FOCUS ON QUALITY ReCAP

Is Advance Care Planning Associated With Decreased Hope in Advanced Cancer?

Michael G. Cohen, MD[1]; Andrew D. Althouse, PhD[2]; Robert M. Arnold, MD[3]; Hailey W. Bulls, PhD[3]; Douglas White, MD, MAS[4]; Edward Chu, MD[5]; Margaret Rosenzweig, PhD, CRNP-C, AOCNP[6]; Kenneth Smith, MD[2]; and Yael Schenker, MD, MAS[3]

QUESTION ASKED: Among patients with advanced solid malignancies, is there an association between 3 domains of advance care planning (ACP; end-of-life conversations with an oncologist, designation of a surrogate decision maker, or completion of an advance directive) and hope?

SUMMARY ANSWER: There is no association between any of the 3 domains of ACP and hope among patients with advanced cancer. Level of hope remains equivalent, even after controlling for variables known to be associated with hope or ACP.

WHAT WE DID: This study was a cross-sectional analysis of baseline data from a randomized controlled trial of a primary palliative care intervention. Patients with advanced solid malignancies, with an Eastern Cooperative Oncology Group performance status of ≤ 2, and for whom their oncologist "would not be surprised if they died within the next year" were enrolled. Patient hope was assessed using the Herth Hope Index, the most common instrument for assessing hope among oncology patients. ACP was assessed by patient response to 3 questions regarding whether they had had an end-of-life conversation with their oncologist, whether they had determined a surrogate decision maker, and whether they had completed an advance directive. Univariable and multivariable analyses were performed, and equivalence testing was done to determine whether levels of hope were different among patients who had and had not engaged in ACP.

WHAT WE FOUND: We found that there was no difference in hope for any of the 3 domains of ACP in univariable or multivariable analysis. On further equivalence testing, hope was equivalent among patients who had and had not completed ACP in all 3 domains.

BIAS, CONFOUNDING FACTORS: Cross-sectional analysis precludes determination of causality. In addition, our population was predominantly White. This may limit generalizability to more racially diverse populations.

REAL-LIFE IMPLICATIONS: Fear of depriving patients of hope has been identified as a key reason that clinicians defer ACP conversations with their patients. Our data demonstrate that there is no association between ACP and hope. As such, our data may help to alleviate this concern and make clinicians more comfortable in having these essential conversations.

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abstract

PURPOSE Providers have cited fear of taking away hope from patients as one of the principal reasons for deferring advance care planning (ACP). However, research is lacking on the relationship between ACP and hope. We sought to investigate the potential association between ACP and hope in advanced cancer.

METHODS This is a cross-sectional analysis of baseline data from a primary palliative care intervention trial. All patients had advanced solid cancers. Three domains of ACP were measured using validated questions to assess discussion with oncologists about end-of-life (EOL) planning, selection of a surrogate decision maker, and completion of an advance directive. Hope was measured using the Hearth Hope Index (HHI). Multivariable regression was performed, adjusting for variables associated with hope or ACP.

RESULTS A total of 672 patients were included in this analysis. The mean age was 69.3 ± 10.2 years; 54% were female, and 94% were White. Twenty percent of patients (132 of 661) reported having a discussion about EOL planning, 51% (342 of 668) reported completing an advance directive, and 85% (565 of 666) had chosen a surrogate. There was no difference in hope between patients who had and had not had an EOL discussion (adjusted mean difference in HHI, 0.55; $P = .181$ for adjusted regression), chosen a surrogate (adjusted HHI difference, 0.31; $P = .512$), or completed an advance directive (adjusted HHI difference, 0.11; $P = .752$).

CONCLUSION In this study, hope was equivalent among patients who had or had not completed 3 important domains of ACP. These findings do not support concerns that ACP is associated with decreased hope for patients with advanced cancer.

