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Determinants of Patient-Oncologist Prognostic Discordance in Advanced Cancer

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Abstract

IMPORTANCE—Patients with advanced cancer often report expectations for survival that differ from their oncologists' expectations. Whether patients know that their survival expectations differ from those of their oncologists remains unknown. This distinction is important because knowingly expressing differences of opinion is important for shared decision making, whereas patients not knowing that their understanding differs from that of their treating physician is a potential marker of inadequate communication.

OBJECTIVE—To describe the prevalence, distribution, and proportion of prognostic discordance that is due to patients' knowingly vs unknowingly expressing an opinion that differs from that of their oncologist.

DESIGN, SETTING, AND PARTICIPANTS—Cross-sectional study conducted at academic and community oncology practices in Rochester, New York, and Sacramento, California. The sample comprises 236 patients with advanced cancer and their 38 oncologists who participated in a randomized trial of an intervention to improve clinical communication. Participants were enrolled from August 2012 to June 2014 and followed up until October 2015.

MAIN OUTCOMES AND MEASURES—We ascertained discordance by comparing patient and oncologist ratings of 2-year survival probability. For discordant pairs, we determined whether patients knew that their opinions differed from those of their oncologists by asking the patients to report how they believed their oncologists rated their 2-year survival.

RESULTS—Among the 236 patients (mean [SD] age, 64.5 [11.4] years; 54% female), 161 patient-oncologist survival prognosis ratings (68%; 95% CI, 62%–75%) were discordant. Discordance was substantially more common among nonwhite patients compared with white patients (95% [95% CI, 86%–100%] vs 65% [95% CI, 58%–73%], respectively; $P = .03$). Among 161 discordant patients, 144 (89%) did not know that their opinions differed from that of their oncologists and nearly all of them (155 of 161 [96%]) were more optimistic than their oncologists.

CONCLUSIONS AND RELEVANCE—In this study, patient-oncologist discordance about survival prognosis was common and patients rarely knew that their opinions differed from those of their oncologists.

Honoring patients' wishes for medical interventions near the end of life requires high-quality communication as death approaches and treatment tradeoffs evolve.^{1,2} For patients who wish to be involved in their treatment decisions, communicating effectively about survival prognosis is crucial.^{3,4} Indeed, the investigators of the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) concluded that “the most fundamental medical choice patients with incurable cancer face—the decision between life-extending therapy and comfort care—may be highly influenced by their understanding of their prognoses.”⁵ However, multiple research studies have observed that patients with advanced cancer often rate their prognosis more optimistically than their oncologists.^{5–9}

In this study, we evaluate how often patient-oncologist discordance occurs when patients know vs do not know that their opinion about survival prognosis differs from the opinion of their oncologist. Sometimes, patients might express personal opinions about their prognosis

that they expect to differ from their oncologists' views and therefore knowingly disagree with what they believe their oncologists think. Other times, however, patients might express opinions about their prognosis that they do not know differ from their oncologists' views and therefore mistakenly believe that they hold a shared understanding with their oncologists. This distinction is crucial because *known discordance* is a form of perspective taking that is expected in shared decision making, whereas *unknown discordance* is suggestive of failed communication. Although both forms of discordance are clinically important, their fundamental differences offer opportunities for tailoring resources to support patients and their oncologists in achieving high-quality treatment decisions. For example, in conversations in which patients know that their opinions are discordant from those held by their oncologists, discussions might initially focus on information sources, belief systems, and criteria for making prognosis- and preference-sensitive decisions.¹⁰ In contrast, in conversations in which patients and physicians do not know that their perspectives differ, physicians might ask patients what they wish to know, provide clear sensitive prognostic information, check their patients' understanding, and only then proceed to decision making.⁴

We also examine whether prognostic discordance, particularly unknown discordance, differs by patient race. Racial disparities in advanced cancer care are substantial, with black patients receiving lower-quality communication and less preference-concordant treatment at the end of life than white patients.^{11–15} Previous work has found that black patients are more likely than white patients to report discordantly optimistic perceptions of their prognosis^{8,16} and that such beliefs are associated with preferences for invasive, life-extending treatments.^{5,17,18} High-quality communication reduces prognostic discordance and promotes preference-concordant treatment in advanced cancer care.^{6,19} A better understanding of prognostic discordance, as we offer herein, holds promise for informing efforts to improve communication and reduce racial disparities in care for advanced cancer.

Methods

This is a cross-sectional analysis of 236 patients with advanced cancer and their 38 oncologists from practices in Rochester, New York, and Sacramento, California, who participated in a randomized trial of a communication intervention in the outpatient oncology setting. All clinician and patient participants provided written informed consent. The University of Rochester and University of California, Davis Research Subjects Review Boards approved this study.

