

# Outcomes of Prognostic Disclosure: Associations With Prognostic Understanding, Distress, and Relationship With Physician Among Patients With Advanced Cancer

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## ABSTRACT

### Purpose

To determine how prognostic conversations influence perceptions of life expectancy (LE), distress, and the patient-physician relationship among patients with advanced cancer.

### Patients and Methods

This was a multicenter observational study of 590 patients with metastatic solid malignancies with progressive disease after  $\geq$  one line of palliative chemotherapy, undergoing follow-up to death. At baseline, patients were asked whether their oncologist had disclosed an estimate of prognosis. Patients also estimated their own LE and completed assessments of the patient-physician relationship, distress, advance directives, and end-of-life care preferences.

### Results

Among this cohort of 590 patients with advanced cancer (median survival, 5.4 months), 71% wanted to be told their LE, but only 17.6% recalled a prognostic disclosure by their physician. Among the 299 (51%) of 590 patients willing to estimate their LE, those who recalled prognostic disclosure offered more realistic estimates as compared with patients who did not (median, 12 months; interquartile range, 6 to 36 months v 48 months; interquartile range, 12 to 180 months;  $P < .001$ ), and their estimates were less likely to differ from their actual survival by  $> 2$  (30.2% v 49.2%; odds ratio [OR], 0.45; 95% CI, 0.14 to 0.82) or 5 years (9.5% v 35.5%; OR, 0.19; 95% CI, 0.08 to 0.47). In adjusted analyses, recall of prognostic disclosure was associated with a 17.2-month decrease (95% CI, 6.2 to 28.2 months) in patients' LE self-estimates. Longer LE self-estimates were associated with lower likelihood of do-not-resuscitate order (adjusted OR, 0.439; 95% CI, 0.296 to 0.630 per 12-month increase in estimate) and preference for life-prolonging over comfort-oriented care (adjusted OR, 1.493; 95% CI, 1.091 to 1.939). Prognostic disclosure was not associated with worse patient-physician relationship ratings, sadness, or anxiety in adjusted analyses.

### Conclusion

Prognostic disclosures are associated with more realistic patient expectations of LE, without decrements to their emotional well-being or the patient-physician relationship.

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## INTRODUCTION

Discussing prognosis is among the most important yet challenging conversations for oncologists and patients with advanced cancer.<sup>1</sup> A realistic sense of prognosis may help patients plan and make informed care decisions as they approach the end of life (EOL).<sup>2,3</sup> Unfortunately, patients with advanced cancer harbor substantial prognostic misconceptions.<sup>3-7</sup>

In a recent study of 1,193 patients with metastatic lung or colorectal cancer, 74% failed to understand that chemotherapy was unlikely to cure.<sup>8</sup> Not only are patients overly optimistic about chemotherapy benefits,<sup>8-11</sup> but they also dramatically over-

estimate life expectancy (LE).<sup>3,4,7,12-14</sup> Gaps in physician-patient communication may contribute to these misunderstandings.<sup>15,16</sup> Although a vast majority of oncologists tell patients if their cancer is incurable,<sup>17,18</sup> in a nationwide survey, only 43% reported usually or always discussing LE.<sup>17</sup>

Why are physicians hesitant to discuss LE?<sup>19-21</sup> First, formulating an accurate survival estimate is difficult,<sup>21-23</sup> and it is not always certain whether patients want this information.<sup>18,24</sup> Furthermore, patients look to their oncologists for hope, a role that can be at odds with discussing a grim prognosis.<sup>25,26</sup> Oncologists understandably worry about damaging patients' emotional well-being or compromising

relationships,<sup>19,27</sup> which might explain why many admit to withholding prognostic information or inflating the estimates they communicate.<sup>22</sup>

Gaps in research have left several unanswered questions about the importance of prognostic disclosures. Although most patients with advanced cancer want some general indication of prognosis (eg, if their cancer is curable),<sup>28-30</sup> it is less clear what proportion desire specific time estimates.<sup>29,31-35</sup> It is also uncertain to what extent physicians influence patients' prognostic beliefs.<sup>36,37</sup> Finally, few studies have evaluated the impact of prognostic disclosures on salient outcomes such as distress and the patient-physician relationship. Here we have quantified the proportions of patients with progressive metastatic cancer who wanted to know their LE and who reported that their physician disclosed a prognostic estimate. We also tested the hypothesis that prognostic disclosure by physicians is associated with more accurate patient perceptions of LE and more frequent advance care planning, without harm to patients' emotional well-being or the patient-physician relationship.