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INTRODUCTION

Advance care planning (ACP) is an important component of high-quality care for patients with advanced cancer.[1-3] Defined as a process to help to ensure that patients receive care consistent with their goals and values,[4] ACP may include one or more of the following: discussing values and preferences for future care, identifying a surrogate decision maker, and completing an advance directive.[4] While oncologists recognize the importance of ACP,[5,6] these activities continue to occur infrequently and late for patients with advanced disease.[7-9] One of the principal reasons that physicians cite for failing to engage patients in ACP until late in a patient's disease course is concern about giving up hope.[10]

Most patients with advanced cancer identify hope as important.[11] Hope may alleviate psychological distress near the end of life (EOL) and may contribute to patients' abilities to cope with their diagnoses.[11,12] While conducting semistructured interviews with patients with cancer receiving palliative treatment, Nierop-van Baalen et al[13] identified hope as a concept that provides resilience and prevents passivity. Limited data have even suggested a correlation between hopelessness and survival among patients with advanced breast cancer, with patients who show increased hopelessness having a relative risk of death of 3.4 compared with those with less hopelessness.[14] However, to date, only one study has reported on the correlation between ACP (using an online decision aid) and hope[15] and found no change in hope with this intervention. Elucidation of the relationship between ACP and hope may allow providers to better understand the impact of recommended ACP activities.

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We therefore designed an analysis to examine associations between ACP and hope among patients with advanced cancer. Our primary aim was to determine whether patients who have engaged in ACP activities have different levels of hope from patients who have not. We hypothesized that patients with advanced cancer who have completed ACP will have equivalent hope to patients who have not completed ACP.

METHODS

Overview and Framework

Our study is a secondary cross-sectional analysis of baseline data collected as part of the A Primary Palliative Care Intervention for Patients with Advanced Cancer (CONNECT) study (ClinicalTrials.gov identifier: NCT02712229). Full details of the study design have been published previously.[16] Data for this analysis were collected at the time of patient enrollment into the study before any palliative interventions. Examination of data from this time point allows us to determine whether associations exist between ACP and hope among patients with advanced cancer, independent of directed ACP or palliative care interventions.

Sample

This study enrolled patients from 17 medical oncology practices within the University of Pittsburgh Medical Center Hillman Cancer Center network in western Pennsylvania between July 2016 and October 2019. Clinic sites were chosen that lacked access to specialty palliative care because the subsequent trial involved randomization to usual care or primary (nurse-led) palliative care.

Patients eligible for the study were adults with advanced solid tumors for whom the oncologist would not be surprised if the patient died within the next year.[17] Eligible patients had an Eastern Cooperative Oncology Group (ECOG) performance status of 0 (fully active, able to carry on all predisease performance without restriction), 1 (restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature [eg, light house work, office work]), or 2 (ambulatory and capable of all self-care but unable to carry out any work activities and up and about > 50% of waking hours)[18] and anticipated receiving ongoing oncology care at their current site. Patients were excluded if they were unable to speak or read English, unable to consent to treatment, or had hematologic malignancies.[16] All patients signed informed consent before participating. This study was approved by the University of Pittsburgh institutional review board.

Measures

All enrolled patients completed a baseline questionnaire. ACP was measured using 3 questions that have previously been used with seriously ill patient populations[19,20]: EOL planning discussion ("Have you and any of your health care providers at the cancer center discussed any particular wishes you have about the care you would want to receive if you were dying?"), surrogate decision maker ("Have you chosen a family member or friend to make decisions for you if you were no longer able to make decisions for yourself?"), and advance directive ("Have you completed a living will or advance directive?"). Hope was assessed by the Herth Hope Index (HHI).[21,22] According to previous research that looked at the various instruments to measure hope, the HHI is the tool most commonly used in oncology.[23] This validated scale contains 12 questions on a 4-point Likert scale that encompass 3 domains of hope: temporality and future, positive readiness and expectancy, and interconnectedness with self and others. The scale itself is scored from 12 to 48, with higher scores indicating higher levels of hope. A prior meta-analysis of interventions designed to address hope found that the HHI is responsive to change in patients with cancer.[24] To date, there is no study of what represents a clinically significant (as opposed to statistically significant) difference in hope. To establish clinical equivalence, we needed to determine a margin of clinical significance. In the absence of a previously derived minimal clinically important difference, the decision was made to turn to expert opinion and consult with the author of the scale. After discussion conducted in November 2019, a 6-point difference was selected as the minimal clinically relevant difference.

