Relationship Between Perceptions of Treatment Goals and Psychological Distress in Patients With Advanced Cancer

Areej El-Jawahri, MD^{1,2}; Deborah Forst, MD^{1,2}; Alyssa Fenech, BA^{1,2}; Keri O. Brenner, MD^{2,3,4}; Amanda L. Jankowski, BA^{1,2}; Lauren Waldman, BS^{1,2}; Isabella Sereno, MEd^{1,2}; Ryan Nipp, MD, MPH^{1,2}; Joseph A. Greer, PhD^{1,2}; Lara Traeger, PhD^{1,2}; Vicki Jackson, MD^{2,3}; and Jennifer Temel, MD^{1,2}

ABSTRACT

Background: Studies have shown gaps in prognostic understanding among patients with cancer. However, few studies have explored patients' perceptions of their treatment goals versus how they perceive their oncologist's goals, and the association of these views with their psychological distress. **Methods:** We conducted a cross-sectional study of 559 patients with incurable lung, gastrointestinal, breast, and brain cancers. The Prognosis and Treatment Perception Questionnaire was used to assess patients' reports of their treatment goal and their oncologist's treatment goal, and the Hospital Anxiety and Depression Scale was used to assess patients' psychological symptoms. **Results:** We found that 61.7% of patients reported that both their treatment goal and their oncologist's treatment goal were noncurative, whereas 19.3% reported that both their goal and their oncologist's goal were to cure their cancer, 13.9% reported that their goal was to cure their cancer whereas their oncologist's goal was noncurative, and 5% reported that their goal was noncurative whereas their oncologist's goal was curative. Patients who reported both their goal and their oncologist's goal as noncurative had higher levels of depression ($B=0.99$; $P=.021$) and anxiety symptoms ($B=1.01$; $P=.015$) compared with those who reported that both their goal and their oncologist's goal was curative. Patients with discordant perceptions of their goal and their oncologist's goal reported higher anxiety symptoms ($B=1.47$; $P=.004$) compared with those who reported that both their goal and their oncologist's goal were curative. **Conclusions:** One-fifth of patients with incurable cancer reported that both their treatment goal and their oncologist's goal were to cure their cancer. Patients who acknowledged the noncurative intent of their treatment and those who perceived that their treatment goal was discordant from that of their oncologist reported greater psychological distress.

J Natl Compr Canc Netw 2020;18(7):849–855
doi: 10.6004/jnccn.2019.7525

Background

Patients with advanced cancer require a clear understanding of their treatment goals and prognosis to make informed decisions about their medical care.^{1–5} Yet multiple studies have shown that patients with advanced cancer often have substantial misperceptions about their illness and treatment goals.^{6–8} Moreover, patients' illness and prognostic understanding are associated with their quality of life (QoL) and mood.^{6,9–12} Specifically, those who perceive their illness as terminal report worse QoL and depression symptoms.^{6,9,11} However, this association may simply reflect that patients with advanced cancer who are nearing the end of life and experiencing worse QoL have a more accurate perception of their health status.⁶ A more sophisticated understanding of how patients view their illness and treatment goals and the implications of these perceptions on their physical and psychological health is needed to ensure that clinicians adequately support patients when disclosing prognostic information.

Although prior literature has focused primarily on assessing patients' prognostic understanding, few studies have explored patients' perceptions of their treatment goals versus those of their oncologist.^{4,11,13} Patients' understanding of their treatment goals is an essential element of the informed consent process when they are initiating cancer therapy.^{4,7} Nipp et al¹¹ reported a lack of concordance between patients' report of their treatment goal and their perception of their oncologist's goal among patients with advanced lung and gastrointestinal cancers. Among patients who reported that their treatment goal was to cure their cancer, nearly half acknowledged that their oncologist's goal differed.¹¹ This discordance in patients' report of their own goals and their perception of their oncologist's goal may reflect their internal struggle in processing and accepting the incurability of their illness.¹¹ However, more data are needed to fully explore patients' perceptions of their treatment goal and those of their oncologist in a larger sample of patients with various types of cancer.

¹Division of Hematology and Oncology, Massachusetts General Hospital Cancer Center, ²Harvard Medical School, and ³Department of Medicine, Division of Palliative Care, Massachusetts General Hospital, Boston, Massachusetts; and ⁴Department of Medicine, Section of Palliative Care, Stanford University, Stanford, California.

