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# Accuracy of Advanced Cancer Patients' Life Expectancy Estimates: The Role of Race and Source of Life Expectancy Information

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BACKGROUND: The objective of this study was to examine the source of advanced cancer patients' information about their prognosis and determine whether this source of information could explain racial disparities in the accuracy of patients' life expectancy estimates (LEEs). METHODS: Coping With Cancer was a prospective, longitudinal, multisite study of terminally ill cancer patients followed until death. In structured interviews, patients reported their LEEs and the sources of these estimates (ie, medical providers, personal beliefs, religious beliefs, and other). The accuracy of LEEs was calculated through a comparison of patients' self-reported LEEs with their actual survival. RESULTS: The sample for this analysis included 229 patients: 31 black patients and 198 white patients. Only 39.30% of the patients estimated their life expectancy within 12 months of their actual survival. Black patients were more likely to have an inaccurate LEE than white patients. A minority of the sample (18.3%) reported that a medical provider was the source of their LEEs; none of the black patients (0%) based their LEEs on a medical provider. Black race remained a significant predictor of an inaccurate LEE, even after the analysis had been controlled for sociodemographic characteristics and the source of LEEs. CONCLUSIONS: The majority of advanced cancer patients have an inaccurate understanding of their life expectancy. Black patients with advanced cancer are more likely to have an inaccurate LEE than white patients. Medical providers are not the source of information for LEEs for most advanced cancer patients and especially for black patients. The source of LEEs does not explain racial differences in LEE accuracy. Additional research into the mechanisms underlying racial differences in prognostic understanding is needed. Cancer 2016;000:000-000. © 2016 The Authors. Cancer published by Wiley Periodicals, Inc. on behalf of American Cancer Society. This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

KEYWORDS: advanced cancer, end of life, illness understanding, life expectancy, racial disparities.

## INTRODUCTION

Many advanced cancer patients lack an accurate understanding of their illness and prognosis.<sup>1,2</sup> Advanced cancer patients tend to underestimate the severity of their diagnosis,<sup>3,4</sup> view their prognosis in overly positive and unrealistic terms,<sup>5-7</sup> and inaccurately believe that the goal of treatment is to cure their cancer.<sup>4,8</sup> In recent studies of advanced cancer patients, fewer than 20% had an accurate understanding of their prognosis.<sup>7,9,10</sup>

These misunderstandings are related to patients' treatment decisions. Advanced cancer patients who do not recognize that their illness is terminal are more likely to prefer<sup>11,12</sup> and receive aggressive care at the end of life (EOL).<sup>5,6</sup> They are also less likely to discuss EOL care with their physicians,<sup>13</sup> complete advance directives,<sup>7,13</sup> receive care consistent with their preferences,<sup>12</sup> and receive hospice services.<sup>11</sup> Patients' estimates of their life expectancy are also related to their treatment preferences. Advanced cancer patients who believe that they have at least a 90% chance of living 6 months or more prefer life-extending care over palliative care at higher rates than patients with more realistic prognostic estimates (<90% chance of living 6 months).<sup>5</sup>

Inaccurate illness understanding is particularly prevalent and problematic among black cancer patients. Despite similar rates of EOL care discussions with providers,<sup>14</sup> black patients are less likely to understand their illness and prognosis than white patients.<sup>15</sup> In addition, black patients are less likely to complete advance directives<sup>14-17</sup> and receive hospice care<sup>17,18</sup> and are more likely to receive aggressive EOL care<sup>14,18,19</sup> and care inconsistent with their preferences<sup>14</sup> than white patients.