Additional information collected during baseline questionnaires included demographic information, cancer type and current treatment, ECOG performance status as determined by the patient's oncologist, symptom burden (assessed by the Edmonton Symptom Assessment Scale [ESAS]; range, 0-100, with higher numbers indicating worse symptom burden),[25] and symptoms of anxiety and depression as measured by the Hospital Anxiety and Depression Scale (HADS; range, 0-21 each for anxiety and depression, with higher scores indicating worse anxiety or depression symptoms).[26]

Statistical Analysis

To describe the study population, continuous variables are presented as mean ± SD; categorical variables are presented as frequency (percentage). Comparisons between patients who answered yes versus no for each of the 3 ACP domains were performed using *t* tests for continuous variables and χ^2 tests for categorical variables.

The two one-sided *t* tests procedure was used to test for equivalence of hope between patients who had undergone ACP versus those who had not, using an equivalence margin of 6 points (corresponding to an average difference of half a point across 12 Likert scale questions). In the absence of a previously derived minimal clinically important difference, this margin was selected on the basis of expert consultation with the author of the index, which was conducted in November 2019. We also performed

TABLE 1. Demographic and Clinical Characteristics of the Study Population

Characteristic	No. (%)
No. of patients	672
Age, years, mean ± SD	69.30 ± 10.20
Sex	
Female	360 (53.6)
Race	
White	632 (94.0)
Black	33 (4.9)
Asian	5 (0.7)
Religious importance	
Not at all	21 (3.1)
Not too	65 (9.7)
Fairly	154 (22.9)
Very	421 (62.6)
Education	
Less than high school	54 (8.0)
High school diploma or GED	281 (41.8)
Some college/college degree	289 (43.0)
Graduate/postgraduate degree	41 (6.1)
Current marital status	
Never married	44 (6.5)
Married	382 (56.8)
Widowed/divorced/separated	239 (35.5)
Ability to manage on income	
Cannot make ends meet	46 (6.8)
Just manage to get by	226 (33.6)
Have enough with a little extra	250 (37.2)
Money is not a problem	108 (16.1)
Time receiving care from current oncologist	
< 1 month ago	42 (6.3)
1-6 months ago	208 (31.0)
6 months-1 year ago	114 (17.0)
1-2 years ago	118 (17.6)
2-5 years ago	119 (17.7)
> 5 years ago	67 (10.0)
Cancer type	
Genitourinary[a]	73 (10.9)
Brain	3 (0.4)
Breast/gynecologic[b]	110 (16.4)
GI[c]	131 (19.5)
Hepatobiliary[d]	79 (11.7)
Head and neck	13 (1.9)
Lung	243 (36.2)
Melanoma	9 (1.3)
Sarcoma	6 (0.9)
Other	2 (0.3)
ECOG performance status	
0	157 (23.4)
1	393 (58.5)
2	122 (18.2)
Symptom burden (ESAS), mean ± SD	25.20 ± 16.00
Symptoms of depression (HADS), mean ± SD	5.41 ± 3.75
Symptoms of anxiety (HADS), mean ± SD	5.78 ± 3.90
Hope (Herth Hope Index), mean ± SD	39.20 ± 5.31

Abbreviations: ECOG, Eastern Cooperative Oncology Group; ESAS, Edmonton Symptom Assessment Scale; GED, General Educational Development; HADS, Hospital Anxiety and Depression Scale; SD, standard deviation.

[a] Genitourinary cancer includes kidney, prostate, and urethral.

[b] Gynecologic cancer includes ovarian and endometrial.

[c] GI cancer includes stomach, esophageal, colon, and rectal.

[d] Hepatobiliary cancer includes gallbladder, liver, and pancreas.

multivariable linear regression analyses while controlling for factors identified as potential confounders on the basis of our clinical experience and a review of the literature.[27-33] The predefined variables included age[27-33]; sex[28,31,32]; marital status[33,34]; socioeconomic status[35,36]; education level[29-32,36]; religious importance[30,32,37]; anxiety/emotional distress[36,38-40]; and clinic site, which served as a proxy for provider.[41-43] All statistical analyses were performed using SAS 9.4 software (SAS Institute, Cary, NC).

RESULTS

A total of 672 patients completed the baseline assessment. The mean age for our population was 69.3 ± 10.2 years, and the most common malignancies were lung (36%), GI (17%), and breast/gynecologic (17%; Table 1). The majority of patients answered all 3 ACP questions. Response rates were 98% (n = 661) for the question about having an EOL conversation with their physician, 99% (n = 666) for the question about a surrogate decision maker, and 99% (n = 668) for the question about an advance directive.

