

## Beliefs About Advanced Cancer Curability in Older Patients, Their Caregivers, and Oncologists

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**Key Words.** Beliefs about cancer curability • Discordance • Older adults • Caregivers • Oncologists

### ABSTRACT

**Background.** Ensuring older patients with advanced cancer and their oncologists have similar beliefs about curability is important. We investigated discordance in beliefs about curability in patient-oncologist and caregiver-oncologist dyads.

**Materials and Methods.** We used baseline data from a cluster randomized trial assessing whether geriatric assessment improves communication and quality of life in older patients with advanced cancer and their caregivers. Patients were aged  $\geq 70$  years with incurable cancer from community oncology practices. Patients, caregivers, and oncologists were asked: "What do you believe are the chances the cancer will go away and never come back with treatment?" Options were 100%, >50%, 50/50, <50%, and 0% (5-point scale). Discordance in beliefs about curability was defined as any difference in scale scores ( $\geq 3$  points were severe). We used multivariate logistic regressions to describe correlates of discordance.

**Results.** Discordance was present in 60% (15% severe) of the 336 patient-oncologist dyads and 52% (16% severe) of the

245 caregiver-oncologist dyads. Discordance was less common in patient-oncologist dyads when oncologists practiced longer (adjusted odds ratio [AOR] 0.90, 95% confidence interval [CI] 0.84–0.97) and more common in non-Hispanic white patients (AOR 5.77, CI 1.90–17.50) and when patients had lung (AOR 1.95, CI 1.29–2.94) or gastrointestinal (AOR 1.55, CI 1.09–2.21) compared with breast cancer. Severe discordance was more common when patients were non-Hispanic white, had lower income, and had impaired social support. Caregiver-oncologist discordance was more common when caregivers were non-Hispanic white (AOR 3.32, CI 1.01–10.94) and reported lower physical health (AOR 0.88, CI 0.78–1.00). Severe discordance was more common when caregivers had lower income and lower anxiety level.

**Conclusion.** Discordance in beliefs about curability is common, occasionally severe, and correlated with patient, caregiver, and oncologist characteristics. *The Oncologist* 2019;24:e292–e302

**Implications for Practice:** Ensuring older patients with advanced cancer and their caregivers have similar beliefs about curability as the oncologist is important. This study investigated discordance in beliefs about curability in patient-oncologist (PO) and caregiver-oncologist (CO) dyads. It found that discordance was present in 60% (15% severe) of PO dyads and 52% (16% severe) of CO dyads, raising serious questions about the process by which patients consent to treatment. This study supports the need for interventions targeted at the oncologist, patient, caregiver, and societal levels to improve the delivery of prognostic information and patients'/caregivers' understanding and acceptance of prognosis.

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## INTRODUCTION

Ensuring patients with advanced cancer have similar beliefs as their oncologists about cancer curability is essential for treatment decision-making, advance care planning, and psychological support. Patients who overestimate the curability of their cancer may be more willing to receive intensive treatment [1] and less likely to use end-of-life care [2, 3]. Studies have shown that up to 69% of patient-oncologist dyads have different beliefs about cancer curability or estimated survival [4, 5]. Although the majority of cancer diagnoses and deaths occur in older adults, few data on beliefs about cancer curability exist in this population. Studies have shown that older adults have lower awareness of their diagnosis and prognosis than their younger counterparts [6–8]. Furthermore, many older adults are frail and have functional, psychological, and social vulnerabilities that may affect how information is communicated and processed. These age-related vulnerabilities are associated with higher morbidity and mortality [9, 10] and add complexities to the care of and treatment decisions among older adults with cancer. Older adults are at a higher risk of experiencing adverse events related to cancer treatments [11]; therefore, ensuring older adults have similar beliefs about curability as their oncologists may allow them to receive goal-concordant care.

In cancer care, discordance in prognostic beliefs is presumed to reflect both patients' understanding of their illnesses and the quality of communication between oncologists and patients [4, 12, 13]. In an effort to improve cancer care delivery, studies have begun to explore the correlates of discordance in prognostic beliefs, although not specifically focusing on older adults [4]. For instance, one study found that discordance in estimated survival was more common when patients were not white [4], which represents a significant health disparity that should be evaluated in the older population.

Caregivers play a significant role in cancer care, especially in older adults; they frequently accompany patients to medical appointments, assist patients in daily activities such as taking medications, and often participate in treatment decision-making. Therefore, ensuring caregivers have the same beliefs about cancer curability as the oncologist can help reinforce the cancer prognosis in home conversations [14] and help caregivers anticipate the outcome of terminal illness. Surprisingly, few studies have examined caregiver-oncologist prognostic discordance [5, 15]. To our knowledge, no studies have examined correlates of caregiver-oncologist discordance in beliefs about curability.

Prior studies on discordance in beliefs about cancer curability or estimated survival have been conducted in specific cancer types, had relatively small sample sizes, or did not focus on older adults and their caregivers [4, 5, 12, 16, 17]. In addition, to our knowledge, there have been no reports about oncologist characteristics associated with discordance, and few studies have examined the severity of discordance in cancer curability [5]. In this study, beyond estimating the prevalence and the severity of discordance in cancer curability in patient-oncologist and caregiver-oncologist dyads, we examined correlates of discordance. We hypothesized that age-related vulnerabilities and non-white race would be associated with discordance in beliefs about curability in both dyads.