Identifying factors that explain patients' understanding of their illness may identify ways to reduce racial disparities in advance care planning and EOL care. Numerous factors, including religious beliefs,<sup>17</sup> care settings (rural vs urban),<sup>18</sup>

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DOI: 10.1002/cncr.30001, Received: January 5, 2016; Revised: February 18, 2016; Accepted: March 8, 2016, Published online Month 00, 2016 in Wiley Online Library (wileyonlinelibrary.com)

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socioeconomic status,<sup>18,20</sup> and the effectiveness of EOL care discussions, may contribute to black/white disparities in illness and prognostic understanding.<sup>14</sup> However, the results of prior research are mixed.<sup>11,15,20</sup> One unexamined factor that may explain cancer patients' misunderstanding of their prognosis and racial differences in this understanding is the patients' source of information on their prognosis. The purpose of this study was to examine the source of advanced cancer patients' information on their prognosis and to determine whether the source of this prognostic information explains racial disparities in patients' understanding of their prognosis.

## MATERIALS AND METHODS

## Participants and Procedures

Coping With Cancer is a National Cancer Institute- and National Institute of Mental Health-funded prospective, longitudinal, multisite study of terminally ill cancer patients and their informal caregivers. Patients were recruited from September 1, 2002 to February 28, 2008. Patients in the current sample were recruited from outpatient clinics at the Yale Cancer Center (New Haven, Conn), the Veterans Affairs Connecticut Healthcare System Comprehensive Cancer Clinics (West Haven, Conn), the Simmons Comprehensive Cancer Center (Dallas, Texas), the Parkland Hospital Palliative Care Service (Dallas, Texas), the Dana-Farber Cancer Institute (Boston, Mass), Massachusetts General Hospital (Boston, Mass), and New Hampshire Oncology-Hematology (NHOH). Approval was obtained from the human subjects committees of all participating centers; all enrolled patients provided written consent and received \$25 for their participation.

The eligibility criteria included a diagnosis of metastatic cancer, disease progression after first-line or later chemotherapy, a life expectancy of 6 months or less as determined by a member of the patient's health care team, a patient age of 21 years or older, adequate stamina to complete study procedures, the presence of an informal caregiver, the absence of significant cognitive impairment in the patient and caregiver,<sup>21</sup> and English or Spanish proficiency.

Trained research staff conducted a structured interview in English or Spanish with each patient at study entry. Each interview lasted approximately 45 minutes. Patients were followed until death or the study's closure in March 2010. For patients surviving beyond the closure of their participating site, the date of death was obtained from the National Death Index (the last death occurred in December 2011). We lacked the necessary information to conduct a National Death Index search for 99 patients; these patients were excluded from these analyses.

Of the 993 eligible patients, 726 (73.1%) completed the study measures. The most common reasons for nonparticipation were a lack of interest (n = 109), caregiver refused (n = 33), and being too upset (n = 23). There were no differences between participants and nonparticipants except that participants were more likely to be Hispanic (12.1% vs 5.8%, P = .005). However, for the current analysis, only patients who identified as non-Hispanic black or white were included.

## Measures

## Demographic and disease characteristics

Self-reported demographic characteristics included age, education, sex, race, marital status, religious affiliation, and insurance status. Each patient's cancer diagnosis was obtained from a medical record review at the baseline. The Charlson comorbidity index, the Karnofsky performance status, and the Eastern Cooperative Oncology Group performance status were obtained by trained research staff using a coding process that was applied uniformly across all patients.

# Self-reported life expectancy estimate (LEE) and LEE source

The self-reported LEE was assessed with a single item: "How long do you think you have left to live?" Patients provided their responses in months and years. Participants were then asked to indicate the source of their LEEs. Response options included the following: oncologist, other clinic staff, palliative care physician, patient's personal belief, patient's religious belief, and other. The oncologist, other clinic staff, and palliative care physician response options were grouped into the single category of medical provider.

#### Accuracy of LEEs

The accuracy of patients' LEEs was calculated through a comparison of patients' self-reported LEEs with their actual survival times. Each patient's actual survival time was based on the date of death. For patients who died within the study observation period, the date of death was collected from patients' medical records. For patients who survived the study observation period, the date of death was obtained from the National Death Index. The accuracy of patients' LEEs was assessed with 5 indicators: 1) the proportion of patients (yes vs no) whose LEEs fell within 3 months of their actual survival, 2) the proportion of patients (yes vs no) whose LEEs fell within 6 months of their actual survival, 3) the proportion of patients (yes vs