Twenty percent of the patients (132 of 661) reported that that they had had an EOL planning discussion with their cancer center provider. There were no differences in EOL planning discussion by age, sex, race, education, religion, marital status, cancer type, ECOG performance status, or treatment status (Table 2). In unadjusted analyses, there was no difference in hope between those who had and had not had an EOL planning discussion with their provider (HHI, 39.2 ± 5.24 *v* 39.1 ± 5.69, respectively; $P = .811$; Fig 1).

TABLE 2. Advance Care Planning Differences by Domain

	EOL Planning Discussion, No. (%)			Surrogate Decision Maker, No. (%)			Living Will or Advance Directive, No. (%)		
Characteristic	**No**	**Yes**	***P***	**No**	**Yes**	***P***	**No**	**Yes**	***P***
No. of patients	529	132		101	565		326	342	
Age, years, mean ± SD	69.30 ± 10.40	69.20 ± 9.46	.929	65.10 ± 10.20	70.10 ± 10.00	< .001	66.30 ± 9.88	72.10 ± 9.67	< .001
Sex			.771			.193			.904
Female	284 (53.7)	69 (52.3)		60 (59.4)	296 (52.4)		175 (53.7)	182 (53.2)	
Race			.713			.136			.012
White	501 (94.7)	123 (93.2)		92 (91.1)	535 (94.7)		298 (91.4)	332 (97.1)	
Black	22 (4.2)	8 (6.1)		9 (8.9)	23 (4.1)		23 (7.1)	8 (2.3)	
Asian	4 (0.8)	1 (0.8)		0 (0.0)	5 (0.9)		3 (0.9)	2 (0.6)	
Religious importance			.404			.862			.436
Not at all	17 (3.2)	4 (3.0)		3 (3.0)	18 (3.2)		12 (3.7)	9 (2.6)	
Not too	47 (8.9)	17 (12.9)		10 (9.9)	55 (9.7)		37 (11.3)	28 (8.2)	
Fairly	120 (22.7)	29 (22.0)		23 (22.8)	129 (22.8)		78 (23.9)	74 (21.6)	
Very	338 (63.9)	78 (59.1)		62 (61.4)	355 (62.8)		194 (59.5)	225 (65.8)	
Education			.75			.101			.002
Less than high school	45 (8.5)	9 (6.8)		15 (14.9)	38 (6.7)		31 (9.5)	23 (6.7)	
High school diploma or GED	221 (41.8)	57 (43.2)		46 (45.5)	233 (41.2)		156 (47.9)	123 (36.0)	
Some college/college degree	223 (42.2)	60 (45.4)		37 (36.7)	249 (44.1)		126 (38.6)	161 (47.1)	
Graduate/postgraduate degree	34 (6.4)	5 (3.8)		2 (2.0)	39 (6.9)		9 (2.7)	35 (9.4)	
Current marital status			.075			.286			.018
Never married	35 (6.6)	9 (6.8)		9 (8.9)	35 (6.2)		27 (8.3)	17 (5.0)	
Married	311 (58.8)	65 (49.2)		54 (53.5)	326 (57.7)		184 (56.4)	196 (57.3)	
Widowed/divorced/separated	177 (33.5)	57 (43.2)		36 (35.6)	199 (35.2)		111 (34.0)	126 (36.8)	
Ability to manage on current income			.855			.001			.001
Cannot make ends meet	35 (6.6)	10 (7.6)		9 (8.9)	37 (6.5)		28 (8.6)	18 (5.3)	
Just manage to get by	183 (34.6)	39 (29.5)		48 (47.5)	175 (31.0)		127 (39.0)	96 (28.1)	
Have enough with a little extra	196 (37.1)	52 (39.4)		32 (31.7)	215 (38.1)		115 (35.3)	135 (39.5)	
Money is not a problem	85 (16.1)	21 (15.9)		5 (5.0)	103 (18.2)		37 (11.3)	71 (20.8)	
Time receiving care from current oncologist			.228			.039			.012
< 1 month ago	35 (6.6)	5 (3.8)		7 (6.9)	33 (5.8)		19 (5.8)	22 (6.4)	
1-6 months ago	168 (31.8)	35 (26.5)		35 (34.7)	172 (30.4)		107 (32.8)	99 (28.9)	
6 months-1 year ago	90 (17.0)	22 (16.7)		27 (26.7)	87 (15.4)		66 (20.2)	48 (14.0)	
1-2 years ago	97 (18.3)	21 (15.9)		10 (9.9)	108 (19.1)		57 (17.5)	61 (17.8)	
2-5 years ago	87 (16.4)	32 (24.2)		15 (14.9)	102 (18.1)		53 (16.3)	66 (19.3)	
> 5 years ago	50 (9.5)	16 (12.1)		7 (6.9)	59 (10.4)		21 (6.4)	45 (13.2)	
Cancer type			.781			.078			.046
Genitourinary	59 (11.2)	13 (9.8)		13 (12.8)	60 (10.6)		31 (9.5)	42 (12.3)	
Brain	2 (0.4)	1 (0.8)		1 (1.0)	2 (0.4)		2 (0.6)	1 (0.3)	
Breast/gynecologic	92 (17.4)	20 (15.1)		12 (11.9)	100 (17.7)		52 (15.9)	61 (17.8)	
GI	110 (20.8)	20 (15.1)		17 (16.8)	113 (20.0)		65 (19.9)	65 (19.0)	
Hepatobiliary	60 (11.3)	15 (11.4)		12 (11.9)	65 (11.5)		34 (10.4)	43 (12.6)	
Head and neck	9 (1.9)	2 (1.5)		5 (5.0)	7 (1.2)		10 (3.1)	2 (0.6)	
Lung	182 (34.4)	58 (43.9)		38 (37.6)	204 (36.1)		125 (38.3)	118 (34.5)	
Melanoma	8 (1.5)	1 (0.8)		0 (0.0)	9 (1.6)		4 (1.2)	5 (1.5)	
Sarcoma	3 (0.6)	1 (0.8)		3 (3.0)	3 (0.5)		2 (0.6)	4 (1.2)	