## MATERIALS AND METHODS

### Study Design, Setting, and Participants

We performed a secondary analysis of data from a cluster randomized trial assessing whether geriatric assessment (GA) improves communication and quality of life in older patients with advanced cancer and their caregivers (University of Rochester Cancer Center 13070; ClinicalTrials.gov: NCT02107443; Principal Investigator: S.G.M.) [18]. The primary study was conducted within the University of Rochester Cancer Center National Cancer Institute Community Oncology Program Research Network and enrolled patients who were aged 70 years and above, had a diagnosis of an incurable stage III/IV solid tumor or lymphoma, had at least one impaired GA domain, and were considering or receiving any kind of cancer treatment. GA assesses age-related vulnerabilities or domains that are predictive of morbidity and mortality in older adults with cancer [19–22]. In our study, GA domains were assessed using validated tools and cutoffs and included comorbidity [23], functional status [24–27], physical performance [28, 29], cognition [30, 31], instrumental social support (e.g., someone to help if you were confined to bed) [32], polypharmacy [33], psychological health [34, 35], and nutrition [36–38] (supplemental online Table 1).

The patient's oncologist and a caregiver were also enrolled in the study. Caregivers were selected by the patient when asked, "Is there a family member, partner, friend, or caregiver (age 21 or older) with whom you discuss or can be helpful in health-related matters?" A total of 31 community oncology practices participated in the study between October 2014 and April 2017. All data reported in this secondary analysis were collected at baseline.

### Measures

Following informed consent, patients provided demographic data and completed the self-reported portion of the GA. Clinical research associates performed the objective assessment portion of the GA. Patients then completed assessments of their beliefs about the curability of the cancer: "What do you believe are the chances the cancer will go away and never come back with treatment?" Response options were 100%, >50%, 50/50, <50%, 0%, or uncertain. We adapted this question from a prior study [39]. We modified this question to decrease the number of response options and to include the option for "uncertain." Missing or "uncertain" responses were excluded from this analysis because the severity of discordance is best examined with numerical data. Belief about curability was thus assessed on a 5-point ordinal scale, ranging from 0% (1 point) to 100% (5 points).

Similarly, caregivers provided demographic data, self-reported their health status, and completed assessments of their beliefs about the curability of the cancer. Oncologists provided demographic data and completed assessments of their beliefs about the curability of the cancer.

### **Dependent Variable for Patients: Patient-Oncologist Discordance in Beliefs About Curability**

Prognostic discordance was defined as the presence of any patient-oncologist difference on the 5-point ordinal scale. If the difference score was  $\geq 3$  points, the prognostic discordance

was categorized as severe. For example, if a patient answered >50% (4 points) and his/her oncologist answered 0% (1 point), then prognostic discordance was present (3 points). Definitions of discordance were based on consensus of the study team.

#### **Dependent Variable for Caregivers: Caregiver-Oncologist Discordance in Beliefs About Curability**

Prognostic discordance was defined as the presence of any caregiver-oncologist difference on the 5-point ordinal scale. If the difference score was  $\geq 3$  points, the prognostic discordance was categorized as severe.

#### **Key Independent Variables for Patients: Age-Related Vulnerabilities and Race**

Age-related vulnerabilities in patients were assessed using the GA as described above. Race was categorized as white (non-Hispanic white) and other.

#### **Key Independent Variables for Caregivers: Age-Related Vulnerabilities and Race**

Caregiver health was assessed using validated instruments including the Older Americans Resources and Services Comorbidity [23], 12-Item Short Form Health Survey (SF-12) [40], distress thermometer [41], Patient Health Questionnaire (PHQ-2) [42], and Generalized Anxiety Disorder (GAD-7) [35]. The SF-12 assesses functional health status and includes physical and mental health, each scored from 0 to 100 with a lower score indicating more impairment [40]. The distress thermometer consists of an 11-point Likert scale, ranging from 0 (no distress) to 10 (extreme distress) [41]. The PHQ-2 consists of two questions: (a) Little interest or pleasure in doing things, and (b) Feeling down, depressed, or hopeless. Each question is scored on a 0–3 scale, 0 indicating not at all and 3 indicating nearly every day, and a total score is generated [42]. The GAD-7 consists of seven questions, all scored on a 0 (not at all) to 3 (nearly every day) scale (possible range 0–21) [35]. Race was categorized as white (non-Hispanic white) and other.

#### **Covariates for Regressions Evaluating Correlates of Patient-Oncologist Discordance**

Covariates included patient demographic (age, gender, education, marital status, and annual household income), clinical (cancer types) and communication variables (communication self-efficacy and patient recall of prognostic discussions) [12, 13], and oncologist variables (age, gender, race, and number of years in practice since completion of oncology fellowship). Communication self-efficacy was assessed using the 5-item Perceived Efficacy in Patient-Physician Interactions (PEPPI) scale; higher scores indicate greater self-efficacy [43]. For recalled prognostic discussion, patients were asked, “To what extent have you discussed your prognosis with your cancer doctor?” and were provided with the following options: completely, mostly, a little, or not at all [4]. These options were collapsed into two levels (completely and mostly vs. a little and not at all).

#### **Covariates for Regressions Evaluating Correlates of Caregiver-Oncologist Discordance**

Correlates included caregiver demographic and communication variables as well as oncologist variables as described above. Demographic variables included caregiver age, gender,

income, education, and marital status. Communication variables included caregiver recalled prognostic discussion with the oncologist [4] and PEPPI [43].

#### **Statistical Analyses**

After describing the population and discordance in beliefs about cancer curability using descriptive analyses, we used bivariate and multivariate logistic regression models to test the hypothesized associations of age-related vulnerabilities and race with discordance and severe discordance in beliefs about curability in the patient-oncologist dyads and to identify other correlates of discordance, including patient and oncologist variables. The same analysis was repeated in the caregiver-oncologist dyads using caregiver and oncologist variables. All variables with a  $p$  value of  $<.20$  in bivariate analyses were entered into multivariate models [44]. Backward stepwise regressions were performed with the final models including only significant variables ( $p < .05$ ). We used generalized estimating equations to account for clustering at the practice level. All statistical analyses were conducted using the SAS software package (version 9.3; SAS Institute, Cary, NC).