Moreover, additional data are needed to examine the relationship between patients' perception of their treatment goal and their oncologist's goal and the association between these views and patient-reported psychological distress and QoL.

The objective of this study was to describe patients' perceptions of their own treatment goal and their oncologist's goal. We also sought to examine the associations between these perceptions with patient-reported psychological distress and QoL.

Methods

Study Procedures

We conducted a cross-sectional analysis of 559 patients with incurable lung, gastrointestinal, breast, or brain cancer who were previously enrolled in supportive care studies at the Massachusetts General Hospital Cancer Center between May 2011 and November 2018.^{9,14,15} All patients completed assessments of their perception of their prognosis and treatment goals, QoL, and psychological distress using the same measures at a minimum of 6 weeks since diagnosis of incurable cancer, which allowed us to combine their data for this secondary cross-sectional analysis. If patients were participating in an intervention trial, then we used their baseline data before randomization and intervention delivery. All studies included in this secondary analysis enrolled consecutively eligible patients who provided informed consent. The studies were approved by the Dana-Farber/Harvard Cancer Center Institutional Review Board.

Participants

This study included adult patients (age ≥ 18 years) with a diagnosis of incurable lung, gastrointestinal, breast, or brain cancer. Incurable disease was defined based on treatment intent as documented in the electronic health record and confirmed with the treating oncology clinician. Patients were also required to receive their care at Massachusetts General Hospital Cancer Center and to be able to read and respond to questions in English or complete questionnaires with minimal assistance from an interpreter. We excluded patients with significant psychiatric or other comorbid disease prohibiting their ability to provide informed consent and participate in study procedures.

Study Measures

Perceptions of Treatment Goals

Participants completed the Prognosis and Treatment Perception Questionnaire (PTPQ) to assess their perceptions of their treatment goal and that of their oncologist.^{9,16} The PTPQ has been used previously in the oncology literature based on its face and content

validity.^{9,16} Specifically, participants were asked to report the primary goal of their current cancer treatment. Response items included (1) "to cure my cancer," (2) "to lessen my suffering as much as possible," (3) "for me and/or my family to be able to keep hoping," (4) "to make sure I have done everything," (5) "to extend my life as long as possible," and (6) "to help cancer research." Responses were grouped into 2 categories: (1) "to cure my cancer" and (2) "other." Similarly, participants were asked to report their perception of their oncologist's primary goal for their cancer treatment using the same response items. These responses were similarly grouped into 2 categories: (1) "to cure my cancer" and (2) "other."

Psychological Symptoms and QoL

We measured participants' anxiety and depression symptoms using the 14-item Hospital Anxiety and Depression Scale (HADS), a measure with strong psychometric properties that has been widely used in medically ill populations, specifically patients with cancer.¹⁷ The HADS consists of 2 subscales assessing anxiety and depression symptoms in the past week, with subscale scores ranging from 0 (no distress) to 21 (maximum distress). A score of >7 on the HADS-anxiety or HADS-depression subscales represents clinically significant anxiety or depression, respectively.¹⁷ We used the Functional Assessment of Cancer Therapy-General (FACT-G) to assess patient-reported QoL.^{18,19} The FACT-G possesses strong psychometric properties and consists of 4 subscales assessing physical, functional, emotional, and social well-being, with a higher total composite score indicating better QoL.

Statistical Analyses

We performed statistical analyses using STATA, version 9.3 (StataCorp LLP). We first calculated descriptive statistics, including means or medians for continuous variables depending on the normality of the data, and proportions for categorical variables. For all analyses, we considered a 2-sided P value of $<.05$ to be statistically significant.

