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Associations of caregiver-oncologist discordance in prognostic understanding with caregiver-reported therapeutic alliance and anxiety

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Abstract

Context—Discordance in prognostic understanding between caregivers of adults with advanced cancer and the oncologist may shape caregivers' views of the oncologist and bereavement outcomes.

Objectives—We examined prospective associations of caregiver-oncologist discordance with caregiver-oncologist therapeutic alliance and caregiver anxiety following patient death.

Methods—We conducted a secondary analysis of data collected in a cluster randomized controlled trial from August 2012 to June 2014 in Western New York and California. At enrollment, caregivers and oncologists used a 7-point scale to rate their beliefs about the patient's curability and living ≥2 years: 100%, about 90%, about 75%, about 50/50, about 25%, about 10%, and 0%. Discordance was defined as a difference of ≥2 points. Outcomes at 7 months after patient death included caregiver-oncologist therapeutic alliance [modified 5-item Human Connection (THC) scale] and caregiver anxiety (Generalized Anxiety Disorder-7). We conducted multivariable linear regression models to assess the independent associations of discordance with alliance and anxiety.

Results: We included 97 caregivers (mean age=63) and 38 oncologists; 41% of caregiver-oncologist dyads had discordant beliefs about the patient's curability and 63% of caregiver-oncologist dyads had discordant beliefs about living ≥2 years. On multivariate analysis, discordance in beliefs about curability was associated with lower anxiety ($\beta=-2.20$, SE=0.77, p=0.005). Discordance in beliefs about length of life was associated with a weaker alliance ($\beta=-5.87$, SE=2.56, p=0.02).

Conclusion: A better understanding of how caregivers understand and come to terms with poor prognoses will guide interventions to improve cancer care delivery and outcomes of cancer treatment.

Keywords

discordance; beliefs about curability; beliefs about length of life; therapeutic alliance; anxiety

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1. Introduction

Caregivers play an important role in the care of patients with advanced cancer. They not only accompany patients to medical appointments, offer advice, and provide emotional support, but also are involved in cancer treatment decision-making. Studies have shown that up to 55% of caregivers have a different understanding of the patient's prognosis relative to their oncologist, most of which are due to caregivers being more optimistic than the oncologist.[1,2]

Prior research has also shown that poor prognostic understanding among patients with cancer is associated with both poor and good outcomes.[3–9] Patients who have poor prognostic understanding are less likely to utilize palliative and hospice care[3–5] and more likely to receive aggressive life-prolonging care,[10] but they report less anxiety and fewer depressive symptoms.[6–9] We are aware of no prior studies examining the relationships between caregiver prognostic understanding and caregiver bereavement outcomes.

Therapeutic alliance is generally described as a collaborative relationship between physicians/oncologists and patients,[11,12] but is applicable to caregivers as well, especially in the setting of advanced life-limiting disease. Just as a stronger patient-physician alliance is associated with better patient outcomes (e.g., higher rates of treatment adherence,[13] superior patient quality of life, greater illness acceptance, lower likelihood of receiving aggressive care[11,14]), a stronger caregiver-physician alliance may reflect better satisfaction with cancer care, perhaps as a consequence of clinician communication.[15] However, the therapeutic alliance between caregivers and oncologists is infrequently studied.[16,17]

The objective of this exploratory secondary analysis was to evaluate the associations of caregiver-oncologist discordance in prognostic understanding, in the form of beliefs about curability and length of life, with caregiver-oncologist therapeutic alliance measured 7 months after the patient's death. In addition, we also evaluated the associations of discordance with caregiver anxiety.

2. Methods

2.1 Study design, setting, and participants

This was an exploratory secondary analysis of a cluster randomized controlled trial [Values and Options in Cancer Care (VOICE); ClinicalTrials.gov, NCT01485627] in Western New York and Northern California (three academic medical centers, three community hospitals, and four community-based cancer clinics). Detailed information on the study has been previously reported.[18–20] Briefly, oncologists were randomized to an intervention or a control arm. In the intervention arm, oncologists received individualized communication training using standardized patient-instructors. Their patients (and caregivers if available) participated in an in-person coaching session and up to three follow-up telephone calls with their coach. Oncologists, patients, and/or their caregivers in the control arm received usual care. Participants were recruited from August 2012 to June 2014. All oncologists, patients, and/or their caregivers provided informed consent prior to study enrollment. The study was approved by the Institutional Review Board at each study site.