## **RESULTS**

Of the 541 patient-oncologist dyads enrolled in the primary study [18], 20 were excluded because the patients ( $n = 17$ ) and/or oncologists ( $n = 8$ ) provided no response. An additional 185 patient-oncologist dyads were excluded because the patients ( $n = 175$ ) and/or oncologists ( $n = 15$ ) were uncertain of the prognosis (supplemental online Fig. 1). Of the 414 caregiver-oncologist dyads enrolled, 3 dyads were excluded because caregiver demographics were completely missing, and 23 dyads were excluded because the caregivers ( $n = 19$ ) and/or oncologists ( $n = 4$ ) provided no response. An additional 146 caregiver-oncologist dyads were excluded because the caregivers ( $n = 140$ ) and/or oncologists ( $n = 12$ ) were uncertain of the prognosis. Therefore, our final analytic sample consisted of 336 patient-oncologist dyads (113 oncologists from 27 practices) and 245 caregiver-oncologist dyads (104 oncologists from 26 practices; supplemental online Fig. 1).

The mean (SD, range) age of the patient and caregiver samples was 76.3 (5.1, 70–93) years and 65.8 (12.4, 26–89) years, respectively. Tables 1 and 2 show baseline demographic and clinical information for the patients and caregivers, respectively, as well as the characteristics of the oncologists. Among the patient-oncologist dyads, 60.2% (197/327) were race-concordant. Among the caregiver-oncologist dyads, 57.9% (138/238) were race-concordant.

#### **Prevalence and Extent of Discordance in Beliefs About Curability**

Figure 1 shows the distribution of beliefs about curability. Discordance was present in more than half of the patient-oncologist (202/336; 60.1%) and caregiver-oncologist (128/245; 52.2%) dyads, with patients (179/202; 88.6%) and caregivers (100/128; 78.1%) reporting a greater likelihood of cure than oncologists ( $p < .01$  for both; Table 3). Severe discordance was present in 15.1% (51/336) of patient-oncologist and 16.3% (40/245) of caregiver-oncologist dyads. In dyads in which patients and caregivers reported a greater likelihood of cure

**Table 1.** Baseline characteristics of the patients and oncologists in the patient-oncologist dyads

| Variables   | n = 336     |
|---|-------------|
| <b>Patients</b>   |             |
| Age, mean (SD), years   | 76.3 (5.1)  |
| Gender, n (%)   |             |
| Male  | 175 (52.1)  |
| Female  | 161 (47.9)  |
| Marital Status, n (%)   |             |
| Married   | 220 (65.5)  |
| Other   | 116 (34.5)  |
| Race, n (%)   |             |
| White   | 308 (91.7)  |
| Non-white   | 28 (8.3)    |
| Education, n (%)  |             |
| Some college or above   | 189 (56.4)  |
| High school graduate  | 107 (31.9)  |
| <High school  | 40 (11.9)   |
| Annual household income, n (%) <sup>a</sup>                                       |             |
| >\$50,000   | 110 (32.9)  |
| ≤\$50,000   | 153 (45.8)  |
| Declined to answer  | 71 (21.3)   |
| Cancer type, n (%) <sup>b</sup>   |             |
| Breast  | 44 (13.1)   |
| Gastrointestinal  | 80 (23.9)   |
| Genitourinary   | 37 (11.0)   |
| Lung  | 88 (26.3)   |
| Other   | 86 (25.7)   |
| Comorbidity, n (%)  |             |
| Impaired  | 220 (65.5)  |
| Physical performance, n (%)   |             |
| Impaired  | 317 (94.4)  |
| Functional status, n (%)  |             |
| Impaired  | 197 (58.6)  |
| Cognition, n (%)  |             |
| Impaired  | 103 (30.7)  |
| Nutrition, n (%)  |             |
| Impaired  | 189 (56.3)  |
| Social support, n (%)   |             |
| Impaired  | 100 (29.8)  |
| Polypharmacy, n (%)   |             |
| Impaired  | 279 (83.0)  |
| Psychological health, n (%)   |             |
| Impaired  | 84 (25.0)   |
| Recalled prognosis, n (%) <sup>a</sup>  |             |
| Completely/Mostly   | 256 (76.7)  |
| A little/Not at all   | 78 (23.4)   |
| PEPPI, mean (SD) <sup>a</sup>   | 21.6 (3.4)  |
| <b>Oncologists</b>  |             |
| Age, mean (SD), years <sup>c</sup>  | 48.4 (10.9) |
| Gender, n (%) <sup>d</sup>  |             |
| Male  | 214 (65.1)  |
| Female  | 115 (35.0)  |
| Race, n (%) <sup>e</sup>  |             |
| White   | 205 (63.6)  |
| Non-white   | 119 (36.4)  |
| Years in practice since completion of oncology fellowship, mean (SD) <sup>e</sup> | 14.3 (11.1) |

<sup>a</sup>Two patients had missing data.<sup>b</sup>One patient had missing data.<sup>c</sup>Not available in eight dyads.<sup>d</sup>Not available in seven dyads.<sup>e</sup>Not available in nine dyads.

than oncologists, severe prognostic discordance was present in 27.8% (50/180) and 37.0% (37/100), respectively. In dyads in which oncologists reported a greater likelihood of cure, severe prognostic discordance was present in 4.3% (1/23) and 10.7% (3/28), respectively.

Rates of patient-oncologist discordance were no different when patients enrolled with a caregiver compared with those who enrolled without a caregiver (61.9% vs. 54.4%,  $p = .24$ ). Corresponding rates for severe prognostic discordance were 14.8% and 16.5% ( $p = .72$ ), respectively. Caregiver-oncologist discordance was more common in the setting of patient-oncologist discordance (76.1% vs. 18.9%,  $p < 0.01$ ).

