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## Don't Shoot the Messenger: Experiences of Delivering Prognostic Information in the Context of Advanced Cancer

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### Abstract

The study of prognostic understanding is imperative as the trend toward individualized medicine continues. However, without guidelines for discussing prognosis, palliative care clinicians face challenges presenting prognostic information in a way that optimizes patient understanding, psychological adjustment, and decision-making. The present study draws on the experiences of experts in the field of palliative care in order to examine the communication of prognostic information. Fifteen oncology, psycho-oncology, and palliative care professionals with expertise in doctor–patient communication participated in semi-structured interviews that focused on identifying the breadth of factors underlying prognostic understanding, as well as methods to identify and quantify this understanding. Three independent raters utilized a thematic content analysis framework to identify core themes that reflected unique aspects of prognostic understanding. Interviews yielded 2 types of information. Participants described the multifaceted nature of prognostic understanding and identified 5 distinct elements of prognostic understanding: understanding of current state of disease, life expectancy, curability, decline trajectory, and available treatment options. Participants also offered “best practice” techniques, including methods for determining a patient’s preferences for and understanding of prognostic information, assessing patient fears and concerns, and communicating medical uncertainties. Results emphasize the need for clinicians to join with patients to ensure that prognostic information is well understood. These results highlight the salience of health information preferences and strategies to provide comprehensive prognostic information, compassionately and with respect for each individual patient.

### Keywords

prognostic understanding; palliative care; end of life conversations; clinician–patient communication; qualitative data; thematic content analysis

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## Introduction

An accurate awareness of one's prognosis is a critical factor in medical decision-making, coping, and psychosocial well-being for patients with advanced cancer.<sup>1</sup> In fact, research shows that a lack of prognostic awareness is associated with a range of negative end-of-life (EOL) outcomes, including unwanted hospital admissions, deaths in acute care settings, late referrals to palliative care, poor symptom control, insufficient EOL planning, and reduced patient autonomy.<sup>2</sup> Given the importance of accurate prognostic understanding among patients with advanced illness, increased attention has been directed to improving communication about health information between clinicians and patients. Specifically, in the United States, best practice standards call for open and honest communication in patient-clinician interactions.<sup>3</sup> However, a recent meta-analysis reported that less than half of all patients studied had an accurate understanding of their prognosis.<sup>4</sup> Furthermore, another systematic review reported that as many as 93% of patients with cancer indicated they were not provided with adequate health information.<sup>5</sup> Provision of information congruent with a patient's needs is an important determinant of patient satisfaction, health-related quality of life (QOL), and anxiety and depression among patients with advanced cancer.<sup>6</sup> Therefore, despite the emphasis placed on honest communication and the importance of prognostic awareness for patient outcomes, it appears that comprehensive conversations regarding the patient's prognosis are often lacking in the context of advanced cancer.<sup>7</sup>

There are several reasons why honesty and transparency may be compromised in the health-care setting, including lack of time, perceived lack of training or expertise in these conversations, uncertainty about prognostication, feelings of inadequacy, and fear of the patient's emotional reaction and/or rapport rupture.<sup>7</sup> Of these, fear of rupturing the clinician-patient relationship may be one of the most substantial barriers to open and honest prognostic discussions. In one study, patients were randomly assigned to watch one of 2 mock prognostic conversations between a clinician and patient.<sup>8</sup> In one video, the clinician delivered promising health information (ie, treatment effectiveness, slowed progression), while in the second, the clinician delivered discouraging health information (ie, treatment ineffectiveness, continued disease progression). Overall, patients perceived the clinician who delivered negative health information to be less compassionate and trustworthy than the clinician who delivered positive information. Although results from this study support concerns cited by clinicians, most research has not demonstrated a clear association between disclosure of prognostic information and psychological harm to patients and/or damage the clinician-patient relationship.<sup>2,9</sup>

