

# Association Between Advanced Cancer Patient-Caregiver Agreement Regarding Prognosis and Hospice Enrollment

Kelly M. Trevino, PhD<sup>1</sup>; Holly G. Prigerson, PhD<sup>2,7</sup>; Megan Johnson Shen, PhD<sup>2,7</sup>; Daniel J. Tancredi, PhD<sup>3</sup>; Guibo Xing, PhD<sup>3</sup>; Michael Hoerger, PhD, MSCR<sup>4</sup>; Ronald M. Epstein, MD<sup>5</sup>; and Paul R. Duberstein, PhD<sup>5,6</sup>

**BACKGROUND:** Patients with advanced, incurable cancer who understand their illness is incurable are more likely to prefer hospice care at the end of life compared with patients who believe their illness is curable. To the authors' knowledge, it is unclear whether patient-caregiver agreement regarding perceived prognosis is associated with hospice enrollment. **METHODS:** The current study examined the prospective relationship between patient-caregiver agreement concerning perceived prognosis and hospice enrollment in the last 30 days of life. Data were collected during a cluster randomized controlled trial examining a communication intervention for oncologists and patients with advanced cancer and their caregivers. At the time of study entry, patients and caregivers (141 dyads) were categorized as endorsing a "good" prognosis if they: 1) reported a >50% chance of surviving  $\geq 2$  years; or if they 2) predicted that the patient's quality of life 3 months into the future would be  $\geq 7$  on an 11-point scale. **RESULTS:** Approximately one-fifth of dyads agreed on a poor prognosis whereas approximately one-half disagreed regarding prognosis. In approximately one-third of dyads, patients and caregivers both believed the patient's future quality of life would be good (34%) and that the patient would live for  $\geq 2$  years (30%). Patients in these dyads were less likely to enroll in hospice compared with patients in dyads who disagreed and those who agreed on a shorter life expectancy and poor future quality of life. **CONCLUSIONS:** Dyadic understanding of patients' projected life expectancy and future quality of life appears to be predictive of care received at the end of life. Improving rates of hospice enrollment may be best achieved with dyadic interventions. *Cancer* 2019;125:3259-3265. © 2019 American Cancer Society.

**KEYWORDS:** cancer, caregiving, hospice, oncology, prognosis.

## INTRODUCTION

Hospice is considered the quality standard of care for patients with advanced terminal illness who have an expected prognosis of  $\leq 6$  months.<sup>1</sup> Patients with cancer who receive hospice care have reported reductions in pain intensity,<sup>2</sup> symptom burden,<sup>3</sup> and distress<sup>3</sup> and receive less burdensome aggressive care compared with patients not enrolled in hospice care.<sup>4,5</sup> Personal (ie, informal, unpaid) caregivers of patients who receive hospice care are more likely to report that the patient received high-quality care<sup>6</sup> and that the patient had a good death compared with caregivers of patients who do not receive hospice care.<sup>7,8</sup> Furthermore, caregivers of patients who receive hospice care have a lower risk of death in the 18 months after the patient's death than caregivers of patients who do not receive hospice care.<sup>9</sup> Caregivers of patients with cancer who die in hospice also report less severe depressive symptoms and grief after the patient's death.<sup>8</sup>

Understanding the factors that predict hospice enrollment is vital to ensuring that patients who would benefit from hospice receive this care; an understanding of the course of their illness among patients with cancer is one such factor. Patients with advanced cancer who understand their illness is terminal are more likely to prefer comfort care over aggressive care<sup>10,11</sup> and die in their preferred place of death (home).<sup>12</sup> These patients also are less likely to receive aggressive care at the end of life (EOL).<sup>13,14</sup> Regarding hospice in particular, patients with advanced cancer who describe their illness as incurable are more likely to prefer hospice care.<sup>15</sup> Furthermore, patients with advanced cancer who are enrolled in hospice care are more likely to describe their disease as incurable compared with patients not enrolled.<sup>16</sup> However, these findings are limited by a primary focus on a hypothetical preference for hospice care rather than actual hospice enrollment and retrospective analysis of prognostic understanding in patients already enrolled in hospice.

