer patients who have a trusting relationship with their primary care physicians may differ from their counterparts in other ways that affect hopes.

Unsurprisingly, we also found that younger patients are more likely to hope for a cure. Older patients may be more likely to accept grim prognoses both because the potential losses are less grievous (fewer years of productive life are being lost) and because they are less likely to have dependent children. Another study has shown that advanced cancer patients with dependent children were more likely to prefer aggressive treatments over palliative care and less likely to engage in advanced care planning,¹⁰ perhaps driven by higher levels of psychological distress at the thought of leaving dependent children behind.

We found that many individuals expressed different hopes at the baseline and three months; however, at the population level, hopes for quality of life remained most common, whereas hopes for cure remained a sizable minority. The concept of evolving goals in individuals was discussed by Sachs et al. in reference to patients with dementia.²⁶ As suggested by Epstein et al., values and preferences evolve as the disease progresses and treatment options change,²⁷ but preferences may also be related to other life events unrelated to the

disease. For example, some of the patients who no longer reported hoping to reach a milestone (e.g., a grandchild’s birth) may have either reached this milestone or changed their priorities.

The primary strength of this study is that we used open-ended questions to allow participants to freely express their hopes at two points in time. However, there are several threats to internal validity including that the survey interviews were brief, and our data on the extent of discussions with primary care physicians and other care team members were subject to recall bias. In addition, our results may not be generalizable to the entire population of advanced cancer patients because patients were recruited from only two geographic areas, and the sample was predominantly white, Christian, and well educated. Although concerns have been raised about the validity of the “surprise” question, especially in noncancer populations,²⁸ we applied this question only to patients with Stage III cancer (Stage IV were automatically eligible), and the median survival in our study was 16 months,¹⁸ indicating that the target population of patients was successfully recruited.

We found that patients with advanced cancer have a wide range of hopes that are often not discussed with members of the health care team or other confidants. While maintenance of quality of life was the most commonly expressed hope, a sizable minority of patients hoped for an unqualified cure despite the poor prognosis of their cancers. By asking about hopes for treatment, physicians and other care team members can provide empathetic education and guidance to help patient establish realistic goals for treatment. Future studies may consider how advanced cancer patients’ hopes for treatment affect medical decisions and how oncologists, primary care physicians, and other members of the patient’s support system can tackle the challenge of helping patients more realistically understand their illness and treatment options while maintaining their well-being.

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Appendix

Supplemental Table 1
Bivariate Associations Between Patient Characteristics and Baseline Hopes for Unqualified Cure

Characteristic	Unqualified Cure Hopes (N = 265)	χ^2	P-Value
Age group			
<57 yrs (youngest quartile)	25%	12.7048	<0.001
≥58 yrs	8%		
Gender			
Male	12%	0.0938	0.76
Female	13%		
Race			
White	13%	1.0389	0.31
Nonwhite	7%		
Education			
≤High school	12%	0.0014	0.97
>High school	13%		
Yearly income			
≤\$50,000	11%	1.0543	0.31
>\$50,000	16%		
Relationship status			
Committed	14%	1.4750	0.22
Not committed	9%		
Religion			
Christian	12%	0.5479	0.46
Other	15%		
Cancer type			
Aggressive	16%	2.7267	0.10
Nonaggressive	9%		
Location			
Sacramento, California	12%	0.0753	0.78
Rochester, New York	13%		
Primary care physician discussion ^a			
Not substantive	16%	5.2633	0.02
Substantive	6%		
Oncologist discussion ^a			
Not substantive	12%	0.0268	0.87
Substantive	13%		
Nurse/nurse practitioner discussion ^a			
Not substantive	14%	0.6533	0.42
Substantive	10%		
Spouse/partner discussion ^a			
Not substantive	14%	0.0005	0.98
Substantive	14%		
Other family or friend discussion ^a			
Not substantive	11%	0.0906	0.76
Substantive	13%		
Clergy discussion ^a			
Not substantive	15%	3.2608	0.07
Substantive	5%		
Support group/online discussion ^a			
Not substantive	13%	0.1687	0.68
Substantive	10%		

^aHope discussion quality was rated by patients on a five-point scale and dichotomized for analysis. "Not substantive" included those who responded they discussed hopes not at all or a little bit, whereas "substantive" included those who responded they discussed hopes somewhat, quite a bit, or very much.

Supplemental Table 2
Bivariate Associations Between Patient Characteristics and Baseline Hopes for Quality of Life

Characteristic	Hopes for Quality of Life (N = 265)	χ^2	PValue
Age group			
<57 yrs (youngest quartile)	36%	1.0702	0.30
≥58 yrs	43%		
Gender			
Male	40%	0.1225	0.73
Female	42%		
Race			
White	42%	0.0317	0.86
Nonwhite	40%		
Education			
≤High school	42%	0.38	0.85
>High school	41%		
Yearly income			
≤\$50,000	42%	0.0007	0.98
>\$50,000	42%		
Relationship status			
Committed	44%	1.0836	0.30
Not committed	37%		
Religion			
Christian	40%	0.8323	0.36
Other	46%		
Cancer type			
Aggressive	47%	2.8684	0.09
Nonaggressive	36%		
Location			
Sacramento, California	32%	5.5232	0.019
Rochester, New York	47%		
Primary care physician discussion ^a			
Not substantive	44%	0.9442	0.33
Substantive	38%		
Oncologist discussion ^a			
Not substantive	43%	0.0609	0.81
Substantive	41%		
Nurse/nurse practitioner discussion ^a			
Not substantive	39%	2.1889	0.14
Substantive	48%		
Spouse/partner discussion ^a			
Not substantive	36%	0.3478	0.56
Substantive	42%		
Other family or friend discussion ^a			
Not substantive	36%	1.0036	0.316
Substantive	43%		
Clergy discussion ^a			
Not substantive	42%	0.2937	0.59
Substantive	38%		
Support group/online discussion ^a			
Not substantive	42%	0.0014	0.97
Substantive	41%		

^aHope discussion quality was rated by patients on a five-point scale and dichotomized for analysis. "Not substantive" included those who responded they discussed hopes not at all or a little bit, whereas "substantive" included those who responded they discussed hopes somewhat, quite a bit, or very much.