Despite reluctance on the part of clinicians, most patients appear to desire accurate information about their medical condition. Of 126 patients with newly diagnosed, incurable, meta-static cancer, over 95% reported wanting to know about the symptoms of their disease, treatment options, and the potential side effects associated with these treatment options.<sup>10</sup> The majority of patients also wanted information about estimated survival, including the longest survival time with treatment (85%), estimated 5-year survival rates (80%), and the average survival time (81%). In the absence of guidelines for how to discuss prognosis with patients, palliative care clinicians face challenges when trying to present prognostic information in a way that optimizes patient understanding, psychological adjustment, and

decision-making. The present study aims to draw on the experiences of clinicians to clarify the concept of prognostic understanding and examine the mechanisms that contribute to patient understanding and uptake of prognostic information.

## Method

This study was approved by the institutional review boards of Memorial Sloan Kettering Cancer Center and Fordham University (#16–316). Data were collected in the first phase of a study of prognostic understanding for patients with advanced or terminal disease. English-speaking, international, expert clinical psychologists and physicians in the fields of oncology, psycho-oncology, and palliative care were identified by the principal investigators (A.A. and B.R.) for participation. Participants were approached by phone and informed of the nature of the study, including potential risks and benefits, and verbal informed consent was provided. In accordance with qualitative research guidelines,<sup>11</sup> recruitment continued until the target sample size of 15 was reached.

Participants subsequently engaged in individual, semi-structured interview conducted by a clinical psychologist or psychology graduate student, trained in interviewing related techniques and procedures. Interview duration ranged from 20 to 40 minutes. The interview, developed by the study investigators, was comprised of open-ended questions addressing the breadth of factors underlying prognostic understanding (see Table 1 for interview guide). Interviews were audio-taped and transcribed by the research team, omitting all identifying information. The final data set included participants' answers to research questions, as well as comments and themes spontaneously generated by participants.

Three independent coders reviewed and interpreted the interview data by thematic content analysis using an inductive, data-driven approach.<sup>12–15</sup> Raters reviewed all interview transcripts and identified salient themes in the participant's responses. These themes were utilized to generate categories that reflected features of prognostic understanding illustrated by study participants. At the second level of coding, all team members reviewed the passages to confirm the identification of content areas of interest. Using inductive coding techniques, the data analysis team identified passages that conveyed participants' perceptions of prognostic understanding among patients and their experiences delivering prognostic information. Three raters conducted the first round of coding independently and met weekly to discuss and revise the codebook. In order to assess inter-rater reliability, all 3 raters coded the entire set of participant transcripts and ultimately produced a code-book consisting of 16 codes.

## Results

### Participants

Of 16 health-care professionals approached, 15 agreed to participate and 1 refused due to scheduling conflicts. All 15 health-care professionals who consented to the study provided complete interview data. For comprehensive demographic information, see Table 2.

## Prognostic Understanding

Participants identified several distinct facets of prognostic understanding: knowledge of current state of disease, life expectancy, curability, anticipated decline trajectory, and available treatment options. Participants also discussed 2 constructs indirectly associated with prognostic understanding: (1) patient health information preferences and (2) issues related to clinician–patient communication of prognostic information.

**Understanding of current state of disease.**—Participants agreed that understanding one’s current state of disease provides the foundational knowledge necessary to discuss other elements of prognostic understanding, such as life expectancy and treatment options. Intertwined with the description of an understanding of the current state of the illness was understanding the illness history. For example, evidence of disease in the lung has a different medical meaning if the lung was the primary tumor site or if the disease originated elsewhere and spread to the lung (ie, understanding disease progression). Hence, inherent in understanding one’s illness is awareness of where the illness has been, where it is currently, and where it could go in the future.

