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RESEARCH ARTICLE

The Roles of Understanding and Belief in Prognostic Awareness

Alexander T. Yahanda[1,3] and Bryan A. Sisk[2,3,4]

[1]Department of Neurosurgery, Washington University School of Medicine, St. Louis, MO, 63110, USA; [2]Division of Hematology/Oncology, Department of Pediatrics, St. Louis Children's Hospital, St. Louis, MO, 63110, USA; [3]Bioethics Research Center, Washington University School of Medicine, St. Louis, MO, 63110, USA and [4]Department of Pediatrics,Washington Univeristy School of Medicine, 660 S Euclid Ave, St. Louis, MO 63110, USA
Corresponding author: Alexander T. Yahanda; Email: ayahanda@wustl.edu

Abstract
Conventional understanding and research regarding prognostic understanding too often focuses on transmission of information. However, merely overcoming barriers to patient understanding may not be sufficient. In this article the authors provide a more nuanced understanding of prognostic awareness, using oncological care as an overarching example, and discuss factors that may lead to prognostic discordance between physicians and patients. We summarize the current literature and research and present a model developed by the authors to characterize barriers to prognostic awareness. Ultimately, multiple influences on prognostic understanding may impede acceptance by patients even when adequate transfer of information takes place. Physicians should improve how they transmit prognostic information, as this information may be processed in different ways. A model of misunderstandings in awareness, ranging from patient understanding to patient belief, may be useful to guide future discussions. Future decision-making studies should consider these many variables so that interventions may be created to address all aspects of the prognostic disclosure process.

Key words: oncology; prognosis; prognostic awareness; prognostic disclosure; prognostic discordance

Introduction

While estimating patients' disease courses can be complex and unpredictable, discussions with patients often rely on estimates of prognosis to guide treatments and decision-making. One of the goals of these discussions should be to instill in patients a proper degree of prognostic awareness – i.e. a reasonable and grounded perspective given their diagnosis. Generating prognostic awareness relies on proper transfer of information from physicians to patient as well as reasonable internalization of this information by patients. In reality, however, barriers to prognostic awareness often arise during these discussions. In this article, using oncologic care as an overarching example given its involved nature and the emotional toll it takes on patients, the authors describe current understanding and research regarding prognostic awareness, present factors that may impede prognostic awareness, and present a model for prognostic awareness that ranges from patient understanding to patient beliefs.

Prognostic awareness and discordance among patients

Open and transparent communication about illness and its prognosis has become a key tenet of cancer care. Although nondisclosure of poor prognoses was historically common,[1] honesty has now become

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expected from clinicians and healthcare organizations.[2] Prognostic awareness occurs when a patient comprehends a realistic outlook for their disease course. This awareness requires that patients receive digestible information about their prognosis and that they have the capacity to comprehend (i.e. understand) and accept (i.e. believe) the information as true. Prognostic awareness is considered an important outcome of physician-patient communication and shared decision-making,[3] and most patients with cancer want detailed prognostic information.[4] Substantial evidence, however, indicates that patients and caregivers often report more favorable prognoses than their physicians.[5] Oncology patients are more likely to report that surgical treatments will cure their cancer, extend their life, or lead to few side effects.[6] Likewise, patients often report that palliative chemotherapy – which offers no chance for cure – will ultimately cure their cancer.[7]

Over the last 3 decades, researchers primarily have studied prognostic communication in cancer while focusing on the disclosure of prognostic information to patients, how patients interpret this information, and how the information affects patients' decision-making.[8] Most of these studies rely on patients or caregivers to provide numerical estimates of their prognosis to determine accuracy. When the patient's estimate does not match the clinician's estimate, it is referred to as prognostic discordance. This discordance could be with respect to multiple outcomes beyond just life expectancy – for example, disease cure or palliation, alleviation of symptoms, morbidity from a treatment, future functional status, and more. Reports of prognostic discordance have been associated with increased patient suffering, decisions for more intensive care, decreased quality of life, decisional regret, and deterioration of trust in physicians.[9]

Current focus on prognostic awareness is too narrow

To date, most studies examining prognostic awareness have focused on prognostic understanding, and specifically on deficient disclosure by physicians as the primary source of prognostic discordance.[10] These studies imply that enhancing physicians' disclosure of prognostic information will improve prognostic awareness. Clinicians are often the primary source of prognostic information and past studies have found that limited prognostic disclosure can impede prognostic awareness.[11] Nonetheless, literature from research ethics and cognitive psychology suggest several other factors that can affect patients' reports of prognosis. To improve prognostic communication, we must understand the multitude of contributors to prognostic awareness and discordance so we can develop tools and recommendations to improve this communication process.