We grouped patients based on their responses to the items regarding their perceptions of their treatment goal and their oncologist's treatment goal into the following categories: (1) patients who reported that both their goal and their oncologist's goal were to cure their cancer, (2) patients who reported that both their goal and their oncologist's goal were noncurative, and (3) patients who reported discordance between their goal and their oncologist's goal. We used descriptive statistics to assess the rates of clinically significant depression and anxiety symptoms based on patients' perceptions of their treatment goal. We used linear regression models to examine the association between patients' perceptions

of their treatment goal with their QoL and depression and anxiety symptoms, adjusting for patient age and sex, which have been shown to be associated with QoL and mood.²⁰

Results

Participant Sample

This study included 559 patients with a diagnosis of incurable lung (n=178; 31.8%), gastrointestinal (n=191; 34.2%), breast (n=122; 21.8%), or brain cancer (n=68; 12.2%). Participants were mostly white (n=536; 96.9%) and non-Hispanic (n=547; 97.8%), and most were women (n=377; 67.4%) and married or with a partner (n=408; 73.1%). Median age of the cohort was 64 years (range, 26.8–89.0 years) (Table 1). All 559 participants in this secondary analysis had complete data on all patient-reported assessments. Notably, there were no significant associations between patient education, race, ethnicity, relationship status, or time since diagnosis of incurable cancer and patient-reported QoL or mood.

Patients' Perceptions of Both Their Treatment Goal and Their Oncologist's Goal

Figure 1 depicts patients' perceptions of their treatment goal and their oncologist's goal. Overall, of the total population, 61.7% of patients (n=345) reported that both their goal and their oncologist's goal for treatment were noncurative, 19.3% (n=108) reported that both their goal and their oncologist's goal were to cure their cancer, 14.0% (n=78) reported that their goal was to cure their cancer whereas their oncologist's goal was noncurative, and 5.0% (n=28) reported that their goal was noncurative whereas their oncologist's goal was to cure their cancer.

Association Between Patients' Perceptions of Treatment Goals and Patient-Reported Outcomes

Figures 2 and 3 depict the rates of clinically significant depression and anxiety symptoms, respectively, based on patients' perceptions of treatment goals. Overall, rates of clinically significant depression and anxiety symptoms in the entire cohort were 25.2% (n=141) and 31.5% (n=176), respectively. The rate of clinically significant depression symptoms was 19.4% (21 of 108) for patients who reported that both their goal and their oncologist's goal were to cure their cancer, 26.9% (21 of 78) for those who reported that their goal was curative whereas their oncologist's goal was noncurative, 21.4% (6 of 28) for those who reported that their goal was noncurative whereas their oncologist's goal was curative, and 27.0% (93 of 345) for patients who reported that both their goal and their oncologist's goal were noncurative. The rate of clinically significant anxiety symptoms was 23.1% (25 of

Table 1. Participant Characteristics

Characteristic	n (%)
Total, N	559
Median age (range), y	64 (26.8–89.0)
Sex	
Female	377 (67.4)
Male	182 (32.6)
Race	
White	536 (96.9)
Black	6 (1.1)
Asian	11 (2.0)
Other	6 (1.1)
Hispanic ethnicity	12 (2.2)
Religion	
Catholic	308 (55.1)
Protestant	108 (19.3)
Jewish	25 (4.5)
Muslim	3 (0.5)
None	78 (13.9)
Other	27 (4.8)
Missing	10 (1.8)
Relationship status	
Married/With partner	408 (73.1)
Single	51 (9.1)
Divorced/Separated	61 (10.9)
Widowed	38 (6.8)
Missing	1 (0.2)
Education	
≤11th grade	17 (3.1)
High school graduate/GED	128 (22.9)
Some college	207 (37.0)
College graduate	102 (18.3)
Master's degree	70 (12.5)
Doctorate/Medical/Law degree	34 (6.1)
Missing	1 (0.2)
Cancer diagnosis	
Lung	178 (31.8)
Gastrointestinal	191 (34.2)
Breast	122 (21.8)
Brain	68 (12.2)

108) for patients who reported that both their goal and their oncologist's goal were curative, 37.2% (29 of 78) for those who reported that their goal was curative whereas their oncologist's goal was noncurative, 39.3% (11 of 28) for those who reported that their goal was noncurative whereas their oncologist's goal was curative, and 32.2%

Figure 1. Patients' perceptions of their treatment goal and of their oncologist's goal.

(111 of 345) for patients who reported that both their goal and their oncologist's goal were noncurative.