The curability and life expectancy of a patient with advanced cancer is not the only prognostic consideration in decision making regarding EOL care. As cancer treatments improve and patients are able to live longer with advanced cancer, the quality of patients' lives becomes increasingly important to consider.<sup>1,17</sup> Indeed, approximately 50% of patients with advanced cancer report that quality and length of life are equally important.<sup>18</sup> In one study, up to

**Corresponding author:** Kelly M. Trevino, PhD, Memorial Sloan Kettering Cancer Center, 641 Lexington Ave, New York, NY 10022; trevinok@mskcc.org

<sup>1</sup>Department of Psychiatry and Behavioral Sciences, Memorial Sloan Kettering Cancer Center, New York, New York; <sup>2</sup>Department of Medicine, Weill Cornell Medicine, New York, New York; <sup>3</sup>Department of Pediatrics, University of California at Davis, Davis, California; <sup>4</sup>Department of Psychology, Tulane University, New Orleans, Louisiana; <sup>5</sup>Department of Family Medicine, University of Rochester Medical Center, Rochester, New York; <sup>6</sup>Department of Health Behavior, Society, and Policy, Rutgers School of Public Health, New Brunswick, New Jersey; <sup>7</sup>Department of Medicine, New York Presbyterian Hospital, New York, New York.

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three-quarters of patients with advanced cancer reported a preference for care that was focused more on comfort than life extension.<sup>19,20</sup> These patients were more likely to receive hospice care than patients who expressed a preference for life-extending care.<sup>21</sup> However, to the best of our knowledge, no prior studies to date have directly assessed patients' or caregivers' beliefs regarding future quality of life and hospice enrollment.

Caregivers play an integral role in the care of and decision making among patients with cancer,<sup>22,23</sup> due in part to patients' desire for less control in decision making as their disease progresses.<sup>24</sup> In fact, approximately 51% of patients with cancer have reported wanting family caregivers and physicians to share responsibility for decision making if they were too ill to participate.<sup>25</sup> As a result, the burden of EOL care decision making often falls on the caregiver.<sup>26</sup> It is nonetheless true that patients and caregivers experience cancer as a dyad and impact each other in important ways.<sup>27-29</sup> Research has indirectly suggested that prognostic understanding in both dyad members is relevant to care received at the EOL.<sup>12,30</sup> However, these studies are limited by a reliance on retrospective caregiver reports in the absence of patient data and the examination of engagement in advance care planning rather than care received at the EOL, respectively.

The purpose of the current study was to examine the relationship between patient-caregiver agreement regarding the patient's future quality of life and life expectancy (ie, prognosis) and hospice enrollment in the last 30 days of life. We hypothesized that patients in dyads in which the patient and caregiver agreed on a good prognosis (ie, good future quality of life and longer life expectancy) would be less likely to enroll in hospice care than dyads in which the patient and caregiver agreed on a poor prognosis or disagreed on prognosis.

## MATERIALS AND METHODS

### *Sample and Procedures*

The current analysis was a longitudinal examination of baseline data collected prior to the initiation of the Values and Options in Cancer Care (VOICE) intervention and hospice enrollment in the last 30 days of life.<sup>31</sup> The intervention had no discernible effect on hospice use<sup>32</sup> and as such, data across intervention conditions were collapsed in analyses for the current study. Participants were recruited from oncology practices and cancer clinics in Rochester/Buffalo, New York, and Sacramento, California. Eligible oncologists were treating patients with solid tumors and were not planning to leave the practice in the following

6 months. Eligibility criteria for patients included: 1) age  $\geq 21$  years; 2) ability to understand spoken English; 3) not hospitalized or enrolled in hospice care at the time of study recruitment or baseline survey administration; and 4) a diagnosis of stage IV nonhematological cancer. Patients with stage III cancer also were eligible if their oncologist reported they "would not be surprised" if the patient were to die within 12 months. Eligible caregivers were: 1) nonprofessional or unpaid (ie, personal) caregivers; 2) aged  $\geq 21$  years; and 3) able to understand spoken English. Patients were staged by their medical teams (not the study team) using the TNM staging system as part of their clinical management.

Oncologists were recruited through study presentations at grand rounds and faculty meetings and from personal contacts of cancer center directors and study team members. Patients were identified through review of the clinic rosters of participating oncologists. Patients were approached about the study by physicians or nurses and then by research staff or were sent a letter, study brochure, and opt-out card in the mail followed by a telephone call from study staff. Caregivers were identified by patients as a "family member, partner, friend or someone else who is involved with your health care issues, for example, someone who you talk to about personal issues including medical decisions or who comes to doctor appointments with you. This person may also help with routine day-to-day activities, like transportation or paperwork."