## PATIENTS AND METHODS

### Study Sample

Coping With Cancer was a multisite, prospective study of patients with advanced cancer, designed to investigate how psychosocial factors, including patient-physician communication, influence patients' understanding of their illness, care preferences, and EOL outcomes. Patients were enrolled between September 2002 and February 2008 from outpatient clinics of the Yale Cancer Center (New Haven, CT), Veterans' Affairs Connecticut Healthcare System Comprehensive Cancer Clinics, Memorial Sloan-Kettering Cancer Center (New York, NY), Simmons Comprehensive Cancer Care Center and Parkland Hospital Palliative Care Service (Dallas, TX), Massachusetts General Hospital and Dana-Farber Cancer Institute (Boston, MA), and New Hampshire Oncology-Hematology. Eligibility criteria were as follows: diagnosis of metastatic cancer, disease progression after  $\geq$  first-line chemotherapy, age  $>$  20 years, presence of an informal caregiver, and adequate stamina to complete the interview. Exclusion criteria included serious cognitive impairment<sup>38</sup> or inability to speak English or Spanish. Study participants provided written informed consent in accordance with the institutional review board of each participating site. Of 993 eligible patients, 726 (73%) enrolled. Sociodemographic characteristics of participants and nonparticipants did not differ, except that participants were more likely to be Hispanic (12.1% *v* 5.8%; *P* = .005). Because the survey version used at Memorial Sloan-Kettering Cancer Center omitted key prognostic questions of interest, 63 patients recruited from this site were excluded from this analysis. Our final cohort was restricted to the 590 patients with nonmissing data regarding prognostic disclosure.

### Protocol and Measures

Patients completed a baseline 45-minute interview in English or Spanish, conducted by trained interviewers. Baseline medical record review confirmed key clinical information. Patients underwent follow-up to death or until study closure (closure of last site in March 2010). For patients surviving beyond closure of their participating site, survival was determined by National Death Index search (date of last death in December 2011). We lacked requisite identifying information to conduct the National Death Index search for 99 patients, yielding complete mortality follow-up for 491 (83.2%) of the total 590 studied patients.

### Assessments

**Clinical factors.** Baseline medical record review determined cancer diagnosis and treatment. Charlson comorbidity index,<sup>39</sup> Karnofsky performance score,<sup>40</sup> and Eastern Cooperative Oncology Group performance status were confirmed by treating physicians.

**Psychosocial and demographic factors.** Patients reported race/ethnicity, age, sex, marital status, family income, health insurance status, years of education, and religious affiliation.<sup>41</sup> The Brief Religious Coping Scale by Pargament et al<sup>42</sup> was used to assess religious coping,<sup>43</sup> and the Fetzer MMRS (Multidimensional Measure of Religiousness and Spirituality) was used to assess religiousness and spirituality.<sup>44</sup> Quality of life was assessed using the McGill instrument, which includes physical health, symptom, psychological, and support subscales.<sup>45</sup>

**Prognostic disclosure, desire for prognostic information, and prognostic understanding.** Patients were asked, "Have the doctors talked with you about how much time you have left to live?" Patients responding yes were asked to indicate the estimate communicated (number of months or years). Patients' open-ended responses were recorded verbatim. Patients were also asked, "If your doctor knew how long you had left to live, would you want him or her to tell you?" To assess prognostic understanding, patients were asked to estimate their own LE. They were also asked to describe their current health status as: (1) relatively healthy, (2) relatively healthy but terminally ill, (3) seriously but not terminally ill, or (4) seriously and terminally ill. Patients who responded with (2) or (4) were considered to acknowledge their terminal illness.<sup>46</sup>

**Psychological distress and patient-physician relationship.** Sad/depressed mood and worry/anxiety were measured by the McGill psychological subscale.<sup>45</sup> The Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders IV<sup>47</sup> and Endicott scale<sup>48</sup> were used to assess mental illness. Five items assessed whether patients trusted and respected their physician, felt comfortable asking their physician questions, felt that their physician saw them as a whole person, and respected them.<sup>46,49,50</sup> A strong patient-physician relationship was considered present when all five relational attributes were endorsed, a measure previously shown to predict quality of life near death.<sup>50</sup>