**Life expectancy and curability.**—Participants also presented life expectancy and curability as intertwined aspects of prognostic understanding, both of which are critical to making informed treatment decisions. One participant explained,

Curability is key, and the other thing which I think is key is that they shouldn’t be making treatment decisions, or shouldn’t be opting for a treatment if it’s based on a wildly incorrect notion of life expectancy. (Participant 106)

According to participants, awareness of one’s life expectancy and the curability of one’s disease provide a framework for developing realistic treatment goals and evaluating treatment options. One clinician noted,

For someone to have a crystal clear understanding, then they should know whether their disease is curable or not, if it’s something that can be fixed or if it’s something that will ultimately end their life, not matter what we do, treatments or what have you. (Participant 102)

For patients struggling to understand their illness and make informed treatment decisions, an understanding of whether or not the disease is curable is critical. Several participants cautioned that unrealistic expectations about the curability of one’s disease can lead patients to choose aggressive (and perhaps harmful) treatments, without understanding the likely outcomes.

**Treatment options.**—A related aspect of prognostic understanding that is critical to treatment decision-making is an understanding of available treatment options. Participants discussed the importance of identifying viable treatment options, but also the need for patients to understand why a specific treatment may (or may not) be appropriate. Furthermore, participants discussed the need to understand the implications of specific treatments, such as the potential effectiveness or ineffectiveness of that intervention. One clinician stated,

Most patients believe, deep down, that you've got a better chance of having increased survival with palliative chemo than without palliative chemo. And doctors know that that's not true. So I think trying to bring patients and clinicians together to be as realistic as possible is really important. (Participant 105)

**Decline trajectory.**—"Decline trajectory" was presented by many participants as information that can often be provided to patients to enhance clarity and overall understanding of what will happen as the disease progresses. One clinician reported,

I think it's how they're going to live while they're alive. It's more than just time, it's the understanding that a person has of their body's frailty, how their body is changing, and what parts of their body are getting sicker. That's a prognostic discussion—their mode of dying, how they will die, and what the pathway in which their own body will gradually fail. (Participant 107)

Although often anxiety provoking, participants also underscored the importance of discussing decline trajectory and death with patients as a means to correcting unrealistic fears about the future:

Understanding can be a further source of reassurance to people who fear the worst and worry that they're going to have a painful death, or a horrible death, or that they will suffer greatly. (Participant 107)

Furthermore, many participants described conversations regarding decline trajectory as opportunities to discuss QOL issues and patient preferences at the end of life.

### Health Information Preferences

The majority of participants spontaneously discussed the importance of assessing and respecting a patient's desire for prognostic information, prior to initiating discussions related to these issues. Clinicians should identify the type of information desired, consider the optimal timing of these discussions, and with whom information should be shared with. One participant offered,

Knowing a hardcore number as to how many months or weeks they might have left, I think that depends on the person. For some people, that information is very helpful, and they really do want to know. But for other people, that information isn't going to change their plans. So, it's tailoring it to the individual. (Participant 112)

Participants also highlighted the dynamic nature of health information preferences. Particularly as the disease progresses, the patient's desire for information about their illness and future often increases. Therefore, it is important to establish an openness to discuss prognosis at any time.

So give permission in terms of if you don't want to talk now, maybe in the future. If you [patient] are ready to talk, I am ready to talk. (Participant 101)

## Clinician–Patient Health Information Communication

**Assessment of patient prognostic understanding.**—Participants reported beginning prognostic conversations by first asking the patient what he or she knows about the disease. Participants highlighted the importance of addressing misperceptions and/or unrealistic expectations to ensure the patient has a clear understanding of the information discussed. Utilization of role-playing activities, during which the patient is invited to share information about the illness and prognosis with a “friend,” and the “teach back” method were proposed by some participants as ways of ensuring that the patient has synthesized the information presented.

**Assessing sources of patient distress and providing supportive information.**

—As discussed above, participants emphasized the importance of balancing respect for a patient’s health information preferences and assessment of underlying fears that may be driving an avoidance of candid prognostic discussions.