After obtaining informed consent, baseline measures were administered by study staff in person; patients and caregivers completed study measures separately and received \$15 for each set of completed surveys. All baseline measures were administered before patients and caregivers were exposed to the intervention. All study methods were approved by the institutional review boards of participating sites (institutional review board #RSRB00035388; ClinicalTrials.gov identifier NCT01485627) and all participants provided written informed consent. Enrollment occurred from August 2012 to June 2014.

### *Measures*

#### **Sample characteristics**

Patients self-reported age, sex, race, educational level, and marital status. Caregivers self-reported age, sex, race, educational level, marital status, and relationship to the patient.

#### **Prognostic understanding**

Prognostic understanding was assessed using 2 indicators.

**Agreement on patient's life expectancy.** Caregiver and patient expectations regarding the patient's life expectancy were assessed with the question "What do you believe are the chances that you [the patient] will live for 2 years or more?"<sup>33</sup> This item was designed to assess a life expectancy unlikely to be reached by the majority of the sample. A 2-year timeline was selected to account for the potentially beneficial impact of novel cancer therapies on life expectancy and the inclusion of cancers that can be managed for extended periods despite being classified as stage III or stage IV disease.

Responses were coded as follows: 0 indicated "100%," 1 indicated "about 90%," 2 indicated "about 75%," 3 indicated "50-50%," 4 indicated "about 25%," 5 indicated "about 10%," and 6 indicated "0%." Dyads were coded as agreeing on a "longer" life expectancy if the patient and caregiver believed that the odds of surviving for  $\geq 2$  years was  $>50\%$  (responded with codes 0-2). Dyads in which both the patient and caregiver responded with codes of 3 to 6 were coded as agreeing on a "shorter" life expectancy. Dyads in which one member responded with a code between 0 and 2 and the other responded with a code between 3 and 6 were coded as disagreeing. Dyads in which the patient or caregiver refused to answer this item or responded "don't know" were excluded from analyses.

**Agreement on future quality of life.** Patient and caregiver perceptions of the patient's future quality of life were assessed with an item adapted from the McGill Quality of Life Questionnaire.<sup>34,35</sup> Patients and caregivers were asked to rate the quality of the patient's life 3 months hence: "Three months from now, how do you believe you will rate the quality of your life?" Response options ranged from "very bad" (0) to "excellent" (10).<sup>36</sup> Caregivers responded to a similar question (eg, "Three months from now, what is your best guess about how [patient] will be doing in terms of quality of life?") using identical response options. Dyads in which both the patient and caregiver responded with codes of 0 to 6 were coded as agreeing on a poor future quality of life. Dyads in which both the patient and caregiver responded with codes of 7 to 10 were coded as agreeing on a good future quality of life. Dyads in which one member responded with a code between 0 and 6 and the other member responded with a code between 7 and 10 were coded as disagreeing.<sup>37</sup>

### Hospice enrollment

Hospice enrollment was defined as use of hospice in the 30 days before death (yes/no). Trained nurses and physicians abstracted this information from the medical

records of deceased patients obtained from relevant hospitals, offices, and hospice organizations.

### Statistical Analysis

Logistic regression analyses were used to examine the relationships between patient and caregiver agreement on the patient's future quality of life and life expectancy, respectively, and hospice enrollment in the last 30 days of life (dichotomous outcome). For patient-caregiver agreement regarding future quality of life and life expectancy, we created 3 categories: 1) dyads that agreed on a good prognosis (reference group); 2) dyads that agreed on a poor prognosis; and 3) dyads that disagreed. All models included physician-level random effects to correct standard errors for within-physician clustering. Multivariable models controlled for other design variables (eg, study site, oncologist subspecialty [breast vs other]) as well as patient demographics known to be associated with hospice use (age, sex, educational level [ $\leq$ high school,  $\geq$ some college]).<sup>16,38-40</sup> We report models that did not include an intervention arm because baseline study measures were administered prior to intervention exposure. Sensitivity analyses in addition adjusted for the intervention arm. All statistical inferences were based on 2-sided tests with  $P < .05$  considered to be statistically significant. Statistical analyses were conducted in version 9.4 of the SAS statistical software.

## RESULTS

### Sample Characteristics

Data were available regarding 141 dyads. Baseline surveys were administered a median of 16 months prior to the patient's death. Demographic characteristics are shown in Table 1. The majority of dyads were married couples (87 dyads; 62%). The majority of patients were white (126 dyads; 89%) and had  $>$ high school education (98 dyads; 70%). The same was true of caregivers.