Given the limited sample size, we combined patients who reported discordance between their goal and their oncologist's goal into one group for all subsequent analyses. Rates of clinically significant depression and anxiety symptoms for patients who reported discordant perceptions of their goal and their oncologist's goal were 25.5% (27 of 106) and 27.7% (40 of 106), respectively. Patients who reported that both their goal and their oncologist's goal were noncurative had higher depression ($B=0.99$; 95% CI, 0.15–1.84; $P=.021$) and anxiety symptoms ($B=1.01$; 95% CI, 0.20–1.82; $P=.015$) compared with those who reported that both their goal and their oncologist's treatment goal were curative (Table 2). In addition, patients with discordant perceptions of their goal and their oncologist's goal reported higher anxiety symptoms ($B=1.47$; 95% CI, 0.46–2.47; $P=.004$) compared

Figure 2. Rates of clinically significant depression symptoms based on patients' perceptions of their treatment goal.

Figure 3. Rates of clinically significant anxiety symptoms based on patients' perceptions of their treatment goal.

with those who reported that both their goal and their oncologist's treatment goal were curative. There were no significant differences in anxiety or depression symptoms between patients with discordant perceptions of their goal and their oncologist's goal compared with those who reported that both their goal and their oncologist's goal were noncurative. Patient-reported QoL was not significantly related to their perceptions of their treatment goals. In addition, the physical, social, and functional well-being subscales of the FACT-G were not significantly related to patients' perceptions of their treatment goals.

Discussion

In this study, we showed that approximately one-fifth of patients with incurable cancer reported that both their treatment goal and their oncologist's goal were curative, highlighting substantial misperceptions in patients' understanding of their treatment intent. In addition, approximately one-fifth of patients with incurable cancer reported discrepancies between their perceptions of their own treatment goal and their oncologist's goal. Note that patients' perceptions of these treatment goals were associated with their psychological symptoms. Specifically, patients who accurately endorsed that their treatment goal and their oncologist's treatment goal were noncurative reported higher depression and anxiety symptoms, compared with those who reported that both their treatment goal and their oncologist's treatment goal were curative. In addition, discordance in patients' perceptions of their treatment goal and those of their oncologist was associated with higher anxiety symptoms. These findings identify patients with incurable cancer at risk for increased psychological distress who may benefit from targeted interventions to promote their ability to cope with their illness and prognosis.

In this study, we observed substantial misperceptions in patients' understanding of the intent of their

Table 2. Association Between Patients' Perceptions of Treatment Goals and Patient-Reported Outcomes

Patient-Reported Outcomes	β	95% CI	P Value
Patient anxiety (HADS-Anxiety)			
Both goals curative	Ref		
Discordant goals	1.47	0.46 to 2.47	.004
Both goals noncurative	1.01	0.20 to 1.82	.015
Patient depression (HADS-Depression)			
Both goals curative	Ref		
Discordant goals	0.92	-0.13 to 1.97	.086
Both goals noncurative	0.99	0.15 to 1.84	.021
Patient QoL (FACT-G)			
Both goals curative	Ref		
Discordant goals	-5.84	-17.10 to 5.43	.309
Both goals noncurative	-3.10	-12.23 to 6.03	.505

All outcomes (depression, anxiety, and QoL) were modeled separately. Models adjusted for age and sex.

Abbreviations: FACT-G, Functional Assessment of Cancer Therapy-General; HADS, Hospital Anxiety and Depression Scale; QoL, quality of life.

treatment, a basic and essential element of the informed consent process when initiating cancer-directed therapy. Prior studies have shown that patients' misperceptions about treatment intent likely impact patients' decision-making throughout their illness trajectory.^{4,7,21} Furthermore, although some studies have suggested that patient-clinician communication about treatment goals and prognosis does not take away patients' hope, our findings of increased psychological distress in patients who accurately perceive their treatment goal as noncurative are important to consider when thinking about the implications of discussing treatment goals and overall prognosis. As noted earlier, prior studies have shown that patients who acknowledge the terminal nature of their illness report worse QoL and psychological distress.^{9,10,15} Thus, these data underscore the need to provide appropriate psychological support for patients with incurable cancer who have an accurate understanding of their illness and treatment goals. Interventions such as specialty palliative care, which promotes adaptive coping, can play an important role in improving the psychological well-being of patients with advanced cancer who are cognitively aware of the incurable nature of their illness.^{22,23}