**EOL care preferences and advance care planning.** At baseline, patients were asked if they had completed a do-not-resuscitate (DNR) order, living will, or health care proxy. An item from the SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) study assessed whether patients preferred EOL focused on life extension or palliative care.<sup>3</sup>

### Statistical Analyses

The Wilcoxon rank sum test compared LE self-estimates of patients reporting prior prognostic disclosure and those reporting no disclosure. Because of skewness in LE estimates, median quantile regression models<sup>51</sup> were used to estimate the effect of prognostic disclosure on patients' LE self-estimates, adjusting for confounds. Model covariates were selected from among the following variables chosen for their potential relationship to prognostic disclosure or understanding: age, race/ethnicity, sex, marital status, education, religiousness, religious coping, cancer type, performance status, McGill symptom subscale, and Charlson comorbidity index. Using a forward-selection method, covariates were entered into the models at a significance threshold of *P*  $<$  .2 and were retained in final models if significant at *P*  $<$  .05.

To explore whether prognostic disclosure was associated with more accurate patient perceptions of LE, we examined prognostic disclosures (yes *v* no) by the proportions of patients whose LE self-estimates fell within 3, 6, and 12 months of their actual survival and the proportions of patients whose self-estimates differed by  $>$  2 and 5 years of their actual survival. Multivariable linear regression was used to estimate associations between prognostic disclosure and distress (from McGill psychological subscale); logistic regression was used to estimate associations between prognostic disclosure and terminal illness acknowledgment and presence of a strong patient-physician relationship. Using a forward-selection model, all variables listed in Table 1 were entered into each model at a threshold of *P*  $<$  .2 and retained in the model if remaining significant at *P*  $<$  .05.

Finally, multivariable logistic regression models were used to analyze relationships between LE self-estimates and advance care planning as well as EOL care preferences. Because of nonnormal distribution, LE self-estimates (in months) were transformed by log base 12 for the analysis. Thus, reported odds ratios (ORs) represent the change in odds of having an outcome (eg, DNR order) for every 12-month increase in a patient's self-estimated LE.

**Table 1.** Patient Demographic and Clinical Characteristics (N = 590)

Characteristic	No. (%)		P
	Willing to Estimate LE (n = 299)	Unwilling to Estimate LE (n = 291)	
Age, years			.776
Mean	58.9	59.2	
SD	13.2	12.6	
Sex			.567
Male	155 (51.8)	144 (49.5)	
Female	144 (48.2)	147 (50.5)	
Married*	198 (67.1)	175 (60.3)	.088
Insurance†			.331
Private	128 (42.8)	90 (30.9)	
HMO	60 (20.1)	48 (16.5)	
Medicaid	27 (9.0)	42 (14.4)	
Medicare	99 (33.1)	92 (31.6)	
Medigap supplemental	14 (4.7)	16 (17.6)	
Self-pay or uninsured	9 (3.0)	10 (3.4)	
Missing	8 (2.7)	1 (0.3)	
Education, years			
Mean	13.4	12.2	
SD	3.7	4.2	
Race/ethnicity			< .001
White	234 (78.3)	183 (62.9)	
African American	35 (11.7)	53 (18.2)	
Hispanic	22 (7.3)	51 (17.5)	
Asian	6 (2.0)	4 (1.4)	
Other	2 (0.7)	0 (0.0)	
Religion			.013
Catholic	122 (40.8)	130 (44.7)	
Protestant	63 (21.1)	48 (16.5)	
Pentecostal	4 (1.3)	6 (2.1)	
Baptist	24 (8.0)	42 (14.4)	
Jewish	10 (3.3)	7 (2.4)	
Muslim	2 (0.7)	1 (0.3)	
None	26 (8.7)	8 (2.8)	
Other	48 (16.1)	49 (16.8)	
Recruitment site			< .001
Yale Cancer Center	70 (23.4)	78 (26.8)	
Veterans Affairs	12 (4.0)	8 (2.8)	
Simmons Center	31 (10.4)	13 (4.5)	
Parkland Hospital	66 (22.1)	117 (40.2)	
Dana-Farber and Massachusetts General	39 (13.0)	13 (4.5)	
New Hampshire Oncology Hematology	77 (25.8)	61 (21.0)	
Missing	4 (1.3)	1 (0.3)	
Cancer type			.331
Lung	70 (23.4)	68 (23.4)	
Colorectal	34 (11.4)	36 (12.4)	
Pancreatic/biliary	22 (7.4)	32 (11.0)	
Esophageal/gastric	16 (5.4)	18 (6.2)	
Other	151 (50.5)	135 (46.4)	
Missing	6 (2.0)	2 (0.7)	
Performance			
ECOG PS‡			.339
Mean	1.7	1.6	
SD	0.9	0.9	
Karnofsky score§			.477
Mean	67.6	66.6	
SD	16.9	17.2	