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no) whose LEEs fell within 12 months of their actual survival, 4) the proportion of patients (yes vs no) whose LEEs differed by greater than 2 years from their actual survival, and 5) the proportion of patients (yes vs no) whose LEEs differed by greater than 5 years from their actual survival

## Statistical Analysis

The relations between race and patient demographic and disease characteristics were examined with the chi-square test or Fisher's exact test for binary characteristics and with the t test or Wilcoxon/Kruskal-Wallis test for continuous characteristics. The relations between race and the accuracy of patients' LEEs and source of LEEs were examined with logistic regression analyses and Fisher's exact test. Finally, univariate and multivariate logistic regression analyses were used to examine the relation between race and the accuracy of patients' LEEs; we controlled for patient demographic and disease characteristics and the source of LEEs. With a forward selection model, demographic and disease characteristics significantly associated with race were entered into the models at a significance threshold of P < .2, and they were retained in the final models if they were significant at P < .05. All analyses were conducted with SAS software (version 9.3; SAS Institute, Cary, NC).

## RESULTS

## Sample Characteristics

The final sample consisted of 229 patients: 198 white patients (86.5%) and 31 black patients (13.5%). The sample was 55% male with an average age of 60.1 years (standard deviation, 12.4 y). White patients were older (P = .03) with higher education levels (P < .001) and were more likely to be married (P = .03) and insured (P < .01). Black patients were less likely to be Catholic (P < .001) and more likely to be Pentecostal (P = .02) and Baptist (P = .004) than white patients. Black patients were also less likely to be recruited from the Simmons Comprehensive Cancer Center (P = .03), the Dana-Farber Cancer Institute or Massachusetts General Hospital (P = .01), and NHOH (P < .01) and were more likely to be recruited from the simmons (P = .01), and NHOH (P < .01) and were more likely to be recruited from the simmons the patients (Table 1).

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## Race and Accuracy of LEEs

Only 11.79% of the sample patients accurately estimated their life expectancy within 3 months of their actual survival (Table 2). Approximately one-quarter of the sample (25.33%) accurately estimated life expectancy within 6 months of survival, and 39.30% accurately estimated it within 12 months of survival. Furthermore, the LEEs of

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43.67% of the sample differed from actual survival by more than 2 years, and the LEEs of 27.95% differed by more than 5 years.

White patients were more likely to accurately estimate their survival within 12 months of their actual survival than black patients (Table 2; odds ratio [OR], 5.18; 95% confidence interval [CI], 1.75, 15.37; P = .003). The LEEs of white patients were also less likely to differ from their actual survival by 2 (OR, 0.18; 95% CI, 0.08-0.44; P < .001) and 5 years (OR, 0.16; 95% CI, 0.07-0.35; P < .001) than the LEEs of black patients. Only 12.90% of black patients' LEEs were within 12 months of their actual survival, 77.42% differed from their actual survival by at least 2 years, and 64.52% differed by at least 5 years. Racial differences in LEE accuracy within 3 and 6 months of actual survival were not significant (P > .05).

## Race and Source of LEEs

Less than one-fifth of the total sample (18.3%) reported that a medical provider was the source of their LEEs. The majority of the sample (70.7%) reported that they based their LEEs on personal beliefs; 6.6% based their LEEs on their religious beliefs. White patients were more likely to base their LEEs on a medical provider than black patients (P < .001; Table 3 and Figs. 1 and 2). Notably, none of the black patients (0%) reported that a medical provider was the source of their LEEs. Black patients were more likely to base their LEEs on their religious beliefs than white patients (OR, 0.04; 95% CI, 0.01-0.13; P < .001).