2.2 Participants and brief description of the primary study

The VOICE trial included medical oncologists who care for patients with non-hematologic malignancies at the participating clinics. Patients of the participating oncologists were recruited. Eligibility criteria for patients included aged ≥21 years, able to understand spoken English, able to provide informed consent, and stage III or IV non-hematologic malignancy (for patients with stage III cancer, their oncologist must affirm that they "would not be surprised" if the patient were to die within 12 months). We excluded hospitalized patients and patients on hospice. For caregivers, patients were asked to identify “a family member, partner, friend, or other individual involved with your health care issues, preferably someone who comes to physician appointments with you”. Caregivers were aged ≥21, able to understand spoken English, and able to provide informed consent. The primary study tracked the patient survival until December 2016. For our analysis, we included caregivers of patients who completed measures 7 months after the patient’s death.

2.3 Measures

Oncologists provided information on their demographics and beliefs about the patient’s chance of cure and length of life at enrollment. For chance of cure, they were asked “what do you believe are this patient’s chances of being cured?” For length of life estimates, they were asked “what do you believe are the chances that this patient will live for 2 years or more?” Response options were 100%, about 90%, about 75%, about 50/50, about 25%, about 10%, 0%, and “don’t know”. These questions and responses were based on the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) measure.[21]

Caregivers completed an assessment at enrollment which included their demographics, their beliefs about the patient’s chance of cure and length of life (question and response options were same as above), and their perceived therapeutic alliance with the patient’s oncologist. Seven months after the patient’s death, caregivers repeated the assessment on therapeutic alliance and also self-reported their anxiety levels.

2.3.1 Key independent variables: Caregiver-oncologists discordance in beliefs about curability and length of life—Discordance was defined categorically as a difference of two or more levels in response options between the caregiver and oncologist based on a prior study.[22] For example, if the caregiver selected 90% and the oncologist selected 50/50, this was considered discordant. If the caregiver selected 90% and the oncologist selected 75%, this was considered concordant.

2.3.2 Key dependent variables: Caregiver-oncologist therapeutic alliance and caregiver anxiety—The dependent variables were assessed approximately seven months after the death of the patient. We selected seven months as it is a common time point in the bereavement literature[14,23,24] as the effects of acute grief may last for a few months, and we conducted the assessments after the effects of acute grief were presumed to resolve. Therapeutic alliance was measured using items from The Human Connection (THC) scale.[11] The 16-item THC scale was originally developed to assess therapeutic alliance between patients and oncologists.[11] Caregivers were asked to answer five adapted questions about the patient’s oncologist with regard to the last months of the patient’s life: 1) How often did the doctor ask you how you were coping with the patient’s illness? 2) How often did the doctor pay close attention to what you were saying? 3) How often did the doctor address your needs as a person? 4) How much did you feel the doctor cared about you? 5) How concerned was the doctor about your quality of life? Each question was rated from 0 (not at all) to 10 (always or completely), and a higher summary score indicated a stronger therapeutic alliance (range 0-50). Anxiety levels over the prior 2 weeks were assessed using the 7-item

Generalized Anxiety Disorder-7 (GAD-7).[25] Items are rated from 0 (not at all sure) to 3 (nearly every day) and higher scores indicate worse anxiety levels (range 0-21).[26] A cut-off score of 5, 10, and 15, respectively, indicate mild, moderate, and severe anxiety.[27]

2.3.3 Covariates—Covariates included caregiver demographics and study arm. Caregiver demographics included age, gender, race (white vs. non-white), marital status (married vs. not-married), and education (at least some high school vs. some college vs. college graduate or above). We did not include patient demographics in the multivariable analyses due to multicollinearity with caregiver demographics.

2.4 Statistical analyses

After conducting descriptive statistics, we examined the bivariate associations between binary independent variables (caregiver-oncologist discordance in beliefs about curability and length of life) and the two dependent continuous outcomes (THC, GAD-7). We further evaluated adjusted associations in four separate linear regression models. We included caregiver demographics and study arm as covariates. In addition, for adjusted analysis for THC scale, we included baseline value (baseline value for GAD-7 was not collected). We used generalized estimating equations to account for clustering at the oncologist level.[28] We performed all analyses using SAS 9.4 (SAS Institute Inc., Cary, NC).