### Agreement Regarding Future Quality of Life and Hospice Enrollment

In 34.0% of dyads (48 dyads), both parties believed the patient would have a good future quality of life and in 23.4% of dyads (33 dyads), both agreed the patient would have a poor quality of life. The remaining dyads disagreed on the patient's future quality of life (60 dyads; 43%). Of the dyads who agreed on a good future quality of life, 50.0% (24 dyads) subsequently enrolled in hospice; 78.8% of dyads who agreed on a poor future quality of life (26 dyads) enrolled in hospice (Table 2). The majority

**TABLE 1.** Sample Characteristics

Characteristic	Dyad No. (%)	
Site		
Western New York (URMC)	102 (72.3)	
Northern California (UCD)	39 (27.7)	
Cancer type		
Breast	21 (14.9)	
Other	120 (85.1)	
Patient-caregiver relationship		
Spouse	87 (61.7)	
Other	54 (38.3)	
	Patients No. (%)	Caregivers No. (%)
Sex		
Male	65 (46.1)	42 (29.8)
Female	76 (53.9)	99 (70.2)
Race		
White	126 (89.4)	125 (88.7)
Other	15 (10.6)	16 (11.3)
Education		
≤High school	43 (30.5)	38 (27.0)
≥Some college	98 (69.5)	103 (73.0)
Marital status		
Committed/married	104 (73.8)	115 (81.6)
Divorced/separated	15 (10.6)	9 (6.4)
Widowed	12 (8.5)	5 (3.5)
Never married	10 (7.1)	12 (8.5)
Median age (SD), y	66.3 (11.1)	60.1 (14.1)

Abbreviations: UCD, University of California at Davis; URMC, University of Rochester Medical Center.

of patients in dyads who disagreed on future quality of life enrolled in hospice (45 dyads; 75%).

Table 3 reports the results of multivariable analyses of the relationship between patient-caregiver agreement regarding future quality of life and hospice enrollment. In contrast to patients in dyads who predicted a good quality of life in the future, patients in dyads who disagreed regarding future quality of life (odds ratio [OR], 3.9 [95% CI, 1.45-10.49];  $P < .01$ ) and patients in dyads who agreed that quality of life would be poor (OR, 4.28 [95% CI, 1.61-11.39];  $P < .001$ ) were significantly more likely to enroll in hospice.

### Agreement on Life Expectancy and Hospice Enrollment

In approximately one-third of dyads (42 dyads; 29.8%), patients and caregivers agreed on a longer life expectancy; in 20.6% of dyads (29 dyads), patients and caregivers agreed on a shorter life expectancy. The remaining dyads disagreed on the patient's life expectancy (70 dyads; 49.6%). Of dyads in which both members projected a longer life expectancy, 52.4% of patients (22 dyads) enrolled in hospice; in contrast, 86.2% of patients in dyads who projected a shorter life expectancy (25 dyads) enrolled in hospice (Table 2).

**TABLE 2.** Frequency Statistics Regarding Hospice Enrollment As a Function of Patient-Caregiver Agreement Concerning Prognosis (Future QOL and Life Expectancy)<sup>a</sup>

	Agree: Good Prognosis	Agree: Poor Prognosis	Disagree
Future QOL			
Enrolled in hospice	24 (50.0)	26 (78.8)	45 (75.0)
Not enrolled in hospice	24 (50.0)	7 (21.2)	15 (25.0)
Life expectancy			
Enrolled in hospice	22 (52.4)	25 (86.2)	48 (68.6)
Not enrolled in hospice	20 (47.6)	4 (13.8)	22 (31.4)

Abbreviations: QOL, quality of life.

<sup>a</sup>Shown as no. (%).

**TABLE 3.** Relationship Between Patient-Caregiver Agreement Regarding Future QOL and Hospice Enrollment

Predictor	OR	95% CI	P
UCD vs URMC	0.26	0.1-0.64	<.01
Breast cancer vs other cancer	0.45	0.16-1.31	.14
Age, y	1.02	0.98-1.06	.26
Male vs female sex	0.35	0.12-0.99	.048
≥Some college vs other	2.45	0.94-6.4	.07
Dyads disagree vs agree on good future QOL	3.90	1.45-10.49	<.01
Dyads agree on worse future QOL vs agree on good future QOL	4.28	1.61-11.39	<.001

Abbreviations: OR, odds ratio; QOL, quality of life; UCD, University of California at Davis; URMC, University of Rochester Medical Center.