## *Race and Source of LEEs in Predicting LEE Accuracy*

Race and the source of LEEs were not significantly associated with LEEs within 3 and 6 months of actual survival in bivariate analyses (P > .05). Additional analyses predicting these indicators of LEE accuracy were not conducted. In univariate analyses predicting the LEE within 12 months of actual survival (Table 4), patients who reported that their medical provider was the source of their LEEs were almost 2.5 times more likely to have an accurate LEE than patients who did not rely on a medical provider (OR, 2.44; 95% CI, 1.24-4.83; P = .01). In multivariate analyses predicting LEEs within 12 months of actual survival, patients who were white (OR, 3.54; 95% CI, 1.13-11.07; P = .03), were not married (OR, 0.52; 95% CI, 0.28-0.98; P = .04), and were recruited from NHOH (OR, 4.71; 95% CI, 2.48-8.94; P < .001) were more likely to have an accurate LEE. The source of LEEs was not associated with LEE accuracy in multivariate analyses.

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	All Subjects	Whites (n = $198$	Blacks (n = $31$		
Characteristic	(n = 229)	or 86.5%)	or 13.5%)	Р	
Age, mean ± SD, y (No.)	60.1 ± 12.4 (229)	60.8 ± 12.4 (198)	55.7 ± 11.7 (31)	.03	
Sex, No. (%)				.33	
Male	126/229 (55.0)	106 (53.5)	20 (64.5)		
Female	103/229 (45.0)	92 (46.5)	11 (35.5)		
Married, No. (%)	147/227 (64.8)	133 (67.9)	14 (45.2)	.03	
Insured, No. (%)	176/224 (78.6)	167 (86.1)	9 (30.0)	<.001	
Education, mean $\pm$ SD, y (No.)	13.6 ± 3.3 (229)	13.9 ± 3.2 (198)	11.2 ± 3.2 (31)	<.001	
Race, No. (%)					
White	198/229 (86.5)				
Black	31/229 (13.5)				
Religion, No. (%) <sup>a</sup>					
Catholic	89/229 (38.9)	86 (43.4)	3 (9.7)	<.001	
Protestant	50/229 (21.8)	44 (22.2)	6 (19.4)	.82	
Jewish	10/229 (4.4)	10 (5.1)	0 (0.0)	.37	
Muslim	1/229 (0.4)	0 (0.0)	1 (3.2)	.14	
No religion	17/229 (7.4)	16 (8.1)	1 (3.2)	.48	
Pentecostal	2/229 (0.9)	0 (0.0)	2 (6.5)	.02	
Baptist	22/229 (9.6)	14 (7.1)	8 (25.8)	.004	
Recruitment site, No. (%) <sup>b</sup>					
Yale Cancer Center	44/228 (19.3)	38 (19.3)	6 (19.4)	1.000	
Veterans Affairs Connecticut Healthcare System	11/228 (4.8)	10 (5.1)	1 (3.2)	1.000	
Simmons Comprehensive Cancer Center	25/228 (11.0)	25 (12.7)	0 (0.0)	.03	
Parkland Hospital	46/228 (20.2)	22 (11.2)	24 (77.4)	<.001	
DFCI/MGH	32/228 (14.0)	32 (16.2)	0 (0.0)	.01	
NHOH	69/228 (30.3)	69 (35.0)	0 (0.0)	<.001	
Cancer type, No. (%)				.214	
Lung	59/225 (26.2)	48 (24.6)	11 (36.7)	.183	
Pancreatic	17/225 (7.6)	16 (8.2)	1 (3.3)	.708	
Colon	26/225 (11.6)	21 (10.8)	5 (16.7)	.358	
Brain	7/225 (3.1)	7 (3.6)	0 (0.0)	.598	
Stomach	2/225 (0.9)	1 (0.5)	1 (3.3)	.249	
Esophageal	11/225 (4.9)	11 (5.6)	0 (0.0)	.367	
Performance status, mean $\pm$ SD (No.)					
Karnofsky score	67.3 ± 17.0 (220)	66.9 ± 17.5	69.7 ± 13.8	.415	
Zubrod score	1.7 ± 0.9 (222)	$1.7 \pm 0.9$	$1.6 \pm 0.8$	.504	
Charlson index	8.3 ± 3.7 (225)	$8.5 \pm 3.9$	$7.5 \pm 2.2$	.061	

## **TABLE 1.** Patient Demographic and Baseline Characteristics

Abbreviations: DFCI, Dana-Farber Cancer Institute; MGH, Massachusetts General Hospital; NHOH, New Hampshire Oncology-Hematology; SD, standard deviation. The percentages listed for Whites and Blacks are based on the total number of Whites and Blacks, respectively.