We have also identified that a substantial minority of patients reported discrepancies between their own treatment goal and their oncologist's goal. We hypothesized that these discrepancies reflected the presence of cognitive and emotional dissonance, although these are difficult constructs to measure and were not directly assessed in this study.^{24,25} Patients may have difficulty responding to questions regarding their treatment goal and may endorse their goal or wish to be cured, even if they cognitively understand that their cancer is

incurable.¹¹ Note that patients who reported these discrepancies in perceptions had worse anxiety symptoms. Higher anxiety symptoms in this population may have reflected patients' internal struggles to reconcile their emotional hopes for a cure while cognitively acknowledging their incurable disease. Thus, patients with perceptions of their treatment goal that are discrepant from their perceptions of their oncologist's goal are also a high-risk population that may benefit from additional psychological interventions to address their prognostic distress.

This work also underscores the limitations of our current approach to measuring patients' understanding of their illness and prognosis. The disconnect between patients' perceptions of their treatment goals and their oncologist's goal likely reflects the difficulty patients experience when answering these questions.¹¹ When asked to report on their primary treatment goal, patients may actually be reporting their hopes or wishes rather than their true understanding.²⁶ Cognitive dissonance has been shown to play an important role in affecting patients' behavior when they respond to survey questions in other clinical contexts.²⁷⁻³² Our current approach to measuring patients' illness and prognostic understanding does not take into account the potential role of cognitive dissonance in affecting patients' survey responses. Future work is critically needed to develop a more sophisticated and valid tool to measure illness and prognostic awareness in oncology that considers both the cognitive and the emotional aspects involved in answering such questions.

This study has several important limitations. First, we conducted this study using data collected at a single cancer center in a patient population with limited racial

diversity, which may limit the generalizability of our findings. Second, given the cross-sectional nature of this study, we are unable to comment on the direction of the associations seen between patients' perceptions of their treatment goals and their psychological distress. Furthermore, because this is a secondary data analysis, the findings should be considered hypothesis-generating and exploratory. Third, we did not capture all variables, such as comorbidities, that may confound the association between patients' perceptions of treatment goals and their psychological outcomes. Fourth, we did not capture oncologists' perceptions of patients' treatment goals and thus are unable to compare them with patients' perceptions. We also lack data about whether oncologists informed patients of their incurable disease and data on changes in patients' perceptions over time. Fifth, we cannot measure cognitive dissonance directly given its complexity and the difficulty of capturing such a construct with survey instruments. Sixth, we grouped patients with discordant views of their goals and their oncologist's goals collectively given the limited sample size in each subgroup, and are thus unable to comment on differences between the groups with discordant views with respect to clinical characteristics or patient outcomes. Future studies should further explore differences between these patients with discordant views; those who report their goal as curative but their oncologist's goal as noncurative may have different experiences with their illness compared with those who report their goal as noncurative but their oncologist's goal as curative.

Conclusions

A substantial minority of patients with incurable cancer reported inaccurate understanding of the intent of their treatment. Notably, patients' perceptions of their treatment goal and their oncologist's goal were associated with their psychological distress. Although patients must have an accurate understanding of their treatment intent to ensure appropriate and informed medical decision-making, these data underscore the need to support patients as they process and cope with the incurable nature of their illness. These findings highlight the importance of identifying patients with incurable cancer at high risk for psychological distress and those struggling with the incurable nature of their illness who may benefit from further interventions to promote effective coping.

Submitted August 17, 2019; accepted for publication December 16, 2019.

Author contributions: Study concept and design: All authors. Data acquisition, analysis, and/or interpretation: All authors. Manuscript preparation and critical revision: All authors.

Disclosures: Dr. Greer has disclosed that he has received grant/research support from and consulting fees from Gaido Health/BCG Digital Ventures. The remaining authors have disclosed that they have not received any financial consideration from any person or organization to support the preparation, analysis, results, or discussion of this article.

Funding: Dr. El-Jawahri has disclosed that she is a scholar in clinical research for the Leukemia and Lymphoma Society. Dr. Temel has disclosed that she receives funding from NCI (K24 CA181253).

Correspondence: Areej El-Jawahri, MD, Division of Hematology and Oncology, Massachusetts General Hospital Cancer Center, 55 Fruit Street, Yawkey 7B, Boston, MA 02114. Email: ael-jawahri@partners.org

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JNCCN-N-0283-0520