Patients in approximately two-thirds of dyads who disagreed on life expectancy enrolled in hospice (48 dyads; 68.6%); rates of hospice enrollment in this group were lower than those among dyads who agreed on a shorter life expectancy and higher than those among dyads who agreed on a longer life expectancy.

Table 4 reports multivariable analyses of the relationship between patient-caregiver agreement on life expectancy and hospice enrollment. In contrast to patients in dyads who agreed on a longer life expectancy, patients in dyads who disagreed on the patient's life expectancy (OR, 3.15 [95% CI, 1.35-7.33];  $P < .01$ ) and patients in dyads who projected a shorter life expectancy (OR, 7.99 [95% CI, 2.4-26.6];  $P < .001$ ) were significantly more likely to enroll in hospice in controlled analyses.

The results in Tables 3 and 4 essentially were unchanged in sensitivity analyses that adjusted for intervention arm.

## DISCUSSION

The current study examined the contributions of patient-caregiver agreement regarding future quality of life and

**TABLE 4.** Relationship Between Patient-Caregiver Agreement Regarding Life Expectancy and Hospice Enrollment

Predictor	OR	95% CI	P
UCD vs URM	0.20	0.08-0.49	<.001
Breast cancer vs other cancer	0.85	0.35-2.07	.71
Age, y	1.01	0.97-1.05	.57
Male vs female sex	0.41	0.15-1.09	.07
≥Some college vs other	2.54	1.08-5.96	.03
Dyads disagree vs agree on longer life expectancy	3.15	1.35-7.33	<.01
Dyads agree on shorter vs agree on longer life expectancy	7.99	2.4-26.6	<.001

Abbreviations: OR, odds ratio; UCD, University of California at Davis; URM, University of Rochester Medical Center.

life expectancy to hospice enrollment in the last 30 days of life. The majority of dyads agreed on the patient's future quality of life and life expectancy.<sup>27-29</sup> Despite the advanced nature of the patient's illness, approximately one-third of dyads agreed on a positive view of future quality of life and life expectancy, and these dyads were less likely to enroll in hospice care.

Unrealistic optimism regarding the future or the tendency to believe one is at lower risk of health problems compared with others<sup>41</sup> may explain patients' and caregivers' positive views of patients' life expectancy and future quality of life and lower rates of hospice enrollment. Past experience is one predictor of unrealistic optimism.<sup>42</sup> For many dyads, advanced cancer is a first-time experience, which may drive optimism regarding the future that is not tempered by an awareness of the likely decline associated with advanced cancer.<sup>41</sup> Providing prognostic information, particularly to dyads in which both members have an optimistic view of the patients' prognosis, and assessing understanding<sup>43,44</sup> may decrease unrealistic optimism.

The relationship between prognostic understanding and hospice enrollment noted in the current study also may be attributable to a desire to maintain hope and a positive perspective.<sup>45</sup> Messages regarding the benefits of hope and a positive attitude often are embedded within cancer care. Moreover, the scientific literature regarding the health benefits of a positive perspective generates considerable media attention.<sup>37</sup> These messages may interfere with patients' and caregivers' willingness to discuss poor prognosis and enroll in hospice.<sup>45,46</sup> Furthermore, hospice enrollment may be considered synonymous with "giving up," thereby reducing patient and caregiver willingness to pursue hospice.<sup>47</sup> Of course, patients can hope for multiple

outcomes simultaneously, such as hoping for good quality of life, a long life, and a good death.<sup>17</sup> Future studies should examine whether hope for outcomes such as a cure and perceived social pressure to "be positive"<sup>48,49</sup> influence untempered optimism regarding life expectancy and low hospice enrollment.