<sup>a</sup>38 subjects had other religion, not specified

<sup>b</sup>1 subject recruited from site "other", not specified.

Patients whose LEEs were based on a medical provider were more than 2 times less likely to report an LEE that differed by 2 years from actual survival than patients who did not rely on a medical provider in bivariate analyses (OR, 0.45; 95% CI, 0.22-0.93; P =.03; data not shown). In multivariate analyses predicting LEEs that differed by 2 years from actual survival, black race (OR, 0.27; 95% CI, 0.11-0.68; P < .01) and personal belief as the sources of the LEE (OR, 2.42; 95% CI, 1.25-4.70; P < .01) were associated with a greater likelihood of an inaccurate LEE. Patients recruited at NHOH were also less likely to report an inaccurate LEE in multivariate analyses (OR, 0.16; 95% CI, 0.08-0.35; P < .001),

In univariate analyses, patients who based their LEEs on a medical provider were more than 3 times more

likely to have an accurate LEE than patients who did not rely on a medical provider (OR, 0.29; 95% CI, 0.11-0.78; P = .02; data not shown). Basing the LEE on religious beliefs was associated with a more than 4 times greater likelihood of an LEE that differed by 5 years from actual survival (OR, 4.34; 95% CI, 1.48-12.74; P = .01). In multivariate analyses, recruitment at the Dana-Farber Cancer Institute/Massachusetts General Hospital (OR, 0.33; 95% CI, 0.11-0.94; P < .05) and NHOH (OR, 0.10; 95% CI, 0.03-0.29; P < .001) were associated with a lower likelihood of an inaccurate LEE. In addition, black race (OR, 0.39; 95% CI, 0.17-0.94; P < .05) was associated with a greater likelihood of an LEE greater than actual survival by 5 years. Patients who based their LEEs on a medical provider were more likely to have an accurate LEE (OR, 0.32; 95% CI, 0.11-0.91; *P* < .05).

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# **TABLE 2.** Relation Between Race (Black/White) and the Accuracy of Patients' Self-Estimates of Life Expectancy (n = 229)

LEE Accuracy <sup>a</sup>	Total Sample, No. (%)	White (n = 198)	Black (n = 31)	OR (95% CI) <sup>b</sup>	Р
Within ± 3 mo of actual survival	27 (11.79)	25 (12.63)	2 (6.45)	2.10 (0.47-9.33)	.33
Within $\pm$ 6 mo of actual survival	58 (25.33)	54 (27.27)	4 (12.90)	2.53 (0.85-7.57)	.10
Within $\pm$ 12 mo of actual survival	90 (39.30)	86 (43.43)	4 (12.90)	5.18 (1.75–15.37)	.003
Differed by >2 y from actual survival <sup>c</sup>	100 (43.67)	76 (38.38)	24 (77.42)	0.18 (0.08-0.44)	<.001
Differed by $>5$ y from actual survival <sup>d</sup>	64 (27.95)	44 (22.22)	20 (64.52)	0.16 (0.07–0.35)	<.001

Abbreviations; CI, confidence interval; LEE, life expectancy estimate; OR, odds ratio.

<sup>a</sup> Patients with LEEs within 3 months of their actual survival are included in the proportion of patients with LEEs within 6 and 12 months of their actual survival; patients with LEEs within 6 months of their actual survival are included in the proportion of patients with LEEs within 12 months of their actual survival. Patients whose LEEs differed from their actual survival by 5 years are included in the proportion of patients whose LEEs differed by 2 years.

<sup>b</sup>White, 1; black, 0.

<sup>c</sup> Ninety-seven patients overestimated their life expectancy by more than 2 years, and 3 patients underestimated their life expectancy by more than 2 years. <sup>d</sup> All 64 patients overestimated their life expectancy by more than 5 years.