Context, Population, and Eligibility

The parent study occurred in academic and nonacademic hospital-based and community-based outpatient oncology practices in Rochester, New York, and Sacramento, California. Participants were enrolled from August 2012 to June 2014 and followed up until October 2015. Patients were eligible to participate if they were aged 21 years or older, were able to understand spoken English and provide consent, and had either (a) stage IV nonhematologic cancer or (b) stage III cancer and whose oncologist “would not be surprised” if the patient were to die within 12 months. We excluded hospitalized patients because the parent trial required the ability to participate in a coaching intervention and outpatient visits with the

primary oncologist. Patients already enrolled in hospice were ineligible because this was among the study outcomes. All oncologists at study practices were eligible to participate if they cared for patients with nonhematologic tumors. Two hundred sixty-five patients enrolled in the parent trial. For this analysis, we excluded 29 patients for whom we could not evaluate discordance because they did not provide an estimate of their survival prognosis ($n = 22$) or did not complete any of the study questionnaire ($n = 7$).

Brief Description of the Parent Trial and Intervention

The Values and Options in the Cancer Experience (VOICE) trial methods are fully described elsewhere.²⁰ The purpose of VOICE was to test a multimodal intervention to promote high-quality communication between patients with advanced cancer and their oncologists. The experimental condition included patient activation coaching (eg, question asking, raising concerns) and physician communication skills training with standardized patients. Randomization occurred at the level of the oncologist. The control condition was usual care. The main outcome was quality of communication, coded from audio recordings of the first postintervention outpatient oncologist patient visit (termed the *index visit*). Patients and physicians completed interviewer-administered questionnaires at baseline, following the first office visit (usually immediately, but up to 1 week afterward in some cases), and quarterly thereafter. For these analyses, we used the patient and oncologist postindex visit questionnaires to best align the timing of their responses to prognosis expectations. We included all participants in this analysis because prognostic discordance did not differ by study arm (68.7% for the intervention arm vs 67.7% for the control arm; $P = .87$).

Measures

Prognostic Discordance—Patients and their oncologists independently reported their survival expectations on the postindex visit questionnaire. Patients were asked, “What do you believe are the chances that you will live for 2 years or more?” and their oncologists were asked, “What do you believe are the chances that this patient will live for 2 years or more?” We used the following response options from the SUPPORT self-rated prognosis measure,⁵ modified to include 100% and 0% options: 100%, about 90%, about 75%, about 50%/50%, about 25%, about 10%, and 0%. We chose the 2-year time frame because the expected median survival for the study population was 12 to 16 months and most patients were unlikely to live for 5 years. We defined prognostic discordance as difference in more than 1 category between patient and physician ratings.

Knowing vs Not Knowing—We were interested in determining whether patients expected that their prognosis opinions differed from those held by their oncologists. Therefore, we asked all patients the following: “What do you believe your doctor believes are the chances that you will live for 2 years or more?” (same response options). Patients who were correct about their oncologists’ ratings or off by only 1 category were defined as knowing their oncologists’ opinions; the rest (including those who selected “I don’t know”) were defined as not knowing the oncologists’ opinions. Using this distinction, we categorized all patients whose self-rating of prognosis was discordant from the rating by their oncologists as either knowingly discordant or unknowingly discordant.

Independent Variables—We measured the following patient factors to evaluate the distribution of prognostic discordance: age, sex, race/ethnicity (self-classified and asked for purposes of investigating potential disparities), educational status, income, aggressiveness of cancer, self-efficacy with health care communication (Perceived Efficacy in Patient-Physician Interactions scale²¹), Preferred Locus of Decision-Making,²² recalled discussion of prognosis with their oncologist, and end-of-life treatment preferences. Using information on cancer type and stage at study baseline, 2 study oncologists assigned each participant as having or not having a highly aggressive cancer. We evaluated recalled prognosis discussion using the following: “To what extent have you discussed your prognosis with your doctor?” (completely, mostly, a little, or not at all). We measured end-of-life treatment preferences by asking patients to select the types of treatments they would want if their physician were to inform them that there were “no further anticancer treatments that would be helpful,” including “palliative care (eg, comfort care, focus on quality of life but not a cure)” (definitely yes, possibly yes, unsure, possibly no, or definitely no).