This body of literature has been important to raise awareness of possible deficiencies in prognostic communication. That said, the current concept of prognostic awareness and discordance has limitations. It assumes that what a patient or caregiver reports in a study accurately reflects their understanding of the likelihood of cure, relief of symptoms, risk of morbidity, or other outcomes. Similarly, most studies equate patient-reported instances of prognostic discordance with a lack of effective clinician disclosure. In other words, if patients report inaccurate prognostic estimates, this is taken to mean that they did not receive sufficient information from clinicians. We argue, however, prognostic discordance has multiple contributors beyond clinician nondisclosure.

A framework to understand various contributors to prognostic awareness

Bryan Sisk and Eric Kodish previously developed a model of therapeutic misperceptions that contributed to unrealistic expectations of benefit from phase I cancer trials.[12] This model maintains that unrealistic expectations can result from a spectrum of causes, ranging from discrepancies in understanding to discrepancies in appreciation. Discrepancy in understanding may impede expectations through therapeutic misconception or a lack of information necessary for informed decision-making. Discrepancy in appreciation may impact expectations via patients' unwillingness or inability to internalize the consequences of their decisions. Patients may pass from one end of this spectrum to the other as they receive

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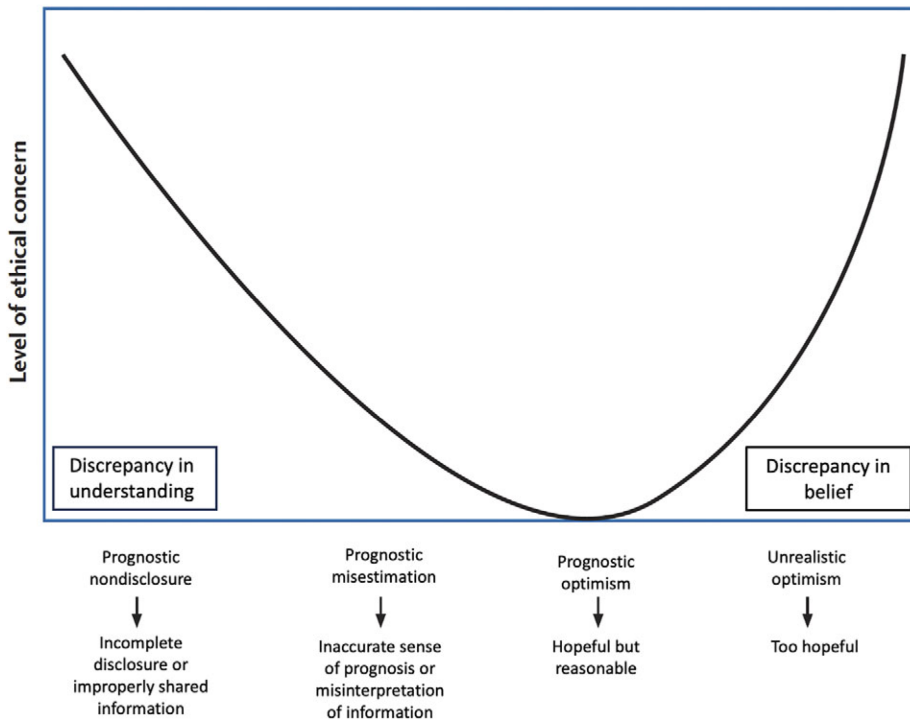

Figure 1. Contisnuum of misconceptions related to prognostic awareness ranging from discrepancy in understanding to discrepancy in belief. Adapted from Sisk and Kodish.

more information that addresses discrepancies in understanding, ultimately exhibiting varying degrees of discrepancy in appreciation.

We propose that unrealistic or inaccurate prognostic expectations during oncologic discussions are similarly driven by a spectrum of causes ranging from understanding to belief (Figure 1). Patients may incorrectly believe that their treatment paths will alter their prognoses in much the same way that they believe they will derive benefit from a phase I clinical trial. The level of understanding, of course, is similar in that a lack of understanding due to improper or incorrect information transmission or lack of disclosure by clinicians will hinder patients' ability to achieve adequate shared decision-making. The level of ethical concern associated with each step from discrepancy in understanding to discrepancy in belief is not equal. Indeed, we outlined multiple intervening stages. Patients may exist anywhere from prognostic nondisclosure to prognostic misestimation to prognostic optimism to unrealistic optimism. Of these, prognostic optimism – which is defined as being hopeful but reasonable – is the least problematic. In this state, patients are understandably hopeful in the face of their prognosis or proposed treatment plans, but also have reasonable expectations for the future. As one heads towards either end of the spectrum, however, the level of ethical concern grows as the odds of true prognostic awareness decline (Figure 1). Prognostic misestimation – that is, having an inaccurate idea of prognosis or misinterpreting information – could be considered less concerning than prognostic nondisclosure or unrealistic optimism, as patients may be attempting to be reasonable in their decision-making but not having an accurate grasp of available data, though it is still suboptimal.