**TABLE 3.** Relation Between Race and the Source of Life Expectancy Estimates (n = 229)

Source of Life Expectancy Estimates	Total Sample, No. (%)	Race, No. (%)		Logistic Regression Analysis		
		White	Black	OR (95% CI)	Р	Fisher's Exact A
Medical provider	42 (18.3)	42 (21.2)	0 (0.0)	a	_	<.001
Patient belief	162 (70.7)	142 (71.7)	20 (64.5)	1.40 (0.63-3.10)	.4138	<.001
Religious belief	15 (6.6)	4 (2.0)	11 (35.5)	0.04 (0.01-0.13)	<.001	<.001
Other	10 (4.4)	10 (5.1)	0 (0.0)			
Total	229	198 (86.5)	31 (13.5)			

Abbreviations: CI, confidence interval; OR, odds ratio.

<sup>a</sup> The OR could not be estimated because of the sparseness of the data.



Figure 1. Sources of life expectancy estimates for white patients (n = 198).



**Figure 2.** Sources of life expectancy estimates for black patients (n = 31).

### DISCUSSION

C O L O R

> This study examined the source of black and white advanced cancer patients' information on their life expectancy and the relation between race and the source and accuracy of patients' LEEs. The majority of the sample reported inaccurate LEEs, and black patients were more likely to have inaccurate LEEs than white patients. Less

than one-fifth of the patients reported basing their LEEs on information from a medical provider. Black patients were less likely to base their LEEs on medical providers than white patients. In fact, no black patients reported basing their LEEs on information from medical providers. In univariate analyses, basing the LEE on a medical provider was associated with a more accurate LEE, whereas C 0 L 0

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**TABLE 4.** Analysis of Race and LEE Source for Predicting the Accuracy of a Patient's LEE Within 12 Months of Actual Survival (n = 229)

Sample Characteristic	LEE Within 12 mo of Actual Survival		Univariate Regression <sup>a</sup>		Multivariate Regression <sup>a</sup>	
	Yes (n = 90 or 39.3%)	No (n = 139 or 60.7%)	OR (95% CI)	Р	OR (95% CI)	Ρ
White, No. (%)	86/90 (95.6)	112/139 (80.6)	5.18 (1.75–15.37)	.003	3.54 (1.13–11.07)	.03
Age, mean ± SD, y	$63.2 \pm 12.3$	58.1 ± 12.1	1.04 (1.01-1.06)	.003		
Married, No. (%)	52/88 (59.1)	95/139 (68.3)	0.67 (0.38-1.17)	.16	0.52 (0.28-0.98)	.04
Insured, No. (%)	73/87 (83.9)	103/137 (75.2)	1.72 (0.86-3.43)	.12		
Education, mean $\pm$ SD, y	$13.6 \pm 3.2$	$13.5 \pm 3.4$	1.00 (0.92-1.09)	.96		
Catholic, No. (%)	46/90 (51.1)	43/139 (30.9)	2.33 (1.35-4.04)	.002		
Muslim, No. (%)	0/90 (0.0)	1/139 (0.7)	0.00 (0.00-1)	.99		
Pentecostal, No. (%)	2/90 (2.2)	0/139 (0.0)	0.00 (0.00-1)	.99		
Baptist, No. (%)	5/90 (5.6)	17/139 (12.2)	0.42 (0.15-1.19)	.10		
Study site, No. (%)						
Simmons Center	4/90 (4.4)	21/138 (15.2)	0.26 (0.09-0.78)	.02		
Parkland Hospital	13/90 (14.4)	33/138 (23.9)	0.54 (0.27-1.09)	.09		
DFCI/MGH	10/90 (11.1)	22/138 (15.9)	0.66 (0.30-1.47)	.31		
NHOH	47/90 (52.2)	22/138 (15.9)	5.76 (3.11–10.66)	<.001	4.71 (2.48-8.94)	<.001
Lung cancer	27/89 (30.3)	32/136 (23.5)	1.42 (0.78-2.58)	.26		
Charlson index, mean $\pm$ SD	9.0 ± 3.0	7.9 ± 4.1	1.09 (1.00-1.20)	.06		
LEE source						
Medical provider	24/90 (26.7)	18/139 (12.9)	2.44 (1.24-4.83)	.01		
Personal belief	60/90 (66.7)	102/139 (73.4)	0.73 (0.41-1.29)	.28		
Religious belief	3/90 (3.3)	12/139 (8.6)	0.36 (0.10–1.33)	.13		