Patients with advanced cancer who recognize that their illness is terminal are more likely to prefer<sup>10</sup> and receive<sup>12</sup> symptom-directed care and less likely to receive futile aggressive care<sup>13</sup> that undermines quality of life.<sup>10,50</sup> The results of the current study add to these findings in 3 notable ways. First, the current study used a dyadic approach to understand the relationship between understanding of life expectancy and future quality of life and hospice enrollment. The identification of patients in dyads in which the patient and caregiver both believe the patient's life expectancy and future quality of life will be good may allow providers to intervene on behalf of patients at greatest risk of not accessing hospice care. Furthermore, if a patient reports believing their life expectancy and future quality of life are good, assessing illness understanding in the caregiver may improve estimates of the likelihood of hospice enrollment. Finally, in the current study, patient and caregiver agreement regarding prognostic understanding >1 year before the patient's death predicted hospice enrollment, suggesting that early evaluation of shared prognostic understanding may help providers to identify patients who may not use hospice services at the EOL. Patient-caregiver disagreement regarding prognosis may indicate poor communication within the dyad that could impair decision making. Early intervention to benefit patient-caregiver communication may improve patient-caregiver agreement regarding prognosis and promote patients' ability to make treatment decisions that are consistent with their prognosis and personal preferences for care.

Second, the current study assessed beliefs regarding quality of life in the future as well as beliefs about life expectancy, consistent with the importance of quality of life to patients with cancer.<sup>18</sup> Discussions of projected life expectancy can be difficult for patients, caregivers, and providers, which can lead to avoidance.<sup>51</sup> In contexts in which assessing a patient's and caregiver's shared understanding of the patient's life expectancy is clinically inappropriate, unlikely to occur, or impaired by distress, assessing their view of the patient's future quality of life may be an informative alternative. In addition, future studies should examine whether a compounding effect of agreement regarding future quality of life and life expectancy exists such that patients in dyads who agree on both aspects of prognosis are more likely to enroll in

hospice compared with patients in dyads who agree on only one component of prognosis.

Third, the majority of research concerning quality of life focuses on current quality of life but more research is needed regarding patients' and caregivers' outlook on their future quality of life. Patients whose current quality of life is good may inaccurately believe this will continue indefinitely, prompting them to make decisions regarding future care based on unrealistic expectations about the future. Assessment of patients' and caregivers' views of quality of life in the future may help providers to identify and correct these unrealistic expectations before they impact treatment decisions.

### Study Limitations and Future Directions

The results of the current study provide a longitudinal dyadic perspective on the relationship between illness understanding and hospice enrollment in the last 30 days of life. Some limitations should be noted when interpreting these findings. First, the sample population primarily was white and married with an educational level >high school. Due to these demographic characteristics of the sample, the results cannot be generalized to other populations. Second, dyads in which one or both members responded "don't know" (22 dyads; 13.8%) to the items assessing estimations of the patient's life expectancy and future quality of life were excluded from analyses given our interest in examining respondents who were willing to harbor a guess about the future. Third, we did not distinguish between the 2 types of dyadic disagreement: 1) patients predicted better prognosis (ie, prediction of longer life expectancy and better future quality of life) than caregivers; and 2) caregivers predicted better prognosis (ie, prediction of longer life expectancy and better future quality of life) than patients. Future dyadic research could examine differences in EOL care as a function of whether a caregiver or patient has more favorable views of prognosis. Finally, the current study was not powered to explore the moderating impact of patient-caregiver relationship variables on hospice enrollment. This association may differ based on caregiver type (eg, spouse or adult child) or relationship variables such as perceived closeness and quality of communication. Evaluation of the moderating impact of these variables on the relationship between patient-caregiver agreement and hospice enrollment could identify dyads at high risk of underuse of hospice services.

The focus of the current study regarding the relationship between patient and caregiver agreement concerning the patient's prognosis and future quality of life

and hospice enrollment adds to our knowledge of factors impacting EOL care. The current study findings have highlighted the importance of assessing illness understanding in patients and caregivers and including both dyad members in conversations regarding the patient's prognosis and quality of life.

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### CONFLICT OF INTEREST DISCLOSURES

Megan Johnson Shen has acted as a paid consultant for Kantar Health for work performed outside of the current study. Guibo Xing has received a grant from the National Cancer Institute for work performed as part of the current study. The remaining authors made no disclosures.

### AUTHOR CONTRIBUTIONS

**Kelly M. Trevino:** Writing—original draft and writing—review and editing. **Holly G. Prigerson:** Conceptualization, funding acquisition, investigation, and methodology. **Megan Johnson Shen:** Writing—review and editing. **Daniel J. Tancredi:** Data curation and formal analysis. **Guibo Xing:** Data curation and formal analysis. **Michael Hoerger:** Writing—review and editing. **Ronald M. Epstein:** Conceptualization, funding acquisition, investigation, methodology, project administration, and writing—review and editing. **Paul R. Duberstein:** Conceptualization, funding acquisition, investigation, methodology, project administration, supervision, validation, and writing—review and editing.

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