(continued on following page)

**Table 1.** Patient Demographic and Clinical Characteristics (N = 590) (continued)

Characteristic	No. (%)		P
	Willing to Estimate LE (n = 299)	Unwilling to Estimate LE (n = 291)	
Charlson comorbidity index			.071
Mean	8.0	8.4	
SD	3.5	2.7	

Abbreviations: ECOG, Eastern Cooperative Oncology Group; HMO, health maintenance organization; LE, life expectancy; PS, performance status; SD, standard deviation.  
 \*Marital status available for 858 of 590 participants.  
 †Percentages do not sum to 100% because of overlap in insurance categories.  
 ‡ECOG PS available for 579 of 590 participants.  
 §Karnofsky score available for 567 of 590 participants.  
 ||Charlson comorbidity index available for 581 of 590 participants.

Covariates were selected using a forward-selection model, as described. ORs were corrected using the method of Zhang et al<sup>52</sup> for correcting ORs in cohort studies of common outcomes. All analyses were performed using SAS software (version 9.3; SAS Institute, Cary, NC).

**RESULTS**

**Sample Characteristics**

Our cohort consisted of 590 patients, of whom 299 (51%) were willing to estimate their LE. Because several key analyses were restricted to patients with available LE self-estimates, Table 1 lists characteristics of patients willing to estimate their LE and patients unwilling to estimate their LE.

**Prognostic Disclosure by Physicians and Patients' Preferences for Prognostic Information**

Only 17.6% (104 of 590) of patients reported that their physician had previously disclosed a prognostic estimate. In this group, the median LE estimate they recalled communicated by their physician was 6 months (interquartile range [IQR], 6 to 12 months). Overall, a majority (71.0%; 419 of 590) of patients wanted to be told their LE, including 67.1% (326 of 486) of patients who reported that their physician had not disclosed prognosis.

**Prognostic Disclosure, Patients' Self-Estimates of LE, and Terminal Illness Acknowledgment**

A total of 299 patients were willing to estimate their own LE, including 66.3% (69 of 104) of patients reporting prognostic disclosure by their physician and 47.3% (230 of 486) of patients reporting no disclosure (P < .001). LE self-estimates were significantly shorter among patients reporting prognostic disclosure (median, 12 months; IQR, 6 to 36 months), as compared with those who did not (median, 48 months; IQR, 12 months to 15 years; P < .001). In analyses adjusted for age, African American race, religiousness, and performance status, a 17.2-month decrease (95% CI, -28.21 to -6.17) in the length of patients' LE self-estimates was associated with prognostic disclosure by physicians (Table 2). Patients who reported prognostic disclosure were also more likely to acknowledge that they were terminally ill (60.8% v 28.7%; adjusted OR, 3.21; 95% CI, 2.00 to 5.15), both in

**Table 2.** Associations Between Patients' Reports of Prognostic Disclosure, Characteristics, and Self-Estimates of LE (n = 299)

Predictor	Bivariable Analysis				Multivariable Analysis			
	Estimate (months)	SE	95% CI	P	Estimate (months)	SE	95% CI	P
Prognostic disclosure	-36.00	9.39	-54.47 to -17.53	< .001	-17.19	5.59	-28.21 to -6.17	.0024
Age, years	-1.29	0.45	-2.16 to -0.41	.0042	-0.73	0.35	-1.42 to -0.03	.0415
African American race	156.00	39.77	77.73 to 234.27	< .001	192.33	41.79	109.98 to 274.68	< .001
Religiousness (MMRS)*	0.60	0.20	0.20 to 1.00	.0032	0.35	0.15	0.05 to 0.65	.0243
Performance status†	-16.33	6.12	-28.38 to -4.28	.0081	-9.54	4.56	-18.52 to -0.55	.0376

NOTE. Median quantile regression were used to model these relationships because of skewness of patients' estimates of LE. Reported estimates represent absolute difference in median length of patients' LE self-estimates (months) associated with each independent variable. Therefore, negative values reflect shorter LE self-estimates, whereas positive values reflect longer LE self-estimates. Analyses restricted to 299 patients willing to estimate their LE.