In sensitivity analyses, we included time from the baseline study visit to the patient's death as a covariate. We then repeated the multivariate analyses.

3. Results

The primary study included caregivers for 204 patients; 127 patients died during the study period, and we collected data 7 months after the patient's death from 97 caregivers. Detailed information on these caregivers were previously described.[20] Mean age of the caregivers was 63.2 (SD 11.6, range 22-83), 65% were female, 93% were white, and 81% were married. Approximately 32% were caregivers of patients with gastrointestinal cancer and 28% were caregivers of patients with lung cancer. Table 1 shows the characteristics of the study sample as well as the 38 oncologists.

3.1 Discordance in beliefs about curability and length of life

Figure 1 shows the distribution of beliefs about curability and likelihood of living 2 years; 4% and 9%, respectively, responded "don't know" when asked about their beliefs about the patient's chance of cure and length of life. Forty-one percent (38/92) of the caregiver-oncologist dyads were discordant in beliefs about curability (caregivers were more optimistic than the oncologist in all dyads). Almost 63% (55/87) were discordant in beliefs about 2-year survival (caregivers were more optimistic than the oncologist in 94% of the dyads). Thirty-two percent (27/84) the dyads were discordant in both beliefs about curability and 2-year survival.

3.2 Caregiver-oncologist therapeutic alliance

Mean THC score at 7 months after the patient's death was 28.2 (SD 15.5, IQR 17-45, range 0-50). No significant differences were observed among dyads that were discordant in beliefs about curability. THC scores were significantly lower in caregiver-oncologist dyads that were discordant in beliefs about 2-year survival at enrollment (24.6 vs. 35.0, p=0.002) (Table 2). On multivariate analysis, discordance in beliefs about 2-year survival was significantly associated with lower THC scores 7 months after the patient's death (β =−5.87, SE=2.56, p=0.00) (Table 3). In other words, compared to the concordant dyads, caregivers in the discordant dyads had a 5.87 point lower score on the THC scale.

3.3 Caregiver anxiety

Mean GAD-7 score at 7 months after the patient's death was 2.7 (SD 4.6, IQR 0-3, range 0-21). Caregiver anxiety levels were lower in dyads that were discordant in beliefs about curability at enrollment (1.6 vs. 3.4, p=0.05) (Table 2). Caregiver anxiety levels were not different in dyads that were discordant in beliefs about 2-year survival. On multivariate analysis, discordance in beliefs about curability was associated with lower anxiety levels (β =−2.20, SE=0.77, p=0.005) (Table 3). In other words, compared to the concordant dyads, caregivers in the discordant dyads had a 2.20 point lower score on GAD-7.

3.4 Sensitivity analyses

After adjusting for time from baseline study visit to the patient's death, results were similar. Discordance in beliefs about length of life was associated with lower THC score (β=−6.01, SE=2.61, p=0.01). Discordance in beliefs about curability was associated with lower anxiety levels (β=−2.27, SE=0.76, p=0.003).

4. Discussion

In this analysis, we found that discordance in beliefs about curability and length of life occurred in 41% and 63% of caregiver-oncologist dyads, respectively. The majority of the discordance was due to caregivers being more optimistic than the oncologist. Consistent with prior research, we found that caregiver-oncologist prognostic discordance was associated with both poor outcome (worse alliance) and good outcome (lower anxiety levels). Our findings reflect the need to assess caregiver beliefs about both the patient's curability and length of life; the latter may be more difficult for caregivers to accept. Caregivers may be less likely to accept a shorter length of life as compared to an incurable cancer, as patients may live a long time irrespective of curability. We are unclear the reasons why discordance in curability and length of life were associated with lower anxiety levels and worse alliance, respectively, but not the other way round. They may be measuring different constructs and therefore more studies are required.[29] Factors contributing to discordance are complex, and these include patient-related factors (e.g., race, education, emotional status, social support, fatalism),[30] caregiver-related factors (e.g., race, education, caregiver health),[30,31] physician-related factors (e.g., clinical experience, comfort with prognostic discussion),[30,32,33] and disease-related factors (e.g., cancer type).[30] The interplay of these factors and how they contribute to discordance need to be further investigated.