### Correlates of Patient-Oncologist Discordance

On multivariate analysis, discordance in beliefs about curability was more common when patients had lung (adjusted odds ratio [AOR] 1.95, 95% confidence interval [CI] 1.29–2.94) or gastrointestinal (AOR 1.55, 95% CI 1.09–2.21) cancers than breast cancer and when patients were non-white (AOR 5.77, 95% CI 1.90–17.50; Table 4). Discordance in beliefs about curability was somewhat less common in dyads that included oncologists who had been in practice longer (5 units increase in the number of years in practice, AOR 0.90, 95% CI 0.84–0.97).

Severe discordance was more common in non-white patients (AOR 4.52, 95% CI 2.38–8.59), patients with lower annual household income (≤\$50,000 vs. >\$50,000; AOR 2.50, 95% CI 1.28–4.88), and patients with impaired instrumental social support (AOR 2.35, 95% CI 1.27–4.36; Table 4).

### Correlates of Caregiver-Oncologist Discordance

On multivariate analysis, discordance in beliefs about curability was more common in non-white caregivers (AOR 3.32, 95% CI 1.01–10.94) and in those with worse self-reported health (5 units decrease in SF-12 physical health, AOR 0.88, 95% CI 0.78–1.00; Table 5).

Severe discordance in beliefs about curability was more common in caregivers with lower annual household income (AOR 1.84, 95% CI 1.03–3.29) and lower anxiety levels (1 unit decrease in GAD-7, AOR 0.90, 95% CI 0.83–0.98).

## DISCUSSION

In this study of community oncologists and their older patients and their caregivers, discordance in beliefs about curability was present in 60.1% of patient-oncologist dyads and 52.2% of caregiver-oncologist dyads and was most often (but not always) attributable to patients and caregivers reporting a greater likelihood of cure than oncologists. More than 15% of discordance was designated as severe.

Discordance in beliefs about curability reflects both a patient's understanding of their illness and the quality of communication between oncologist and patient. A prior study suggested that a majority of discordance in estimated survival was attributable to patients misunderstanding their oncologists' opinions [4], perhaps due to the strategies employed by oncologists in communicating prognosis. For example, one study showed that oncologists' use of pessimistic statements



**Table 2.** Baseline characteristics of the caregivers and oncologists in the caregiver-oncologist dyads

| Variables   | n = 245     |
|---|-------------|
| <b>Caregivers</b>   |             |
| Age, mean (SD), years   | 65.8 (12.4) |
| Gender, n (%)   |             |
| Male  | 64 (26.1)   |
| Female  | 181 (73.9)  |
| Marital status, n (%)   |             |
| Married   | 200 (81.6)  |
| Other   | 45 (18.4)   |
| Race, n (%)   |             |
| White   | 224 (91.4)  |
| Non-white   | 21 (8.6)    |
| Education, n (%)  |             |
| Some college or above   | 173 (70.6)  |
| High school graduate  | 61 (24.9)   |
| <High school  | 11 (4.5)    |
| Annual household income, n (%) <sup>a</sup>                                       |             |
| >\$50,000   | 39 (16.0)   |
| ≤\$50,000   | 123 (50.4)  |
| Declined to answer  | 82 (33.6)   |
| Comorbidity, n (%)  |             |
| Impaired  | 94 (38.4)   |
| Anxiety (GAD-7), mean (SD) <sup>a</sup>   | 3.2 (4.5)   |
| Depression (PHQ-2), mean (SD)   | 0.6 (1.2)   |
| Self-rated health (SF-12), mean (SD) <sup>a</sup>                                 | 98.6 (14.3) |
| Distress, mean (SD) <sup>b</sup>  | 3.3 (3.0)   |
| Recalled prognosis, n (%)   |             |
| Completely/Mostly   | 158 (64.5)  |
| A little/Not at all   | 87 (35.5)   |
| PEPPI, mean (SD) <sup>a</sup>   | 21.7 (3.3)  |
| <b>Oncologists</b>  |             |
| Age, mean (SD), years <sup>c</sup>  | 49.1 (10.7) |
| Gender, n (%) <sup>d</sup>  |             |
| Male  | 167 (69.9)  |
| Female  | 72 (30.1)   |
| Race, n (%) <sup>c</sup>  |             |
| White   | 145 (60.9)  |
| Non-white   | 93 (39.1)   |
| Years in practice since completion of oncology fellowship, mean (SD) <sup>e</sup> | 14.8 (10.6) |

<sup>a</sup>One caregiver had missing data.

<sup>b</sup>Three caregivers had missing data.

<sup>c</sup>Not available in seven dyads.

<sup>d</sup>Not available in six dyads.

<sup>e</sup>Not available in nine dyads.

Abbreviations: GAD-7, General Anxiety Disorder 7-item scale; PEPPI, Perceived Efficacy in Patient-Physician Interactions; PHQ-2, Patient Health Questionnaire-2; SF12, 12-Item Short Form Health Survey.