Abbreviations: LE, life expectancy; MMRS, Multidimensional Measure of Religiousness and Spirituality.

\*From MMRS scale of 0 to 80, where higher scores represent increasing religiousness.

†From Eastern Cooperative Oncology Group scale of 0 to 4, where 0 indicates asymptomatic and 4 indicates bedridden.

bivariate analyses and analyses adjusted for the following confounders: African American race, performance status, and McGill symptom subscale.

**Prognostic Disclosure and Accuracy of Patients' Self-Estimates of LE**

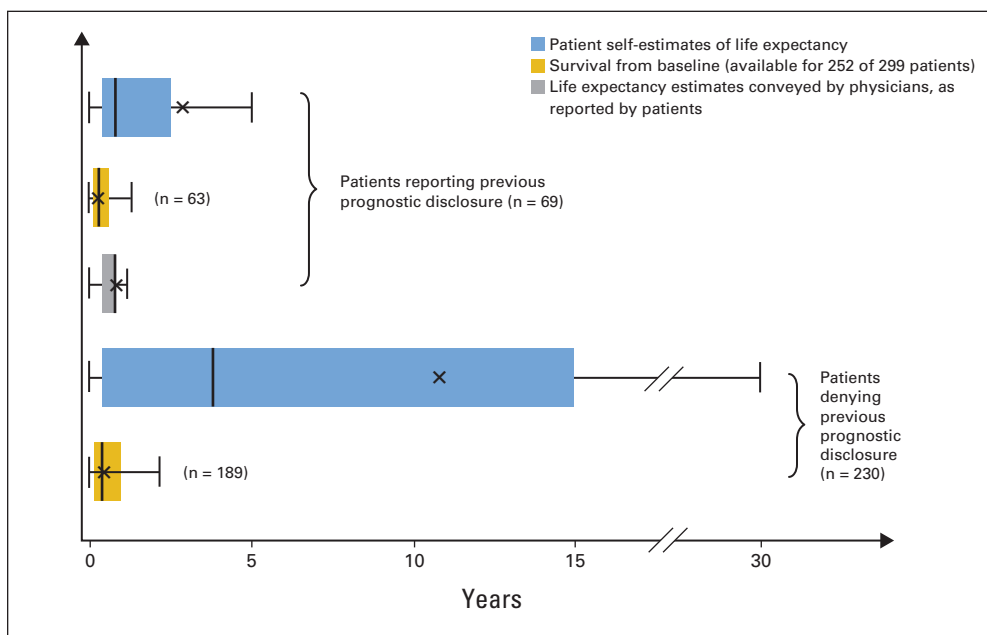
Survival data were available for 491 (83.2%) of 590 patients who lived a median of 5.4 months (IQR, 2.2 to 12.7 months) from baseline survey completion. Survival did not significantly differ between patients reporting prognostic disclosure and those who did not (median, 4.8 v 5.8 months; P = .07).

Among the 299 patients willing to estimate their LE, survival data were available for 252. Overall, 86.5% (218 of 252) overestimated their LE as compared with their actual survival. Nearly half (45.6%; 115 of 252) overestimated their LE by > 2 years, and 29% (73 of 252) overestimated their LE by > 5 years. **Figure 1** compares actual patient

survival with patients' self-estimates of LE and the prognostic estimates reportedly communicated by physicians. Physicians' prognostic estimates were relatively accurate, whereas patients were overly optimistic, most notably those reporting no prognostic disclosure. As summarized in **Table 3**, prognostic disclosure was associated with more accurate patient perceptions of LE and seemed to exert the greatest influence on reducing gross overestimates of LE.

**Prognostic Disclosure, Distress, and Patient-Physician Relationship**

Prognostic disclosure was associated with higher levels of sadness/depressed mood in bivariate analyses; however, this association became nonsignificant after adjusting for age, sex, race/ethnicity, recruitment site, cancer type, and performance status (**Table 4**). Recall of prognostic disclosure was not associated with worried/anxious mood or likelihood of meeting criteria for major depression or



**Fig 1.** Patients' self-estimates of life expectancy versus actual patient survival according to patients' recall of whether their physician disclosed prognosis (n = 299). Data are presented with Tukey box-whisper plots, where boxes represent medians and interquartile ranges (IQRs), and whiskers represent data within 1.5x IQR; X indicates mean.