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TABLE 2. Advance Care Planning Differences by Domain (continued)

	EOL Planning Discussion, No. (%)			Surrogate Decision Maker, No. (%)			Living Will or Advance Directive, No. (%)		
Characteristic	**No**	**Yes**	***P***	**No**	**Yes**	***P***	**No**	**Yes**	***P***
ECOG performance status			.554			.381			.702
0	126 (23.8)	29 (22.0)		18 (17.8)	136 (24.1)		76 (23.3)	79 (23.1)	
1	312 (59.0)	75 (56.8)		64 (63.4)	326 (57.7)		187 (57.4)	205 (59.9)	
2	91 (17.2)	28 (21.2)		19 (18.8)	103 (18.2)		63 (19.3)	58 (17.0)	
Symptom burden (ESAS), mean ± SD	24.40 ± 16.10	27.80 ± 14.80	.027	27.30 ± 17.10	24.60 ± 15.60	.126	26.40 ± 16.30	23.90 ± 15.30	.041
Symptoms of depression (HADS), mean ± SD	5.36 ± 3.81	5.47 ± 3.46	.755	5.81 ± 3.88	5.31 ± 3.71	.214	5.97 ± 3.90	4.81 ± 3.49	< .001
Symptoms of anxiety (HADS), mean ± SD	5.63 ± 3.96	6.21 ± 3.54	.125	6.15 ± 4.37	5.67 ± 3.79	.253	5.90 ± 4.10	5.61 ± 3.65	.326
Hope (Herth Hope Index), mean ± SD	39.20 ± 5.24	39.1 ± 5.69	.811	38.6 ± 5.75	39.3 ± 5.21	.22	39.0 ± 5.35	39.5 ± 5.29	.223

Abbreviations: ECOG, Eastern Cooperative Oncology Group; EOL, end of life; ESAS, Edmonton Symptom Assessment Scale; GED, General Educational Development; HADS, Hospital Anxiety and Depression Scale; SD, standard deviation.