As mentioned previously, prognostic nondisclosure is a prevalent factor that could contribute to a lack of prognostic awareness, but it is by no means the only factor. Thus, in this article we highlight several factors beyond clinician disclosure that might affect prognostic understanding and prognostic belief. This list of factors is not meant to be exhaustive. Rather, we hope these concepts will emphasize the need for further studies that may provide important nuance to this literature.

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Factors impacting prognostic understanding

Lack of disclosure or improperly shared disclosure

The simplest contributor to prognostic discordance is physicians failing to disclose prognostic information, or doing so in a way that goes largely unheard by patients.[13] This may occur for a variety of reasons.[14] Certain physicians might withhold information with the intention of protecting patients from undue mental stress, diminishment of hope, difficulties with coping, and worse outcomes.[15] Other physicians are uncomfortable making prognostic estimates or do not feel equipped to have meaningful prognostic discussions with their patients, perhaps fearing patients' negative emotional responses.[16] Receiving a cancer diagnosis is understandably a traumatic event for patients, and prognostic discussions that are held soon after this diagnosis may be subject to "cognitive shut-down" wherein the patient is not fully absorbing the information being relayed to them by their physician.[17] Indeed, studies show that patients may recall less than half of the information that physicians share with them.[18] Prognostic disclosure practices that are improperly tailored to a patient's emotional state may risk prognostic discordance, even if the information relayed is appropriate.

Additionally, disclosure occurs in shades rather than in black and white. Some physicians discuss prognosis in vague generalities, whereas other physicians end prognostic statements with overly-optimistic turns or disclosure.[19] To deflect from what they feel is distressing news, physicians might focus most of the discussion on topics such as treatment options or next steps rather than on the prognosis itself.[20] Oftentimes, prognostic disclosure occurs over many encounters rather than at a single time point. While this approach might meet the needs and desires of some patients and families, it also may contribute to misunderstandings of prognosis.

Innumeracy

The presentation of prognostic and treatment information demands that patients interpret absolute risks, relative risks, conditional probabilities, and other forms of statistical information.[21] Unfortunately, patients often have trouble with statistics, probabilities, and percentages, exhibiting so-called innumeracy.[22] But patients must understand these concepts if they are to incorporate them into decision-making. Making decisions based on incompletely or incorrectly understood information will create similar challenges as making decisions based on incompletely disclosed information. Patients with low numeracy may be more prone to interpreting incompletely-understood information in overly-optimistic ways.[23] These patients with poor numeracy are also more likely to report feeling overwhelmed by information and to hold more fatalistic beliefs of cancer compared to patients with higher numeracy.[24] Many tools exist to assist with communication of statistics (e.g. decision aids), but these tools are not uniformly available or utilized in oncology. Challenges posed by innumeracy are exacerbated when patients have low health literacy, even if the physician has presented all desired and necessary information in a simplified form.[25]

Factors impacting prognostic beliefs

Performative language

When a patient reports an overly optimistic prognostic estimate, this optimistic language might serve performative functions. That is, patients might use optimistic statements in the hopes of improving their outcomes. Studies of hope and optimism in early phase clinical trials support this perceived role of performative language. Daniel Sulmasy and colleagues interviewed 45 participants in phase I or II cancer trials in a qualitative study assessing hope and optimism.[26] Thematic analysis revealed "performative language" to be a major theme from these interviews. As the authors noted, "Many participants (36 of 45) explained their expressions of optimism regarding the individual therapeutic benefit they expected through participation in the research protocol as performative expressions."[27] These participants believed that thinking and expressing optimistic thoughts would improve their chances of benefitting

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from the experimental agent. One participant responded, “You know, I probably should have said 100 (laughter). You know, realism with, you know, always being optimistic… That’s a big part of recovery, that’s a big part of your treatment, is your right attitude and being optimistic and believing that things are going to work.” Though these patients outwardly demonstrated an overly optimistic outlook, they actually seemed to have a clearer understanding of their prognosis.[28]

Optimistic bias

Optimistic bias (also termed unrealistic optimism) is a cognitive bias that leads individuals to believe their chances of success are better than others in identical situations. As noted in a recent review article, “Researchers have documented this unrealistic optimism in over a thousand studies and for a diverse array of undesirable events including diseases, natural disasters, and a host of other events ranging from unwanted pregnancies and home radon contamination to the end of romantic relationships.”[29] Of note, patients with unrealistic optimism understand prognostic information from their physicians, but they do not believe this information applies to them.