**Table 3.** Prognostic Disclosure and Accuracy of Patients' Self-Estimates of LE (n = 252)

Self-Estimate	Total Cohort (n = 252)	No. (%)		OR (95% CI)
		Prognostic Disclosure		
		Yes (n = 63)	No (n = 189)	
Within ± 3 months of actual survival	28 (11.1)	10 (15.9)	18 (9.5)	1.79 (0.78 to 4.12)
Within ± 6 months of actual survival	62 (24.6)	22 (34.9)	40 (21.6)	1.99 (1.07 to 3.73)
Within ± 12 months of actual survival	97 (38.5)	32 (50.8)	65 (34.4)	1.97 (1.11 to 3.51)
Differed by > 2 years of actual survival*	117 (46.4)	19 (30.2)	98 (49.2)	0.45 (0.14 to 0.82)
Differed by > 5 years of actual survival†	73 (29.0)	6 (9.5)	67 (35.5)	0.19 (0.08 to 0.47)

NOTE. Restricted to number of patients willing to estimate LE for whom date of death was known.  
 Abbreviations: LE, life expectancy; OR, odds ratio.  
 \*Total of 115 patients overestimated their LE by > 2 years, and two patients underestimated their LE by > 2 years.  
 †All 73 patients overestimated by > 5 years.

generalized anxiety disorder in bivariate or multivariable analysis; neither were there any differences in the proportion of patients reporting a strong patient-physician relationship according to prognostic disclosure.

**Prognostic Understanding, Advance Care Planning, and EOL Care Preferences**

We hypothesized that patients who perceived themselves to have a longer LE would be less likely to complete advance directives and more likely to prefer care focused on prolonging life rather than comfort (Table 5). Multivariable models confirmed these hypotheses, revealing that for each 1-year increase in the length of a patients' LE self-estimate, the likelihood of a DNR order decreased by approximately 2.5-fold (OR, 0.406; adjusted OR, 0.439; 95% CI, 0.296 to 0.630), the likelihood of having completed a living will and/or health care proxy decreased by nearly two-fold (OR, 0.526; adjusted OR, 0.722; 95% CI, 0.539 to 0.906), and the likelihood of

preferring life-prolonging over comfort-oriented care increased by more than 1.5-fold (OR, 1.638; adjusted OR, 1.493; 95% CI, 1.091 to 1.939).

**DISCUSSION**

In this multicenter longitudinal study of 590 patients with progressive metastatic solid tumors, we found substantial discrepancies between what patients wanted to be told and what they reported being told about prognosis. Although 71% of patients wanted to be told their LE, only 17.6% reported having received a prognostic estimate from their physician. Recall of prognostic disclosure was associated with substantially more realistic and accurate perceptions of prognosis, which was in turn associated with higher rates of advance care planning and preference for comfort-oriented EOL care. Our findings suggest that more frequent prognostic discussions would be welcomed by most

**Table 4.** Associations Between Prognostic Disclosure, Distress, and Patient-Physician Relationship (N = 590)

Outcome	Unadjusted Analysis			Adjusted Analysis		
	LS Mean (SE)			LS Mean (SE)		
	Prognostic Disclosure			Prognostic Disclosure		
	Yes (n = 104)	No (n = 486)	P	Yes (n = 104)	No (n = 486)	P
Mood*						
Sad/depressed†	6.73 (0.55)	5.11 (0.25)	.008	5.50 (0.96)	4.87 (0.79)	.299
Worried/anxious‡	6.54 (0.55)	5.64 (0.25)	.136	8.11 (0.79)	7.44 (0.65)	.255
	Prognostic Disclosure			Prognostic Disclosure		
	No. (%)			No. (%)		
	Yes	No	OR (95% CI)	Yes	No	AOR (95% CI)
Major depressive disorder§	10 of 102 (9.8)	26 of 475 (5.5)	1.88 (0.88 to 4.03)	10 of 100 (10.0)	26 of 470 (5.5)	1.85 (0.83 to 4.14)
Generalized anxiety disorder	1 of 100 (1.0)	13 of 474 (2.1)	0.36 (0.05 to 2.77)	1 of 98 (1.0)	13 of 465 (2.8)	0.31 (0.04 to 2.44)
Patient-physician relationship rated strongly¶	74 of 104 (71.2)	329 of 485 (67.8)	1.18 (0.74 to 1.85)	74 of 104 (71.2)	329 of 485 (67.8)	1.20 (0.75 to 1.93)