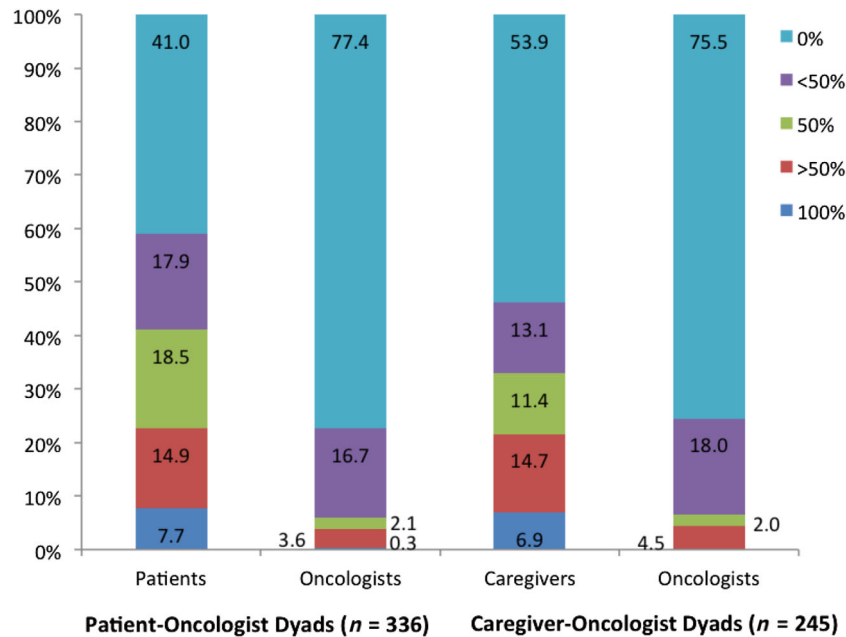
was more likely to lead to concordance [12]. Discordance may also occur as a result of avoidance of prognostic discussions by patients and physicians [45, 46], physicians' discomfort in discussing prognosis [47], or physicians' lack of confidence in responding to patients' emotions [48]. Oncologists rarely offer prognostic information unless asked by patients [49], which can be a barrier for older adults who may be less likely to ask questions [50]. In addition, discordance may stem from fixed patient/caregiver beliefs or inaccurate interpretations of prognostic information [51].

We found that severe discordance in beliefs about cancer curability was more common in older patients with impaired instrumental social support. This may reflect the lack of a support system, which is common among older adults, that affords an opportunity for older patients to discuss their prognosis [52]. It may also represent inadequate discussion of prognosis by oncologists with older patients who lack instrumental social support due to oncologists' concerns that older patients may not be able to cope with the information. It is interesting that cognition was not associated with discordance, because cognitive impairment may affect the ability of older patients to understand their disease and prognosis. Our study only recruited patients who were considering or receiving active treatments, and it is possible that older patients with severe cognitive impairment were screened out from the study. Discordance was more common in caregivers with poorer self-reported physical health, although the reason for this is unclear. A prior study has shown that patients with better performance status were more likely to have inaccurate beliefs about cancer curability [53]. The relationship between caregiver health and discordance should therefore be further investigated. This is important because many caregivers of older adults have poor physical health and comorbidities [54].

Prior studies have demonstrated that acceptance of prognosis is associated with greater anxiety symptoms in patients, but this association is less well studied in caregivers [55, 56]. We showed that caregiver anxiety was lower in dyads characterized by severe discordance in beliefs about curability, which, like in patients [55], may reflect a lack of acceptance of prognosis or the use of coping mechanisms to ward off anxiety. However, this area requires further investigation. Although discussion of prognosis may raise anxiety in some caregivers and patients, it might strengthen the patient-physician relationship [57]. Oncologists who convey accurate prognostic information might also expose patients to fewer unnecessary and aggressive treatments that can cause more harm than benefits over the longer term. Palliative care interventions could help support oncologists' efforts to convey prognosis [55].

Consistent with prior research [4] and our hypothesis, discordance was more prevalent among dyads with non-white patients and non-white caregivers. Oncologist race was not associated with discordance in beliefs about curability. Higher discordance in patients and caregivers of non-white race may be partially due to cultural barriers [58, 59] associated with the delivery of prognostic information [60]. In addition, disease perceptions vary based on racial and cultural background [61–63], which may affect how prognostic information is processed, encoded, recalled, and accepted.

Compared with patient-oncologist dyads involving older patients with breast cancer, dyads in which patients had lung cancer or gastrointestinal cancer were more likely to be discordant in their beliefs about curability. This intriguing finding might suggest differences in how oncologists communicate prognosis with older patients who have lung or gastrointestinal cancer compared with breast cancer [64, 65]. Perhaps oncologists are more reluctant to share prognostic information with older patients with lung or gastrointestinal cancer. It is also possible that older patients with advanced gastrointestinal or



**Figure 1.** Distribution of beliefs about curability (patients, caregivers, and oncologists were asked the following question: “What do you believe are the chances the cancer will go away and never come back with treatment?”).

**Table 3.** Prevalence and extent of prognostic discordance between patients and oncologists, and between caregivers and oncologists

| Patient—Oncologist Dyads, n = 336  | Discordance <sup>a</sup>                      |            |                       |           |  |          |          | Concordance |
|------------------------------------|---|------------|-----------------------|-----------|--|----------|----------|-------------|
|                                    | Patient reported a greater likelihood of cure |            |                       |           | Oncologist reported a greater likelihood of cure |          |          |             |
| Total, n (%)                       | 179 (53.3%)                                   |            |                       |           | 23 (6.8%)  |          |          | 134 (39.8%) |
| Scale points selected              | 1 point                                       | 2 points   | 3 points <sup>b</sup> | 4 points  | 1 point  | 2 points | 3 points |             |
| Number selecting that point, n (%) | 70 (20.8%)                                    | 59 (17.6%) | 33 (9.8%)             | 17 (5.1%) | 20 (6.0%)  | 2 (0.6%) | 1 (0.3%) |             |

| Caregiver—Oncologist Dyads, n = 245 | Discordance <sup>a</sup>                        |            |                       |           |  |          |          | Concordance |
|-------------------------------------|---|------------|-----------------------|-----------|--|----------|----------|-------------|
|                                     | Caregiver reported a greater likelihood of cure |            |                       |           | Oncologist reported a greater likelihood of cure |          |          |             |
| Total, n (%)                        | 100 (40.8%)                                     |            |                       |           | 28 (11.4%)                                       |          |          | 117 (47.8%) |
| Scale points selected               | 1 point   | 2 points   | 3 points <sup>c</sup> | 4 points  | 1 point  | 2 points | 3 points |             |
| Number selecting that point, n (%)  | 34 (13.9%)                                      | 29 (11.8%) | 26 (10.6%)            | 11 (4.5%) | 22 (8.9%)  | 3 (1.2%) | 3 (1.2%) |             |

<sup>a</sup>Beliefs about curability in patients, caregivers, and oncologists were assessed on a 5-point ordinal scale, including 100% (1), >50% (2), 50/50 (3), <50% (4), 0% (5). Patient-oncologist and caregiver-oncologist prognostic discordance were defined as the presence of any difference on the 5-point ordinal scale.