A total of 565 (84.8%) of 666 patients reported that they had chosen a surrogate decision maker. Patients who had designated a surrogate decision maker were significantly more likely to be older, comfortable with their current income, and less recently diagnosed (Table 2). There was no difference in hope between patients who had and had not designated a surrogate decision maker (HHI, 39.3 ± 5.21 *v* 38.6 ± 5.75, respectively; $P = .220$; Fig 1)

Three hundred forty-two patients (51.2%) had completed an advance directive. Patients who had completed an advance directive were significantly more likely to be older, more highly educated, retired, comfortable with their current income, and less recently diagnosed with cancer (Table 2). Depression scores were also significantly lower in those who completed an advance directive (HADS depression score, 4.81 ± 3.49 *v* 5.97 ± 3.90, respectively; $P < .001$). There was no difference in hope between those who had and had not completed an advance directive (HHI, 39.5 ± 5.29 *v* 39.0 ± 5.35, respectively; $P = .223$; Fig 1)

After adjusting for age, sex, marital status, socioeconomic status, education level, religious importance, anxiety, symptom burden (ESAS), time receiving care from current oncologist, and clinic site, there remained no difference in hope by each individual ACP domain (Table 3). Additional testing was performed to confirm statistical equivalence. Setting a margin of clinical significance of 6 points on the HHI (mean, 0.5 points per question difference), testing was performed to determine whether hope was clinically equivalent for each ACP domain. The equivalence tests provided evidence that the difference in hope was less than the prespecified margin of 6 points for those who had engaged in each of the ACP domains compared with those who had not. For all 3 domains, both the adjusted and the unadjusted hope scores were equivalent within a 6-point margin (for all, $P < .001$).

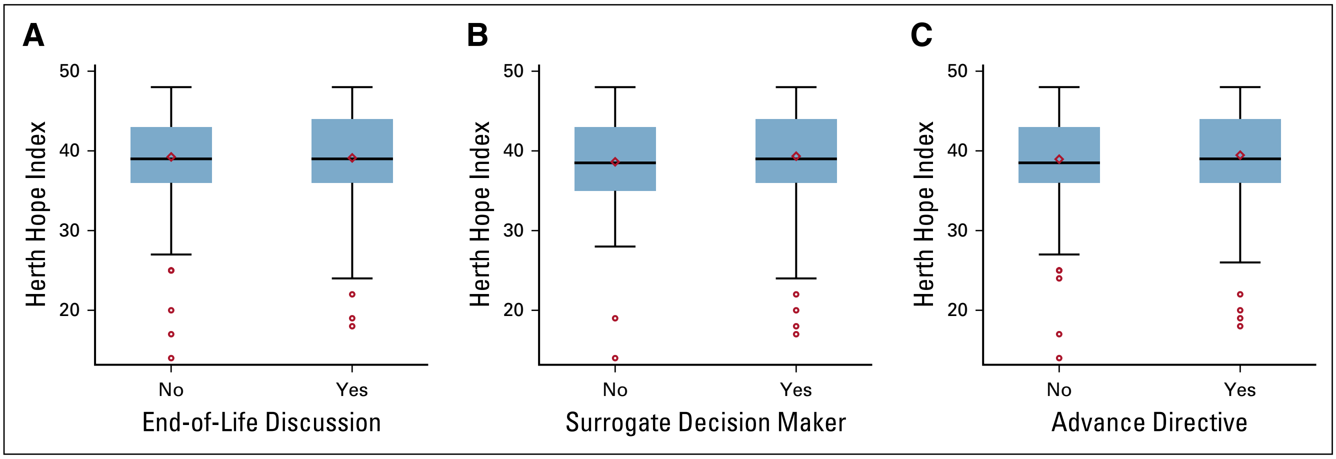

FIG 1. Box plots of Herth Hope Index scores by advance care planning domain: (A) end-of-life discussion, (B) surrogate decision maker, and (C) advance directive.

TABLE 3. Unadjusted and Adjusted Mean Difference in Hope by Each ACP Domain

ACP Domain	Unadjusted Mean Difference in Hope	Unadjusted 95% CI	*P*	Adjusted Mean Difference in Hope	Multivariable-Adjusted 95% CI	*P*
Have had EOL planning discussion	−0.12	−1.14 to 0.89	.811	0.55	−0.25 to 1.35	.181
Chosen surrogate decision maker	0.70	−0.42 to 1.83	.220	0.31	−0.61 to 1.23	.512
Completed advance directive	0.50	−0.30 to 1.31	.222	0.11	−0.59 to 0.81	.752

NOTE. Analyses are adjusted for age, sex, marital status, socioeconomic status, education level, religious importance, anxiety/emotional distress, and clinic site (which served as a proxy for provider).