Abbreviations: AOR, adjusted odds ratio; LS, least squares; OR, odds ratio.  
 \*Sad/depressed and worried/anxious moods assessed using psychological subscale of McGill Quality of Life Questionnaire (scale of 0 to 10, where 0 is undesirable and 10 is desirable).  
 †Adjusted for age, sex, race/ethnicity, recruitment site, cancer type, and Eastern Cooperative Oncology Group performance status.  
 ‡Adjusted for age, sex, race/ethnicity, Karnofsky score, recruitment site, and cancer type.  
 §Assessed using Endicott scale, adjusted for cancer type.  
 ||Adjusted for age and cancer type.  
 ¶Adjusted for education, race/ethnicity, and religion.

**Table 5.** Associations Between Patients' Self-Estimates of LE, EOL Care Preferences, and Advance Care Planning (n = 299)

Outcome	Self-Estimate of LE (months)	Unadjusted Analysis		Adjusted Analysis	
	Median (Q1 to Q3)	Corrected OR (95% CI)*	P	Corrected OR (95% CI)	P
Prefers life-prolonging care†		1.638 (1.241 to 2.064)	< .001	1.493 (1.091 to 1.939)	.0138
Yes (n = 71)	60.0 (12.0 to 240.0)				
No (n = 206)	24.0 (12.0 to 120.0)				
DNR order‡		0.406 (0.280 to 0.575)	< .001	0.439 (0.296 to 0.630)	< .001
Yes (n = 117)	13.0 (6.0 to 60.0)				
No (n = 174)	60.0 (15.0 to 240.0)				
Living will/health care proxy§		0.526 (0.386 to 0.686)	< .001	0.722 (0.539 to 0.906)	.0024
Yes (n = 199)	24.0 (8.0 to 60.0)				
No (n = 92)	97.0 (18.0 to 240.0)				

Abbreviations: DNR, do not resuscitate; EOL, end of life; LE, life expectancy; OR, odds ratio; Q, quartile.

\*For all analyses: because independent variable (patients' self-estimated prognosis in months) was not normally distributed, this variable was transformed by log base 12 for purposes of analysis; thus, ORs represent change in odds of outcome (eg, DNR order) for every 12-month increase in patients' self-estimated prognosis.

†ORs have been corrected using method of Zhang et al<sup>52</sup> for correcting ORs in cohort studies of common outcomes.

‡Adjusted for age, sex, and recruitment site.

§Adjusted for sex and Eastern Cooperative Oncology Group performance status.

||Adjusted for education, white race, Baptist religion, and recruitment site.

patients and could have substantial benefits without harming patients' emotional well-being or the patient-physician relationship.

It is striking that only 17.6% of patients in our study recalled prior prognostic disclosures, particularly considering that 37% of our cohort reported previously discussing their EOL care preferences.<sup>46</sup> This difference suggests that discussing one's hypothetical EOL preferences may be less threatening than discussing the timeframe of one's death, a hypothesis supported by a qualitative study from Walczak et al.<sup>53</sup> The frequency of prognostic disclosure reported here is also less than indicated in physician surveys. For example, 43% of oncologists in a nationwide survey reported usually or always discussing LE with patients with advanced cancer,<sup>17</sup> and 65% of physicians in the Cancer Care Outcomes Research and Surveillance (CanCORS) Consortium study indicated that they would discuss prognosis now, if a patient had 4 to 6 months to live.<sup>37</sup> What might explain this discrepancy? First, these two studies described physicians' general approach to prognostication, as opposed to the frequency of actual disclosure. Moreover, evidence suggests that physicians' reports of prognostication may be inflated<sup>34,54,55</sup> and that prognosis is frequently discussed in vague terms,<sup>56</sup> which could easily be missed or misinterpreted by patients. Conversely, it is likely that some patients in our study may not have recalled prognostic disclosures because of denial<sup>6</sup> or simply being overwhelmed at the time these conversations occurred. Lastly, our study would not have captured prognostic conversations occurring after the baseline assessment. Future longitudinal studies pairing audio-recorded patient-physician conversations with survey assessments will be necessary to elucidate why patients are not hearing the prognostic information that many oncologists intend to convey.