We measured oncologist self-efficacy with end-of-life communication via a modified²³ 14-item measure (Cronbach $\alpha = 0.93$) on which oncologists reported their perceptions about their skill with specific communication tasks (eg, “giving bad news,” “eliciting patient fears about end of life”) on a 5-point scale from basic to advanced. We assessed oncologist recall of prognosis discussions using the following: “To what extent have you discussed prognosis with this patient?” (completely, mostly, a little, or not at all). All measures are fully described elsewhere.²⁰

Statistical Analysis

This is a descriptive study. As such, we evaluated the frequency and distribution of all study variables, including patient physician prognostic discordance. To account for the clustering of multiple patients within physicians, we used survey data analysis procedures for clustered data to estimate 95% confidence intervals for prevalence estimates and to perform χ^2 tests of association (using the Wald log-linear χ^2 method for survey data). We then described the proportion of discordant pairs involving knowingly discordant and unknowingly discordant patients. For scale variables (eg, Perceived Efficacy in Patient-Physician Interactions) or multicategory items (eg, Preferred Locus of Decision-Making), we either used clinically relevant thresholds or created low, middle, and high categories based on the observed distributions of our data to explore potential dose response relationships. We used χ^2 tests for associations with discordance frequency. We used mixed-effects multiple logistic regression for evaluation of confounding, with random intercepts for physicians, to account for clustering. We used both forward and backward model-building procedures to assess potential confounding, using change in magnitude of association as an indicator of confounding.

Results

Among 236 patients (mean [SD] age, 64.5 [11.4] years; 54% female), 161 (68%; 95% CI, 62%–75%) rated their 2-year survival prognosis discordantly from their oncologists; 144 of the 161 patients (89%) did not know that their opinions differed from the opinions of their

oncologists. Among this unknowingly discordant group, 29% (42 of 144) were aware that they did not know their oncologists' opinions (ie, indicating "I don't know" when asked about their oncologists' prognosis ratings). Nearly all of the discordant dyads (155 of 161 [96%]) involved patients who rated their prognosis more optimistically than their physicians.

As shown in the Table, the prevalence of prognostic discordance did not differ substantively based on patients' income, education, sex, confidence with patient-physician communication, or recalled extent of prognosis communication with their oncologist; oncologists' perceived end-of-life communication skills or recalled extent of prognosis communication with the patient; or study site. Non white patients were substantially more likely than white patients to endorse prognostic expectations that were discordant from their oncologists (95% [95% CI, 86%–100%] vs 65% [95% CI, 58%–73%], respectively; $P = .03$); this persisted for unknowing discordance (91% [95% CI, 82%–99%] vs 62% [95% CI, 56%–69%], respectively; $P = .04$). In mixed-effects models with physician-level random effects, the association between race and discordance was not substantively changed by controlling for any combination of age, sex, ethnicity, income, educational attainment, or aggressiveness of cancer type.

Among the 161 discordant dyads, 159 (99%) involved patients who wished to be involved in treatment decision making, 113 (70%) included patients who answered definitely yes or possibly yes when asked whether they wished to involve palliative care when their end of life becomes near, and 83 (52%) occurred despite oncologists recalling having completely thorough discussions about prognosis with the patient.

Discussion

This study evaluated patient-oncologist prognosis discordance in a multisite sample of patients with advanced cancer. As with other work, we observed a high prevalence of such discordance in the setting of advanced cancer.^{5–9}

Four of our observations add substantively to the existing scientific literature. First, we observed that only a small fraction of discordant dyads involved patients who knew that their opinions differed from the opinions of their oncologists. The vast majority of prognostic discordance happened among patients who either reported a mistaken understanding of their oncologists' opinions or were unable to guess what their oncologist thought. Second, we observed that nearly all occurrences of discordance involved patients who wished to be actively engaged in treatment decision making. Third, 70% of discordant pairs were among patients who preferred to have increasing support for quality of life near the end of life—a decision that would require understanding when death was approaching.

Finally, we observed discordance more frequently among nonwhite patients compared with white patients. This work does not directly evaluate actual patient-oncologist communication. However, our findings identify that the most common form of patient-oncologist discordance in prognosis expectations involves patients being unknowingly discordant, and we propose that this is a marker for inadequate communication. Therefore, our findings are consistent with previous literature documenting suboptimal communication

between physicians (usually white) and nonwhite patients who are seriously ill.^{11–15} A growing body of evidence suggests that the quality of communication—including communication about prognosis^{6,9,11–13,16}—represents an important and mutable source of disparity in end-of-life care.