Prognostic understanding is variably defined in existing literature and includes unrealistic belief about prognosis,[34,35] overestimation of prognosis relative to their oncologist,[2,6,22] and overestimation of prognosis compared to the patient's actual prognosis.[36] While all three constructs are relevant, we chose to study caregiver beliefs about the patient's prognosis relative to the because this is the most used definition in research. Caregivers are an essential component of patient-centered care as they play a major role in cancer treatment decision-making.[37] However, studies of caregiver prognostic understanding are limited. The percentage of discordance between caregivers and oncologists in our study was comparable to that seen in prior studies.[1,2] In older patients with advanced cancer seen by community oncologists in the United States, caregiver-oncologist discordance in beliefs about curability was 50%.[2] In another study of patients with cancer in South Korea, caregiver-oncologist discordance in beliefs about curability was 45%, discordance about treatment goals was 70%, and discordance about disease stage was 66%.[1] These findings emphasize the need to improve communication between oncologist and caregivers.[38] Given the central role that caregivers play in treatment decision-making, working to build trust and ensuring they have accurate information may help improve their satisfaction with cancer care. In addition, caregivers may also help patients understand their disease, treatment, and prognosis, especially when many patients are not able to retain/recall information from clinic encounters.[39]

The importance of caregiver-oncologist therapeutic alliance does not end after the patient's death. Caregivers' experiences during the care of their loved ones may shape how they subsequently interact with the healthcare system.[40] Caregivers who have had a bad experience may be less likely to seek treatment when needed and cope with bereavement.[41] In addition, there is typically little contact between caregivers and oncologists after the patient's death, which deprives caregivers of a source of support. The positive association between caregiver-oncologist discordance in beliefs about 2-year survival and lower therapeutic alliance underscores the need for research on how discordance undermines the alliance.[42] This may help to guide interventions to improve the delivery of prognostic information while strengthening the alliance..[43]

Compared to other studies, caregivers in our sample reported relatively low levels of anxiety. Mean GAD-7 score was 2.7 compared to 9.0 in caregivers of patients with advanced cancer in the inpatient palliative care setting[44] and 4.6-6.1 among patients seen in the primary care setting.[27] Nonetheless, caregivers with a different belief about the patient's curability had even lower anxiety levels after the patient's death, suggesting that they may be actively defending against negative thoughts and emotions.[45] Alternatively, low anxiety might reflect the protective role of optimism. Whether this relationship persists beyond 7 months is unclear and needs to be studied over a longer period of time. In addition, the associations of discordance with other bereavement outcomes such as prolonged grief, physical and mental health, and distress, especially during stressful life events should be further investigated.

Our study has several strengths. First, this was a multicenter study recruited from both academic and community cancer clinics. Second, the study provides a longitudinal relationship of caregiver-oncologist discordance at baseline with caregiver-oncologist therapeutic alliance and caregiver anxiety levels. There are several limitations to our study.

First, most of the caregivers were white and well-educated, and therefore our findings may not be generalizable to non-white caregivers and those with lower education levels. Second, patient deaths were tracked for 30 months after the last patient was enrolled onto the study and therefore caregivers of the patients who died after that were not included. Future studies could examine long-term caregiver outcomes and their associations with discordance prior to the patient's death. In addition, nearly one-third of dyads were excluded from the regression analyses either because caregivers were lost to follow-up 7 months after the patient's death or because oncologists/caregivers responded "don't know" with regards to their beliefs about the patient's chance of cure and prognosis. The latter subgroup may merit further investigations. Third, we did not measure caregiver anxiety levels at baseline. Forth, we used binary classification of prognostic understanding into discordance and concordance, which was commonly used in published studies.[6,22,30,46] Prognostic understanding may be dynamic, and we only measured it at enrollment. Future studies should explore degree of and change in discordance. Fifth, the THC scale was validated for use between patients and oncologists,[11] but not between caregivers and oncologists. However, a prior study has used the THC scale for caregivers in the intensive care unit setting.[16] Therapeutic alliance was also measured at 7-month following patient death and this may be subjected to recall bias. Sixth, we did not collect information on what the oncologist actually communicated to the caregiver in terms of the patient's cancer curability and length of life. Finally, given this is an exploratory analysis, we did not adjust for multiple testing.