In keeping with published research,<sup>3,7,8,10,37</sup> a majority of patients in our study were remarkably optimistic about prognosis, or were unwilling to estimate it. Our findings suggest this may be driven partly by physician communication, an observation supported by a recent CanCORS analysis, in which patients were found to have much more realistic perceptions of LE when cared for by physicians describing a proactive approach to prognostication.<sup>37</sup> Our data do not imply that physicians are exclusively responsible for patients' understanding. Although expectations were much more realistic among patients who

recalled prognostic disclosures, patients' LE self-estimates still generally exceeded the estimates communicated by their physicians. We also found that patients' personal characteristics, such as race/ethnicity, religiousness, and performance status, were strongly associated with prognostic expectations—a finding substantiated by existing qualitative research.<sup>36</sup>

Prognostic disclosures were not associated with measurable harm to patients' emotional well-being or physician relationships, although we acknowledge that patients who engage in these conversations might be self-selected and therefore unlikely to experience poor consequences. In a recent study examining patients' reactions to video depictions of mock prognostic conversations, Tanco and Bruera<sup>57</sup> reported that oncologists delivering negative prognostic information were perceived to be less compassionate and trustworthy than those delivering optimistic messages. The findings of Tanco and Bruera could be interpreted as evidence that prognostication degrades trust and rapport; however, in real life, these discussions usually evolve over time and arise from longstanding relationships that cannot be replicated experimentally, yet undoubtedly shape patients' reactions. In contrast, our data are naturalistic, arising from real-world contexts and established relationships rather than experimental simulations involving actors. Our observations should therefore reassure oncologists that in everyday practice, therapeutic relationships do not seem to suffer irreparable damage from disclosure of a poor prognosis. It is of course possible that certain patients could experience harm from prognostic disclosures, particularly those who do not want LE estimates, as indicated by nearly one third of patients in our study. We would not suggest disclosing this information indiscriminately, but recommend tailoring prognostic conversations to the preferences of individual patients and caregivers.

Some may question the value of a realistic prognostic understanding. In a classic analysis from the SUPPORT study, Weeks et al<sup>3</sup> first reported that patients' perceptions of survival shape their EOL care preferences. Our study supports and extends these findings by demonstrating that patients with a realistic prognostic understanding are not only more likely to prefer comfort-oriented care, but also more likely to engage in advance care planning—an important outcome in

light of the fact that advance directives facilitate provision of EOL care consistent with patients' preferences.<sup>58</sup> Beyond these potential benefits conceived in terms of health care, a realistic sense of survival may also help patients prioritize their limited time to invest in relational, spiritual, and practical endeavors important to their vision of a good death.<sup>59</sup>

Our study has several limitations. Most importantly, prognostic disclosures were assessed by patient report, which may be subject to recall bias. Causal relationships are uncertain in this observational study, and hidden confounders may have influenced associations. Similar to other studies, many patients were unwilling or unable to estimate their prognosis, which may have biased our analysis of the impact of prognostic disclosure on patients' LE self-estimates. Nevertheless, the magnitude and strength of this association and the association between prognostic disclosure and terminal illness acknowledgment (item with few missing data) suggest a true effect. Finally, despite the age of our data (enrollment period, 2002 to 2008), there is little or no evidence to suggest that patterns of prognostic communication or patients' prognostic expectations have substantially changed in the interim.

In summary, this study suggests that patients with advanced cancer are remarkably optimistic about their LE and that physician communication has the potential to correct these misconceptions without harming patients' emotional well-being or the patient-

physician relationship. A realistic understanding of LE may benefit patients by facilitating advance care planning and helping patients adjust their goals of care toward ensuring comfort at EOL. Efforts to increase the frequency and quality of prognostic conversations might have substantial benefits on patients' prognostic understanding, advance care planning, and quality of EOL cancer care.

**AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST**

Disclosures provided by the authors are available with this article at [www.jco.org](http://www.jco.org).

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## GLOSSARY TERM

**palliative care:** care designed to address symptoms and maximize quality of life, regardless of patient prognosis.



**AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST**

**Outcomes of Prognostic Disclosure: Associations With Prognostic Understanding, Distress, and Relationship With Physician Among Patients With Advanced Cancer**

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