This study has important limitations. First and foremost, the data presented herein do not permit us to determine why discordant patients do not know their oncologists' opinions about prognosis or why this differs by race. However, other work finds that communicating about prognosis in advanced cancer is not merely a straightforward exchange of information; it is affective²⁴ and, when it happens, it occurs amid substantial uncertainty, confusion, and often terror. Related work in palliative care settings—where prognostic discussions occur routinely²⁵—observes that prognosis communication is a complex and relational process²⁶ that is linked closely with conversation about treatment goals and personal values.^{2,27} The degree to which the observed high prevalence of unknowing discordance in this study reflects patient and/or oncologist hesitancy (or other barriers) to engage in such conversation, differential interpretation or poor recall of conversations that have occurred, or self-report phenomena that distort true beliefs (eg, optimistic prognostic ratings for purposes of avoiding superstitions about predicting death) remains unclear. Second, our sample of nonwhite participants is small and includes persons from multiple racial groups. All but 1 of the 22 participants in this group exhibited prognostic discordance. Although this provides compelling evidence of a strong association, the exact magnitude is subject to some instability. Therefore, we focus our main findings on directly observed prevalence estimates and cluster-adjusted confidence intervals. We limit our use of multivariate modeling to evaluate potential confounding by a relatively small confounder set. Further work with larger nonwhite populations is necessary for more precise estimates and more exploration of interacting phenomena (ie, mediators and moderators). Third, this study does not attempt to determine prognostic accuracy. Indeed, prognostication is quite challenging and some related work suggests that patients' perceptions of prognosis might hold some independent prognostic value in advanced cancer,²⁸ further complicating what it means to be accurate. Rather, we focus herein on the plausible decision-making implications of holding differing prognostic perceptions. Future research on prognostic discordance will need to help us understand the conditions under which discordant perceptions are advantageous and disadvantageous to well-being, survival, and decision making.

Conclusions

Our findings suggest that patient-oncologist prognostic discordance is common in advanced cancer and that it is usually due to patients not knowing their oncologists' prognosis opinions. We propose that this unknowingly discordant status is a marker, at least on average, for inadequate patient-physician communication about a topic of high relevance to treatment decision making in advanced cancer. Therefore, this study supports the urgent clinical and societal need to better understand what it means to communicate well about prognosis to achieve treatment that honors patients' values, preferences, and wishes.

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Key Points

Question

When patients with advanced cancer report beliefs about their survival prognosis that differ from the expectations of their oncologists, how often do they know that their beliefs differ?

Findings

In this cross-sectional analysis of 236 patients and 38 oncologists, 68% of patients held opinions about their survival prognosis that differed from their oncologist and only 1 in 10 discordant patients knew that their opinions differed.

Meaning

In this study, patient-oncologist discordance about survival prognosis was common and usually due to patients' inaccurate understanding of their oncologists' expectations.

TableFrequency and Distribution of Discordant Survival Expectations^a

Characteristic	Sample Size, No.	Prognostic Discordance, No. (% [95% CI])
Full sample	236	161 (68 [62–75])
Sex		
Women	128	88 (69 [60–78])
Men	108	73 (68 [59–76])
Race ^b		
Nonwhite	22	21 (95 [86–100])
White	214	140 (65 [58–73])
Ethnicity		
Latino	6	6 (100 [100–100])
Non-Latino	230	155 (67 [61–74])
Age, y		
<60	76	54 (71 [60–82])
60–71	92	60 (65 [55–75])
>71	68	47 (69 [57–82])
Income, \$		
Missing	31	18 (58 [43–73])
20 000	44	30 (68 [55–81])
20 001–50 000	65	47 (72 [59–85])
50 001–100 000	66	43 (65 [54–77])
>100 000	30	23 (77 [60–94])
Education		
<High school	15	10 (67 [43–91])
High school graduate	46	32 (70 [54–85])
Some college	96	65 (68 [59–76])
Bachelor's degree	79	54 (68 [56–80])
Study site		
New York	150	104 (69 [60–79])
California	86	57 (66 [59–74])
Aggressive cancer type		
Yes	121	88 (73 [64–82])
No	115	73 (63 [54–73])
Patients' self-efficacy with patient-physician communication		
Low	86	58 (67 [57–78])
Middle	92	60 (65 [57–74])
High	58	43 (74 [61–88])
Oncologists' self-efficacy with end-of-life communication		

Characteristic	Sample Size, No.	Prognostic Discordance, No. (% [95% CI])
Low	85	57 (67 [59–76])
Middle	74	49 (66 [53–80])
High	64	46 (72 [58–86])
Patients' recalled extent of prognosis discussion		
Mostly or completely	204	138 (68 [61–75])
Partially	23	17 (74 [57–91])
None	9	5 (56 [17–94])
Oncologists' recalled extent of prognosis discussion		
Mostly or completely	222	150 (68 [61–74])
Partially	14	11 (79 [55–100])
None	0	0

^aPatient-oncologist dyadic data involve 236 patients and 38 physicians. We used survey data analysis methods for clustered survey data to estimate 95% confidence intervals and to perform Wald log-linear χ^2 tests.

^b $P < .05$ (χ^2 test).