Abbreviations: ACP, advance care planning; EOL, end of life.

DISCUSSION

The primary aim of our study was to determine whether an association existed between ACP and hope in patients with advanced cancer. Our results indicate that hope is equivalent for patients who have and have not had an EOL discussion with their oncologist, designated a surrogate decision maker, or completed an advance directive, even after controlling for variables known to be associated with either hope or ACP. No other studies to our knowledge have tested for equivalence in hope between patients who have engaged in ACP and those who have not. However, our data are consistent with other studies in the field that have not demonstrated a relationship between ACP and hope.[15] This work, by Green et al,[15] looked at the impact of a web-based ACP intervention on hope in a population of 200 patients with advanced malignancy. The researchers found that compared with simply providing patients with the American Hospital Association guidelines on ACP, provision of a web-based ACP intervention did not affect hope. Similarly, previous qualitative research has been done to understand hope among patients with advanced lung cancer. In one study, it was found that although hope for a cure (sometimes called false hope) is prevalent in this population, hope for a good future and for living well in the time that remains is also common. The notion that patients hope to have some control surrounding the end of their life also suggests that ACP does not interfere with hope.[44]

Hope is an important component in caring for patients with advanced cancer at EOL,[11,45] and providers often cite fear of giving up hope as the principal reason for deferring ACP discussions with their patients.[13] Our data provide evidence that hope is equivalent among patients who have and have not completed 3 domains of ACP. These findings may help to reassure physicians who defer discussions about EOL wishes or surrogate decision makers or who delay introducing advance directives because of concerns about patients losing hope.

Although our data show that many variables are associated with ACP in a univariable analysis, when controlling for these variables in a multivariable analysis, they ultimately have no impact on the relationship between ACP and hope (Table 3). From the standpoint of hope, patients should be considered candidates for ACP regardless of their age, cancer type, religiosity, or clinic location. Indeed, our findings provide further support to previous research that has indicated that open and honest conversation, even at EOL, helps to maintain hope.[46,47] ACP provides patients with a locus of control that may help to maintain hope at EOL.[46,48,49]

Low rates of engagement in ACP in our study are consistent with prior literature in advanced cancer populations. In a previous study of 185 patients with advanced cancer, 70% reported that they would like to have a conversation with their physician about EOL goals and preferences, but only 11% reported engaging in these conversations.[50] Similarly, in a study of 118, only approximately half of patients with advanced cancer were found to have any formal advance directive documented in their chart.[51] These data are consistent with our finding that 20% of patients with advanced cancer reported an EOL discussion, and 51% had an advance directive.

These findings must be interpreted in the context of the following limitations. First, the patients in this study all voluntarily enrolled in a study that involved a primary palliative care intervention. At baseline, patients and providers who were amenable to receiving palliative care may have been more open to ACP because the two are intricately linked. Second, our population was 94% White and 1.3% Hispanic. This finding is representative of the homogeneity of suburban and rural western Pennsylvania, where most counties report demographics consistent with our findings.[52] We recognize that there is racial and cultural variation in attitudes toward and acceptance of ACP. Our racially and ethnically homogeneous population may limit broad generalizability. Third, because this is a cross-sectional analysis, we were unable to determine when ACP occurred, although any ACP would theoretically have been at some point before completing the baseline questionnaire. In addition, cross-sectional data allowed us to determine association but precluded us from determining causation. Finally, all ACP outcomes are patient reported. At times, providers may view a discussion they had as an EOL conversation, and patients may not have interpreted it this way or may not have recalled it. As such, the degree of engagement in ACP may be under-reported.

In conclusion, patient hope is equivalent after engaging in ACP in the form of an EOL discussion with a provider, designation of a surrogate decision maker, or completion of an advance directive. With no association between ACP and hope, providers may be able to feel more comfortable with having ACP conversations with their patients.

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST AND DATA AVAILABILITY STATEMENT

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Is Advance Care Planning Associated With Decreased Hope in Advanced Cancer?

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