If a person has told you that they don’t want to know, then tell you what their worst fears are, you get some sense of understanding what’s going on for them. Those questions give me insight.” (Participant 113)

In some cases, the clinician may identify unrealistic worries that drive the patient’s desire to avoid discussions related to their illness. In these instances,

I think it can be a duty of care to let them know that their outlook is in fact much better than they fear it is. And that can be very helpful to them. It can give them fresh hope. It can pick their morale up. It can make a big difference to their level of angst and suffering. (Participant 113)

**Challenge communicating medical uncertainty.**—The majority of participants acknowledged that prognostication is not a perfect science and spoke to the difficulty inherent in providing uncertain information in a comprehensible manner. As one clinician explained,

The other real challenge today is truly understanding what someone’s prognosis is, let alone getting to the point of communicating and sharing it because there is a lot of medical uncertainty, and how you communicate that to people is challenging. (Participant 101)

Difficulties communicating medical uncertainty were most often discussed in the context of discussions about life expectancy. Participants reported that patients often want specific information about how long they can expect to live, which is one of the most challenging elements of prognosis. Participants presented strategies for meeting their patients’ information needs, while acknowledging the degree of uncertainty in their projections. For example, some participants suggested providing a range of possibilities, which include the best case, worst case, and most likely scenarios.

## Discussion

Participants identified 5 primary components of prognostic understanding: understanding the current state of one's disease, life expectancy, curability, anticipated decline trajectory, and available treatment options. This analysis is far more comprehensive than those captured by the measures of prognostic understanding used in prior research studies. For example, a review of 34 published studies found that prognostic awareness was typically defined in one of the following 3 ways: (1) curability of the patient's disease (ie, advanced, incurable, terminal, or life-threatening), (2) estimated life expectancy, and (3) the intent of treatment (curative versus palliative).<sup>4</sup> Hence, these findings underscore the multidimensional nature of prognostic awareness and highlight additional facets of prognosis that a patient may need to understand in order to make well-informed treatment decisions.

Best practice guidelines suggest that it is essential for clinicians to understand a patient's goals and preferences for information in order to provide high-quality care.<sup>2</sup> Indeed, discussions of treatment goals and information preferences that occur early in the course of treatment are associated with better QOL, fewer aggressive treatments near death, enhanced goal-consistent treatment, and reduced health-care costs.<sup>16</sup> Participants in this study concurred with this assessment, identifying the assessment of patient preferences for health information and goals as a preliminary step in the process of engaging in an illness-related or prognostic discussion.

Research suggests that the majority of patients desire some degree of information about their illness.<sup>3</sup> However, the prospect of receiving threatening information can serve as a barrier to the receipt of health information. Rates of anxiety are high among patients with advanced cancer; between 25% and 50% of patients with advanced cancer experience significant anxiety symptoms.<sup>16</sup> Study participants advocated for the use of prognostic discussions as a means to alleviate fears and anxiety, rather than allowing the presence of anxiety to serve as a barrier to prognostic conversations. If clinicians can identify the factors that underlie a desire to avoid candid discussions of health information (eg, anxiety), they may be able to reduce this distress and increase the patient's openness to receiving accurate health information. One research study found that once patients understood that receipt of information could be tailored to their preferences (ie, desired timing and extent of information), they were more likely to desire health information.<sup>3</sup> Participants also highlighted the fluctuations in patient desire for health information, as this often evolves as illness progresses and anxiety waxes or wanes. Hence, discussions of patient preferences for health information and goals should occur throughout the physician-patient relationship to ensure that participants are aligned with patients and able to broach prognostic discussions with the patient's wishes and desires in mind.