Abbreviations: CI, confidence interval; DFCI, Dana-Farber Cancer Institute; LEE, life expectancy estimate; MGH, Massachusetts General Hospital; NHOH, New Hampshire Oncology-Hematology; OR, odds ratio; SD, standard deviation.

<sup>a</sup> Accurate within 12 months (no, 0; yes, 1), marital status (other, 0; married, 1), insured (no, 0; yes, 1), white (no, 0; yes, 1), religious affiliations (no, 0; yes, 1), study sites (no, 0; yes, 1), lung cancer (no, 0; yes, 1), and LEE source (no, 0; yes, 1).

basing the LEE on religious beliefs was associated with a less accurate LEE. However, racial differences in LEE accuracy remained after we had controlled for the source of LEEs. Black race was associated with a greater likelihood of an inaccurate LEE after we had controlled for sociodemographic and disease characteristics and the source of LEEs.

The small proportion of patients who reported basing their LEEs on information from their medical providers is concerning. An advanced cancer patient's life expectancy is determined primarily by the characteristics of the patient's disease and treatment response,<sup>22,23</sup> and this is the expertise of the medical team. However, patients are not basing their LEEs on the source most able to provide accurate information. This pattern may explain research indicating that advanced cancer patients frequently do not understand the terminal nature of their illness.<sup>5,6,9,11,15</sup> These findings are problematic in light of evidence that patients who overestimate their prognosis are less prepared for EOL and prefer and receive more aggressive EOL care,<sup>5,11</sup> which has been associated with greater distress and worse quality of life and death for patients and worse bereaved caregiver adjustment.<sup>24,25</sup>

Rather than relying on their medical providers, the majority of both black and white patients in this study reported basing their LEEs on their personal beliefs. *Religious beliefs* was an alternative response option for this item; therefore, we can assume that these personal beliefs are not religious in nature. Outside this, however, the characteristics, content, and source of these beliefs are unclear. Additional research is needed to understand the nature of these beliefs.

Racial differences in the source of prognostic information were striking. Notably, none of the black patients reported basing their LEEs on information from medical providers. This finding is concerning in light of evidence that minority cancer patients are more likely to receive aggressive care at the EOL than white patients<sup>19</sup> and are less likely to receive EOL care consistent with their stated preferences.<sup>14,19</sup> Black cancer patients have less trust in the health care system and medical providers than white patients.<sup>26,27</sup> This mistrust may explain black patients' tendency to rely on other sources of information for their LEEs to a greater degree than white patients. Furthermore, the majority of oncologists are white<sup>28</sup> and do not share the cultural and educational background of their black patients; this may affect communication<sup>29</sup> and reduce patients' willingness to rely on the information provided by their medical providers.

Black patients were also more likely to base their LEEs on their religious beliefs than white patients. Across studies, racial minorities endorse higher levels of religiosity and greater use of religion to cope.<sup>27</sup> This study adds

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to this body of work by suggesting that black patients also rely on their religious beliefs to explain specific aspects of their cancer. Integrating black patients' religious beliefs into patient-provider discussions of prognosis may be a culturally sensitive strategy for improving patients' understanding of prognostic information.

After we had controlled for sociodemographic characteristics and the source of LEEs, race remained a significant, albeit slightly weaker, predictor of LEE accuracy. Black patients were 2 to 3 times less likely to have an accurate LEE than white patients in adjusted analyses. These findings indicate that the source of LEEs is important but does not completely explain racial differences in prognostic understanding. Racial categories place a single label on complex cultural beliefs and values that vary across and within racial groups. Because of this complexity, it is not surprising that single indicators such as the source of LEEs do not account for racial differences in prognostic understanding. However, the source of LEEs may be one factor that contributes to racial differences in prognostic understanding. Furthermore, the relation between the source and accuracy of LEEs in this study suggests that the source of LEEs is an important factor to consider when we are attempting to improve patients' understanding of their illness.