<sup>b</sup>In 26 (78.8%) of the 33 patient-oncologist dyads in this column, patients selected >50% and oncologists selected 0%.

<sup>c</sup>In 23 (88.5%) of the 26 caregiver-oncologist dyads in this column, caregivers selected >50% and oncologists selected 0%.

lung cancer may have a different understanding about the chance of cure compared with those with breast cancer [56, 66, 67]. These differences may be driven by several factors. Prognoses of lung and gastrointestinal cancers are generally worse than those of breast cancer; the worse the news, the more difficult it might be for patients to process and encode [68]. Moreover, given the gravity of the prognoses in lung and gastrointestinal cancers, it might be more difficult for older patients to accept terrifying prognostic information, even if it is understood and encoded [69]. There are also different societal perceptions, with more negative attitudes toward lung versus breast cancer [70].

Along similar lines, societal efforts in promoting cancer awareness have historically focused more on breast cancer [70, 71].

Individuals with fewer years of education and those with lower incomes are more likely to receive chemotherapy and be hospitalized before death and less likely to be referred for palliative care or hospice [72–74]. Observed socioeconomic disparities in cancer care outcomes remain poorly understood. We showed that severe discordance in beliefs about curability was more common in older patients and caregivers with lower annual household incomes, which is an indicator of socioeconomic status (SES). Lower levels of health literacy and higher

**Table 4.** Bivariate and multivariate analyses evaluating correlates of patient-oncologist discordance

| Variables  | Yes         | No          | OR (95% CI)       | <i>p</i> value | AOR (95% CI) ( <i>n</i> = 322) | <i>p</i> value |
|--|-------------|-------------|-------------------|----------------|--------------------------------|----------------|
| Prognostic discordance, <i>n</i> (%) <sup>*</sup>        |             |             |                   |                |                                |                |
| Race   |             |             |                   |                |                                |                |
| White  | 177 (87.6)  | 131 (97.8)  | Reference         | —              | Reference                      |                |
| Non-white  | 25 (12.4)   | 3 (2.2)     | 6.17 (2.14–17.73) | <.001          | 5.77 (1.90–17.50)              | .002           |
| Annual household income <sup>a</sup>                     |             |             |                   |                |                                |                |
| >\$50,000  | 59 (29.2)   | 51 (38.4)   | Reference         | —              | —                              | —              |
| ≤\$50,000  | 97 (48.0)   | 56 (42.1)   | 1.50 (0.97–2.31)  | .07            | —                              | —              |
| Declined to answer                                       | 45 (22.4)   | 26 (19.6)   | 1.50 (0.93–2.40)  | .10            | —                              | —              |
| Cancer type <sup>b</sup>                                 |             |             |                   |                |                                |                |
| Breast   | 21 (10.4)   | 23 (17.3)   | Reference         | —              | Reference                      |                |
| Gastrointestinal   | 48 (23.8)   | 32 (24.1)   | 1.64 (1.06–2.54)  | .01            | 1.55 (1.09–2.21)               | .02            |
| Genitourinary  | 17 (8.4)    | 20 (15.0)   | 0.93 (0.48–1.81)  | .83            | 0.92 (0.45–1.89)               | .81            |
| Lung   | 57 (28.2)   | 31 (23.3)   | 2.01 (1.18–3.44)  | .01            | 1.95 (1.29–2.94)               | .002           |
| Other  | 59 (29.2)   | 27 (20.3)   | 2.39 (1.32–4.33)  | .004           | 2.29 (1.28–4.10)               | .003           |
| Cognition  |             |             |                   |                |                                |                |
| Impaired   | 68 (33.7)   | 35 (26.1)   | 1.44 (0.97–2.13)  | .07            | —                              | —              |
| Recalled prognosis <sup>a</sup>                          |             |             |                   |                |                                |                |
| Completely/Mostly  | 144 (72.0)  | 112 (83.6)  | Reference         | —              | —                              | —              |
| A little/Not at all                                      | 56 (28.0)   | 22 (16.4)   | 3.92 (0.74–20.72) | .11            | —                              | —              |
| Oncologists' age in years, mean (SD) <sup>c</sup>        | 47.7 (10.6) | 49.4 (11.4) | 0.99 (0.97–1.00)  | .06            | —                              | —              |
| Oncologists' years in practice, mean (SD) <sup>d</sup>   | 13.0 (10.5) | 16.3 (11.5) | 0.87 (0.82–0.93)  | <.001          | 0.90 (0.84–0.97)               | .004           |
| Severe prognosis discordance, <i>n</i> (%) <sup>**</sup> |             |             |                   |                |                                |                |
| Age in years, mean (SD)                                  | 77.6 (5.8)  | 76.1 (4.9)  | 1.05 (0.99–1.12)  | .09            | —                              | —              |
| Marital status   |             |             |                   |                |                                |                |
| Married  | 28 (54.9)   | 192 (67.4)  | Reference         | —              | —                              | —              |
| Other  | 23 (45.1)   | 93 (32.6)   | 1.70 (1.06–2.72)  | .03            | —                              | —              |
| Race   |             |             |                   |                |                                |                |
| White  | 40 (78.4)   | 268 (94.0)  | Reference         | —              | Reference                      |                |
| Non-white  | 11 (21.6)   | 17 (6.0)    | 4.33 (2.26–8.33)  | <.001          | 4.52 (2.38–8.59)               | <.001          |
| Education  |             |             |                   |                |                                |                |
| Some college or above                                    | 24 (47.1)   | 165 (57.9)  | Reference         | —              | —                              | —              |
| High school graduate                                     | 17 (33.3)   | 90 (31.6)   | 2.29 (0.69–7.58)  | .17            | —                              | —              |
| <High school   | 10 (19.6)   | 30 (10.5)   | 1.30 (0.83–2.02)  | .25            | —                              | —              |
| Annual household income <sup>a</sup>                     |             |             |                   |                |                                |                |
| >\$50,000  | 8 (60.0)    | 102 (43.3)  | Reference         | —              | —                              | —              |
| ≤\$50,000  | 30 (16.0)   | 123 (35.9)  | 3.11 (1.57–6.14)  | .001           | 2.50 (1.28–4.88)               | .007           |
| Declined to answer                                       | 12 (24.0)   | 59 (20.8)   | 2.59 (0.91–7.39)  | .07            | 2.38 (0.85–6.64)               | .10            |
| Cancer type <sup>b</sup>                                 |             |             |                   |                |                                |                |
| Breast   | 5 (9.8)     | 39 (13.7)   | Reference         | —              | Reference                      |                |
| Gastrointestinal   | 9 (17.8)    | 71 (25.0)   | 0.99 (0.27–3.58)  | .99            | 1.26 (0.35–4.50)               | .72            |
| Genitourinary  | 3 (5.9)     | 34 (12.0)   | 0.69 (0.21–2.21)  | .53            | 1.14 (0.30–4.28)               | .84            |
| Lung   | 14 (27.5)   | 74 (26.1)   | 1.48 (0.69–3.14)  | .31            | 1.83 (0.63–5.27)               | .27            |
| Other  | 20 (39.2)   | 66 (23.2)   | 2.36 (0.97–5.78)  | .06            | 3.39 (1.23–9.32)               | .02            |
| Instrumental social support                              |             |             |                   |                |                                |                |
| Impaired   | 24 (47.1)   | 76 (26.7)   | 2.44 (1.43–4.17)  | .001           | 2.35 (1.27–4.36)               | .007           |
| Oncologist race <sup>e</sup>                             |             |             |                   |                |                                |                |
| White  | 27 (55.1)   | 181 (65.1)  | Reference         | —              | —                              | —              |
| Non-white  | 22 (44.9)   | 97 (34.9)   | 1.17 (0.93–1.48)  | .18            | —                              | —              |