The most significant challenge identified by participants in our sample was communicating medical uncertainty in the context of advanced disease and prognostication. This finding is supported by research which shows that physician uncertainty about prognostic accuracy serves as a barrier to initiating prognostic conversations.<sup>17</sup> Despite the difficulties inherent in delivering medical uncertainties in a clear and concise manner, physicians in our sample offered a number of strategies, such as utilizing ranges and probabilities to communicate all

possibilities, while still highlighting the most likely outcomes, to aid patients in understanding this aspect of prognosis. Although considerable research has identified physicians' fear of causing distress in their patients as a barrier to prognostic conversations, these study participants did not identify this as a challenge. The absence of expressed concerns may reflect the level of expertise in our sample, as experienced clinicians may have more confidence in their ability to communicate effectively without engendering distress.

### Limitations

The expertise of our study participants may have impacted study findings in other ways besides the lack of concern about engendering distress. For example, the perspectives offered by these participants cannot be considered an indication of what a typical clinician might think but rather reflect the opinions of experts in palliative care, oncology, and psycho-oncology. In addition, the use of a structured interview may have inadvertently inhibited participants from discussing important areas that were not broached or triggered by the interview questions. Further, it is possible that experts who specialize in other advanced or terminal illnesses (eg, renal failure, dementia) may identify elements of prognosis that were not elucidated by this study.

### Future Directions

Our findings highlight the multidimensional nature of prognostic understanding and a range of considerations for engaging in prognostic discussions with patients with advanced disease. Although participants demonstrated confidence and comfort delivering prognostic information, research suggests that many clinicians feel unprepared for EOL conversations<sup>18</sup> and report inadequate training in this area.<sup>19</sup> Hence, training programs for providers working with patients with terminal illness should increase their focus on communication skills, helping health-care professionals to sensitively consider a patient's readiness for prognostic discussions, cultural background, and desire for family members' involvement in the discussion process.<sup>20,21</sup> These training programs will allow clinicians to increase their competence and confidence when engaging in these challenging conversations.

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**Table 1.**

Expert Interview Guide.

Question #	Interview Question
1	If you want your patient to have a crystal clear understanding of his or her prognosis, what are the most important things to talk about (list as many as you can think of)?
2	Are there any observable behaviors or signs that tell you that a patient does not understand his or her prognosis?
3	Do you have any techniques for gauging a patient's understanding of prognosis?
4	What areas of a patient's prognosis do you have trouble communicating to a patient?
5	Are there some aspects of a patient's prognosis that you find hard to broach?
6	Are there some aspects that are hard for patients to understand or accept?
7	If a patient does not seem to understand some aspects of his or her prognosis, which aspects are so important that you feel the need to explain them again or more thoroughly?
8	What types of questions should patients ask in order to gain a complete understanding of prognosis?
9	Are there aspects of the illness or treatment that patients may want to know about that you think are unnecessary (or rarely necessary) to discuss?
10	If a patient resists discussion of some aspect of his or her prognosis, are there some topics that are so important that you feel compelled to discuss them anyway? If so, which topics?
11	How do you differentiate optimism or hopefulness from denial about prognosis in your patients?
12	Is there a point where optimism becomes unrealistic?
13	Is that different than denial of prognosis?
14	Have you noticed any differences among patients from various cultural groups in how they speak about or understand the term prognosis?
15	Do you alter how you discuss prognosis based upon patients' ethnic or cultural background

**Table 2.**

## Participant Demographic Information.

Variable	n (%) / M (SD)
Race	
White/Caucasian	14 (93)
Black/African American	1 (7)
Ethnicity	
Hispanic	1 (7)
Non-Hispanic	14 (93)
Age	49 (10.2)
Gender	
Male	11 (73)
Female	4 (27)
Profession	
Physician	13 (87)
Psychiatrist	2 (13)
Discipline specify	4 (27)
Medical oncologist	6 (40)
Palliative medicine	3 (20)
Combination internal medicine/palliative medicine psychiatry	2 (13)
Years practicing	16.6 (11.7)
Population	
Adult	10 (67)
Pediatrics	1 (7)
Combination	4 (26)
Setting	
Residential inpatient	1 (7)
Hospital outpatient	6 (40)
Other	2 (13)
Combination	6 (40)