This study is limited by the small sample of black patients and a cross-sectional design that does not allow for an examination of changes in patients' LEEs over time. In addition, these results cannot be generalized to patients with diseases other than advanced cancer and patients of other racial and ethnic backgrounds. Research on patients with other terminal illnesses and patients from different racial and ethnic backgrounds such as Hispanic and Asian Americans will provide insight into strategies for tailoring prognostic discussions to meet the unique needs of a greater range of diverse patient populations. Furthermore, because of the small number of patients who reported basing their LEEs on palliative care physicians and other clinic staff, we were unable to examine differences in LEE accuracy across different medical providers. Future research that examines differences in LEE accuracy across providers will provide insight into the most effective source of this information for black and white advanced cancer patients. Finally, the majority of the sample patients overestimated their life expectancy. As a result, we were unable to examine differences between patients who overestimated their life expectancy and patients who underestimated their life expectancy. Overestimation of life expectancy likely has different implications for patients' psychosocial well-being, advance care planning, and treatment decisions than underestimation. Understanding predictors of overestimation versus underestimation, including racial and ethnic differences, will provide a more detailed understanding of various ways in which patients misunderstand their illness, help to identify patients at risk for overestimation and underestimation, and inform interventions to correct unique types of illness misunderstanding. Despite these limitations, this study points to the need for culturally sensitive communication training programs for medical providers that consider patients' religious and personal beliefs. However, it is important to note that the source of patients' LEEs did not explain racial differences in the accuracy of LEEs.

Ongoing research is needed to understand the mechanisms underlying racial differences in patients' understanding of their illness. Important factors to explore include the timing, source, and content of discussions of a patient's prognosis and how black and white patients understand and use this information to make treatment decisions. In addition, explication of the nature of patients' religious and personal beliefs related to prognostic understanding will allow providers to integrate these beliefs into prognostic discussions. Because of the personal and potentially individualized nature of these beliefs, mixed methods research designs that provide both indepth and aggregate views of these factors will be important. These findings will inform targeted interventions to improve all patients' illness understanding and to reduce racial disparities in illness understanding.

## FUNDING SUPPORT

This research was supported in part by the following grants: MH63892 (to Holly G. Prigerson) from the National Institute of Mental Health, CA106370 (to Holly G. Prigerson) and CA197730–NCI R35 (to Holly G. Prigerson) from the National Cancer Institute, MD007652 (to Paul K. Maciejewski and Holly G. Prigerson) from the National Institute on Minority Heath and Health Disparities, and K23AG048632 (to Kelly M. Trevino) from the National Institute on Aging and American Federation for Aging Research.

#### CONFLICT OF INTEREST DISCLOSURES

The authors made no disclosures.

#### AUTHOR CONTRIBUTIONS

Kelly M. Trevino: Conception and design, financial support, data analysis and interpretation, manuscript writing, and final approval of the manuscript. **Baohui Zhang:** Conception and design, collection and assembly of data, data analysis and interpretation, manuscript writing, and final approval of the manuscript. **Megan J. Shen:** Conception and design, data analysis and interpretation, manuscript writing, and final approval of the manuscript. **Holly G.** 

## <u>Original Article</u>

**Prigerson:** Conception and design, financial support, administrative support, provision of study materials or patients, collection and assembly of data, data analysis and interpretation, manuscript writing, and final approval of the manuscript.

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# Accuracy of Advanced Cancer Patients' Life Expectancy Estimates: The Role of Race and Source of Life Expectancy Information

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The majority of advanced cancer patients have an inaccurate understanding of their life expectancy and do not rely on medical providers for information on life expectancy. Black patients are less likely than white patients to have an accurate understanding of their life expectancy and to rely on their medical providers for information on life expectancy.