Researchers have proposed several causes of unrealistic optimism. James Shepperd and colleagues, for instance, highlighted three main contributors.[30] First, many people are simply motivated to believe that they will experience favorable outcomes.[31] They believe that being overly optimistic is preferable to being accurate or pessimistic when predicting their likely outcomes.[32] Second, individuals have unique information about themselves that they do not have about others. Due to this lack of information regarding others, patients might fail to recognize how similar they are to the “average person.” In fact, researchers have shown that providing more information about an “average person” might decrease one’s unrealistic optimism by disabusing this concept of uniqueness.[33] Finally, as stated by Shepperd et al., “unrealistic optimism can be a natural consequence of the way people process information.”[34] People might employ a representativeness bias in their reasoning “whereby people judge their likelihood of experiencing an event based on how well they match their stereotype of the people who experience the event.”[35]

Studying Prognostic Awareness – Future Directions

The aforementioned concepts may all contribute to prognostic discordance and have different effects on prognostic awareness. Innumeracy could contribute to an actual misunderstanding of prognosis. Performative language might signal a misunderstanding when the patient has a clear understanding of prognosis. Optimistic bias represents a discrepancy in beliefs rather than understanding. These patients can understand the information provided by clinicians, but they do not believe the information applies to them. Beyond these three factors, myriad other contributors likely affect patients’ prognostic estimates, including cultural beliefs,[36] emotional distress, and trust in the medical team. Furthermore, each of these factors may interact in a particular situation – e.g., a patient could misunderstand a poor prognosis, which might exacerbate an underlying optimistic bias.

It is imperative for physicians and communication researchers to understand what patients mean when they offer inaccurate prognostic estimates. Attempts to improve prognostic awareness will only work if interventions target the causes of the discordance. Increasing disclosure by clinicians is necessary, but likely insufficient, to improve prognostic awareness for all patients, as it may not address the root cause related to discrepancy in beliefs. It is entirely possible that the patient understands the information they have been given but that they do not internalize such information into realistic acceptance of their prognosis or treatment options. In these instances, physicians cannot rely solely on disclosure, no matter how well it has been performed. Indeed, doing so may prove detrimental. For example, reiterating a poor prognosis because a patient is using performative language (even though they truly understand the prognosis) might negatively affect the patient-clinician relationship. Similarly, providing more statistics regarding poor prognosis to a patient with an optimistic bias will not change their beliefs. These patients often understand the information, but they don’t believe it applies to them.

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There is a need for future studies that seek to understand what kind of information patients want and how they use prognostic data that they consider relevant to inform their beliefs. To date, most literature has focused on discrepancies in understanding while fewer studies have examined how to address discrepancies in belief. As such, it is imperative to determine what it means to have successful prognostic disclosure. Should successful disclosure be defined as a patient having complete understanding of their prognosis (i.e., the outcome is understanding)? Should it be defined as a patient having adequate knowledge to make treatment decisions that align with their preferences, goals, and beliefs (i.e., the outcome is more functional)? Or should it be defined as enabling patients to appreciate or believe their prognosis? To that end, certain programs – such as the 1-2-3 Project initiated at Memorial Sloan Kettering Cancer Center – are helping to better define answers to these questions, but these have yet to gain nationwide traction.[37]

In 2017, a group of communication experts and researchers proposed an agenda for communication research in the setting of serious illness. One proposed area of focus was a deeper exploration of the "basic science of communication."[38] Given the complexity of contributors to prognostic discordance, we need to apply this concept of "basic science of communication" to prognostic disclosure. Ideally, this work could lead to tools and training to prepare clinicians to ascertain what their patients understand and believe about prognosis.[39] Past literature on prognostic disclosure has created a strong foundation that demonstrates deficiencies and proposes initial steps to improving prognostic awareness. However, we cannot meet the needs of individual patients until we better understand how to identify and address the myriad contributors to prognostic discordance.

Conclusions

In this article we use the framework of oncological care to highlight and discuss contributors to prognostic discordance and have outlined a framework to prognostic awareness that encompasses both discrepancies in understanding and discrepancies in belief as well as the ethical concern associated with each step along the spectrum. There are multiple influences on prognostic understanding that may impede acceptance by patients even when adequate transfer of prognostic information takes place. Accordingly, even if physicians improve how they transmit essential prognostic information, they should recognize that this information may be processed in different ways. Additionally, future decision-making studies should consider these many variables – rather than solely focusing on what physicians say – so that novel interventions may be created to address all aspects of the prognostic disclosure process or to allow clinicians to present prognostic information in varied ways.

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Notes

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