\*Total number for Yes, *n* = 202; for No, *n* = 134.

\*\*Total number for Yes, *n* = 51; for No, *n* = 285.

<sup>a</sup>Two patients had missing data.

<sup>b</sup>One patient had missing data.

<sup>c</sup>Evaluated in a separate multivariate model because of significant correlation with oncologists' years in practice.

<sup>d</sup>Five units decrease in the number of years in practice.

<sup>e</sup>Data on oncologist's race were missing in nine patients.

Abbreviations: —, not significant; AOR, adjusted odds ratio; CI, confidence interval; OR, odds ratio.

**Table 5.** Bivariate and multivariate analyses evaluating correlates of caregiver-oncologist discordance

| Variables  | Yes         | No          | OR (95% CI)       | p value | AOR (95% CI) (n = 245) | p value |
|--|-------------|-------------|-------------------|---------|------------------------|---------|
| Prognostic discordance, n (%) <sup>*</sup>             |             |             |                   |         |                        |         |
| Race   |             |             |                   |         |                        |         |
| White  | 112 (87.5)  | 112 (95.7)  | Reference         | —       | Reference              | —       |
| Non-white  | 16 (12.5)   | 5 (4.3)     | 3.20 (0.85–12.01) | .08     | 3.32 (1.01–10.94)      | .05     |
| Education  |             |             |                   |         |                        |         |
| Some college or above                                  | 85 (66.4)   | 88 (75.2)   | Reference         | —       | —                      | —       |
| High school graduate                                   | 38 (29.7)   | 23 (19.7)   | 1.71 (0.98–2.98)  | .06     | —                      | —       |
| <High school   | 5 (3.9)     | 6 (5.1)     | 0.86 (0.30–2.51)  | .79     | —                      | —       |
| Annual household income <sup>a</sup>                   |             |             |                   |         |                        |         |
| >\$50,000  | 58 (45.7)   | 35 (29.9)   | Reference         | —       | —                      | —       |
| ≤\$50,000  | 47 (37.0)   | 65 (55.6)   | 1.50 (0.84–2.70)  | .17     | —                      | —       |
| Declined to answer                                     | 22 (17.3)   | 17 (14.5)   | 1.45 (0.60–3.49)  | .41     | —                      | —       |
| Comorbidity  |             |             |                   |         |                        |         |
| Impaired   | 72 (56.3)   | 79 (67.5)   | 1.62 (0.91–2.87)  | .10     | —                      | —       |
| SF-12 physical health, mean (SD) <sup>a-c</sup>        | 46.2 (11.0) | 48.7 (10.3) | 0.89 (0.79–1.00)  | .06     | 0.88 (0.78–1.00)       | .05     |
| Severe prognostic discordance, n (%) <sup>**</sup>     |             |             |                   |         |                        |         |
| Age in years, mean (SD)                                | 69.6 (11.8) | 65.1 (12.4) | 1.18 (0.99–1.40)  | .06     | —                      | —       |
| Education  |             |             |                   |         |                        |         |
| Some college or above                                  | 24 (60.0)   | 88 (72.7)   | Reference         | —       | —                      | —       |
| High school graduate                                   | 13 (32.5)   | 23 (23.4)   | 1.68 (0.87–3.25)  | .12     | —                      | —       |
| <High school   | 3 (7.5)     | 6 (3.9)     | 2.33 (0.63–8.56)  | .20     | —                      | —       |
| Annual household income <sup>a</sup>                   |             |             |                   |         |                        |         |
| >\$50,000  | 17 (40.0)   | 106 (52.0)  | Reference         | —       | Reference              | —       |
| ≤\$50,000  | 16 (42.5)   | 66 (32.4)   | 1.51 (0.88–2.60)  | .14     | 1.84 (1.03–3.29)       | .04     |
| Declined to answer                                     | 7 (17.5)    | 32 (15.7)   | 1.36 (0.48–3.89)  | .56     | 1.35 (0.49–3.74)       | .56     |
| Comorbidity  |             |             |                   |         |                        |         |
| Impaired   | 18 (45.0)   | 76 (37.1)   | 1.39 (0.85–2.27)  | .19     | —                      | —       |
| GAD-7  | 2.8 (2.8)   | 3.4 (4.7)   | 0.91 (0.84–0.99)  | .02     | 0.90 (0.83–0.98)       | .01     |
| PHQ-2 <sup>d</sup>                                     | 0.4 (0.9)   | 0.7 (1.2)   | 0.74 (0.53–1.04)  | .08     | —                      | —       |
| SF-12 mental health, mean (SD) <sup>a-d</sup>          | 52.9 (8.2)  | 50.8 (10.4) | 1.12 (0.98–1.28)  | .10     | —                      | —       |
| Oncologist gender                                      |             |             |                   |         |                        |         |
| Male   | 31 (79.5)   | 136 (68.0)  | Reference         | —       | —                      | —       |
| Female   | 8 (20.5)    | 64 (32.0)   | 0.55 (0.22–1.36)  | .19     | —                      | —       |
| Oncologist race  |             |             |                   |         |                        |         |
| White  | 27 (69.2)   | 118 (59.3)  | Reference         | —       | —                      | —       |
| Non-white  | 12 (30.8)   | 81 (40.7)   | 0.65 (0.37–1.23)  | .13     | —                      | —       |
| Oncologists' years in practice, mean (SD) <sup>e</sup> | 16.9 (11.3) | 14.4 (10.5) | 1.11 (0.96–1.30)  | .15     | —                      | —       |