In conclusion, caregiver-oncologist discordance in beliefs about curability and 2-year survival was common. Although caregiver-oncologist discordance may protect against anxiety, it may compromise the caregiver-oncologist therapeutic alliance and potentially caregiver satisfaction with cancer care. A better understanding of how caregivers understand and come to terms with poor prognoses is needed to improve cancer care delivery and outcomes of advanced cancers.

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Key Message:

Forty-one percent of caregiver-oncologist dyads had discordant beliefs about the patient's curability and 63% of caregiver-oncologist dyads had discordant beliefs about living ≥2 years (caregivers were more optimistic in 94% of dyads). Caregiver-oncologist discordance may protect against anxiety but compromise the caregiver-oncologist alliance

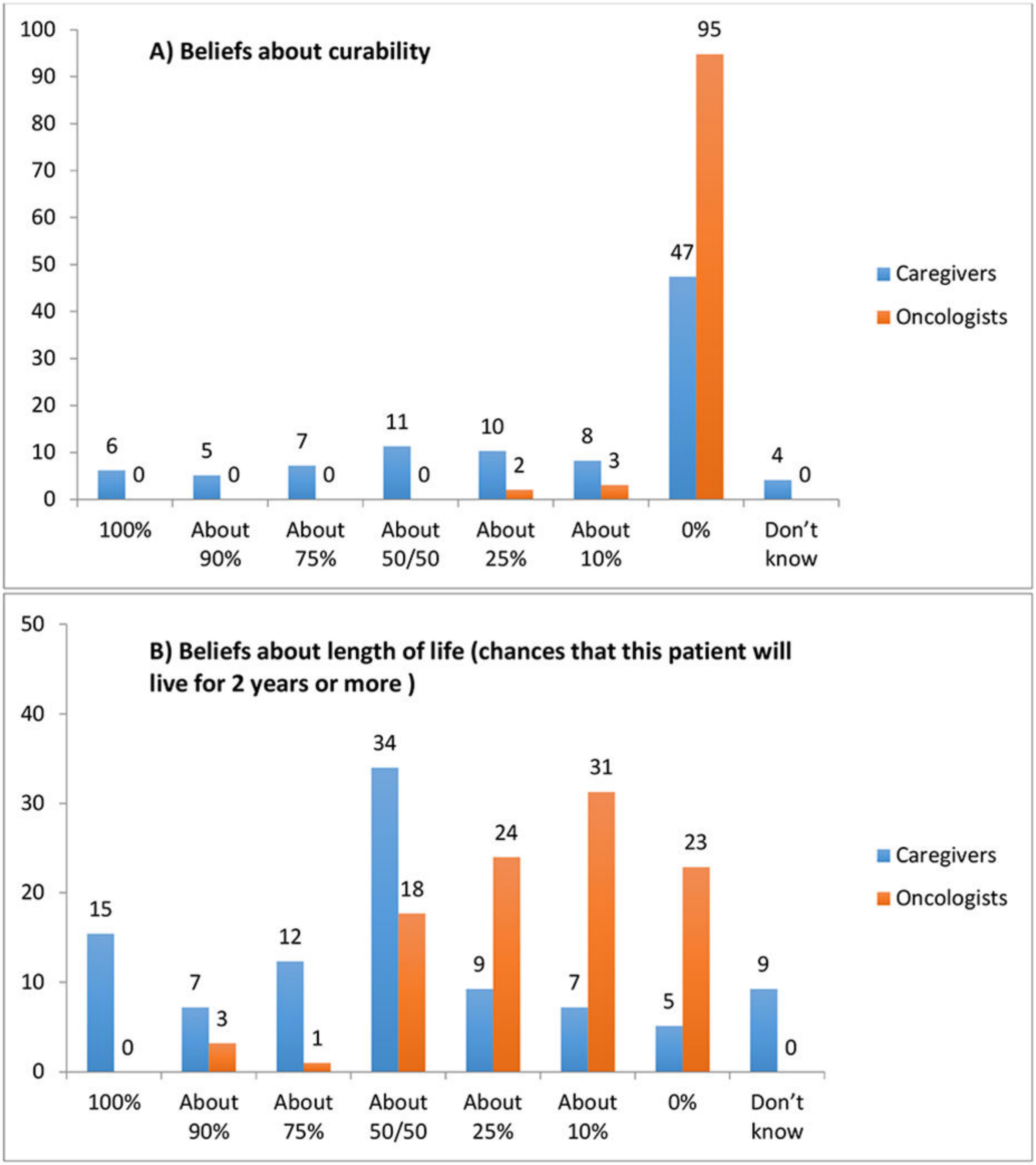

Figure 1:

Distribution of caregiver and oncologist A) beliefs about curability and B) beliefs about length of life

Table 1:

Characteristics of the study sample

Variables		
Caregivers (N=97)		
Age, mean (SD)		63.2 (11.6)
Gender, N (%)	Male Female	34 (35.1) 63 (65.0)
Race, N (%)[a]	White Non-white	87 (92.6) 7 (7.5)
Marital Status, N (%)	Married Non-married	79 (81.4) 18 (18.6)
Education, N (%)	College degree or above Some college High school or below	39 (40.2) 31 (32.0) 27 (27.8)
Cancer type (patient), N (%)[b]	Gastrointestinal Lung Other	31 (32.3) 27 (28.1) 38 (39.6)
Study arm, N (%)	Control Intervention	49 (50.5) 48 (49.5)
Discordance in beliefs about curability, N (%)[c]	Yes No	38 (39.2) 54 (58.7)
Discordance in length of life, N (%)[d]	Yes No	55 (63.2) 32 (36.8)
Therapeutic alliance (THC scale) at baseline, mean (SD)[e]		27.5 (12.7)
Oncologist (N=38)		
Age, mean (SD)		44.3 (9.8)
Gender, N (%)	Male Female	26 (68.4) 12 (31.6)
Race, N (%)	White Non-white	20 (52.6) 18 (47.4)
Years in practice, mean (SD)		11.8 (10.4)

[a] 3 caregivers had missing data

[b] 1 patient had missing data

[c] 4 patients selection the “don’t know” option and 1 oncologist did not provide response, therefore discordance cannot be determined

[d] 9 patients selection the “don’t know” option and 1 oncologist did not provide response, therefore discordance cannot be determined

[e] 2 caregivers had missing data

Abbreviation: THC scale, the human connection scale

Table 2:

Bivariate analyses of beliefs about curability and length of life with outcomes at 7 months after the patient's death

Outcomes at 7 month after the patient's death	**Total**	**Discordance in beliefs about curability (N=92)**			**Discordance in beliefs about length of life (N=87)**		
		Yes (N=38)	**No (N=54)**	**P-value**	**Yes (N=55)**	**No (N=32)**	**P-value**
Caregiver-oncologist therapeutic alliance (THC scale)[a]	28.3 (15.5)	26.7 (14.7)	29.2 (16.1)	0.46	24.6 (15.2)	35.0 (14.0)	0.002
Caregiver anxiety (GAD-7)[b]	2.7 (4.6)	1.6 (3.2)	3.4 (5.1)	0.05	2.8 (4.6)	2.8 (4.7)	0.98

[a] A higher score indicates better caregiver-oncologist therapeutic alliance

[b] A higher score indicates higher caregiver anxiety

Abbreviations: THC scale, the human connection scale; GAD-7, Generalized Anxiety Disorder-7

Table 3:

Multivariate analyses of beliefs about curability and length of life with outcomes at 7 months after the patient's death

Outcomes at 7 month after the patient's death	**Discordance in beliefs about curability (N=92)**			**Discordance in beliefs about length of life (N=87)**		
	Beta Estimate	**Standard Error**	**P-value**	**Beta Estimate**	**Standard Error**	**P-value**
Caregiver-oncologist therapeutic alliance (THC scale)[a,b]	−2.57	2.26	0.26	−5.87	2.56	0.02
Caregiver anxiety (GAD-7)[c,d]	−2.20	0.77	0.005	−0.09	1.06	0.93

[a] A higher score indicates better caregiver-oncologist therapeutic alliance

[b] Adjusted for caregiver age, gender, race, education, marital status, study arm, baseline THC scale, and clustering at the oncologist level

[c] A higher score indicates higher caregiver anxiety

[d] Adjusted for caregiver age, gender, race, education, marital status, study arm, and clustering at the oncologist level

Abbreviations: THC scale, the human connection scale; GAD-7, Generalized Anxiety Disorder-7