<sup>\*</sup>Total number for Yes, n = 128; for No, n = 117.

<sup>\*\*</sup>Total number for Yes, n = 40; for No, n = 205.

<sup>a</sup>One caregiver had missing data.

<sup>b</sup>SF-12 physical or mental health ranges from 0 to 100, with a lower score indicating more impairment.

<sup>c</sup>Five units increase or decrease in SF-12 physical or mental health score.

<sup>d</sup>There were significant correlations between GAD-7, PHQ-2, and SF-12 Mental Health, so these variables were evaluated in a separate multivariate model.

<sup>e</sup>Five units decrease in the number of years in practice.

Abbreviations: —, not significant; AOR, adjusted odds ratio; CI, confidence interval; GAD-7, Generalized Anxiety Disorder-15; OR, odds ratio; PHQ-2, Patient Health Questionnaire-2; SF12, 12-Item Short Form Health Survey.

levels of fatalism are both common in patients with lower SES [75], both of which may contribute to prognostic discordance [51]. Power asymmetries in the patient/caregiver-clinician relationship [76, 77] are accentuated in the care of individuals with lower SES. Many studies have shown that individuals with lower SES perceive that their physicians treat and communicate with them differently, and believe that there may be differences in testing, medication, access to care, and quality of care [78–80]. In the cancer setting, these perceptions might heighten patient/caregiver distrust of physicians and contribute to discordance in beliefs about curability.

Discordance in beliefs about curability was less common in dyads involving oncologists who practiced longer. Experienced oncologists may have a higher propensity [81] or comfort level [82] for discussing prognosis, which can help patients understand their illness. It is also possible that older patients are more likely to believe or trust more experienced oncologists [83].

Taken together, our findings suggest that discordance about beliefs about curability is present in more than 50% of oncologist-patient and oncologist-caregiver dyads. In more than 15% of these dyads, the discordance may be severe enough to



raise difficult questions about whether patients are sufficiently informed to make treatment decisions. An intervention that focuses on communication was attempted to promote greater agreement about prognosis but was unsuccessful, suggesting that more than communication training is required [4, 39]. Multimodal interventions are needed to improve how oncologists communicate prognosis and to empower older patients and their caregivers to enquire about prognosis, taking into account the racial, cultural, and socioeconomic backgrounds of the patients and caregivers as well as their beliefs, emotions, and fears [39]. In addition, the problem of severe discordance may require broader public health and policy initiatives to assess whether patients are adequately informed to provide consent to potentially toxic treatments [84, 85]. Nonetheless, although avoiding discordance would seem to be clinically intuitive, it is important to note that, unlike patient's perceived prognosis and curability, the association of discordance in beliefs about curability with outcomes is not well studied, and future studies are needed to assess its relationship with outcomes.

The strengths of our study include the number of older patients and their caregivers enrolled as well as its enrollment in the community oncology setting. There are several limitations to our study. First, this observational study was not designed to determine how or why discordance in beliefs about curability occurs. Second, our study included a small number of non-white patients and caregivers. Third, our study is likely underpowered to detect significant associations between oncologist race and discordance in beliefs about curability, and these associations require further investigations. Finally, the psychometric properties of the item used to assess beliefs about curability are unknown.

## CONCLUSION

Discordance in beliefs about curability is common and occurred in more than half of patient-oncologist and caregiver-oncologist dyads. In about 15% of these dyads, discordance was severe enough to raise serious questions about the process by which older patients consent to treatment. Our study supports the

need for interventions targeted at the oncologist, patient, caregiver, and societal levels to improve the delivery of prognostic information and patients'/caregivers' understanding and acceptance of prognosis.

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## DISCLOSURES

The authors indicated no financial relationships.

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