

CLINICAL PRACTICE

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Navigating and Communicating about Serious Illness and End of Life

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This Journal feature begins with a case vignette highlighting a common clinical problem. Evidence supporting various strategies is then presented, followed by a review of formal guidelines, when they exist. The article ends with the authors' clinical recommendations.

A 71-year-old man had previously received a diagnosis of stage IV non–small-cell lung cancer that was positive for epidermal growth factor receptor (EGFR) and metastatic to the spine. The cancer responded to treatment with an EGFR tyrosine kinase inhibitor, providing the patient with an excellent quality of life for 3 years. During that time, his main priority was caring for his wife, who has dementia. The patient now has leptomeningeal disease and worsening back pain. His oncologist reports the news of the disease progression and discloses the prognosis that the patient's remaining life may be as short as a few months. Despite multiple conversations with his clinician, the patient continues to state that he hopes to live several more years and that he feels his oncologist is giving up on him. In addition to starting chemotherapy and radiation therapy and referring the patient to outpatient palliative care, how can his clinicians support him in integrating information regarding his prognosis and help him with end-of-life planning?

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THE CLINICAL PROBLEM

CONVERSATIONS ABOUT PROGNOSIS CAN BE DIFFICULT AND CONFUSING for both patients and clinicians. It is not uncommon that patients who have a serious illness, such as cancer or heart failure, continue to express seemingly unrealistic hopefulness despite conversations in which accurate prognostic information has been well communicated and tailored to the patient's preferences. This reaction is disconcerting for clinicians who want to understand what is most important to the patient and are rightly concerned that a patient may not be prepared for the end of life.¹ Such concerns that lack of preparation can lead to poor-quality end-of-life care are supported by evidence of late referrals to hospice and unwanted in-hospital deaths.²

Several factors contribute to the difficulty of conversations about prognosis. Consideration of matters related to death is difficult for patients and clinicians across most cultures, and therefore, patients may have a poor understanding of their illnesses and clinicians may not know how to help patients cope. The task of the clinician is to assess and guide the patient's awareness and adaptive coping process, including discerning the patient's priorities for this last part of life. Such considerations include the patient's relationships; their feelings regarding disability, pain, and treatment invasiveness; and the evolving nature of all these issues. As the prognosis translates into medical decisions, the process must be coordinated across medical teams. These tasks are as yet imperfectly practiced.²

KEY CLINICAL POINTS

NAVIGATING AND COMMUNICATING ABOUT SERIOUS ILLNESS AND END OF LIFE

- Partnering with patients as they navigate serious illness requires effectively communicating prognostic information while responding to the emotions generated by the conversation.
- Clinicians should expect, and have the skill, to engage in a continuum of conversations that allow patients to integrate prognostic information cognitively and emotionally.
- Patients oscillate between expressions of intense hopefulness and more realistic aspirations; this a normal and expected part of the process.
- Facilitating patient exploration of their hopes and worries allows them to grieve, understand their priorities, and build coping skills for living with a serious illness.
- As patients integrate prognostic information, clinicians should discuss what is most important to the patient given the likely illness trajectory and incorporate these goals and values into a recommendation about medical care, including care at the end of life.

Many clinicians have not had the opportunity to master the communication skills necessary to help seriously ill patients cope with their illnesses. These skills include recognizing that a patient's continued extreme hopefulness is a normal part of coming to terms with an uncertain or poor prognosis. To help patients with serious illness develop their capacity to cope with the enormity of their illness, clinicians need skills that go beyond selecting the most appropriate scripts for communicating bad news. These skills should include recognition of the patients' current understanding of their illness and their capacity to adaptively cope with prognostic information, and clinicians should be able to help cultivate prognostic awareness and existential maturation.³⁻⁹

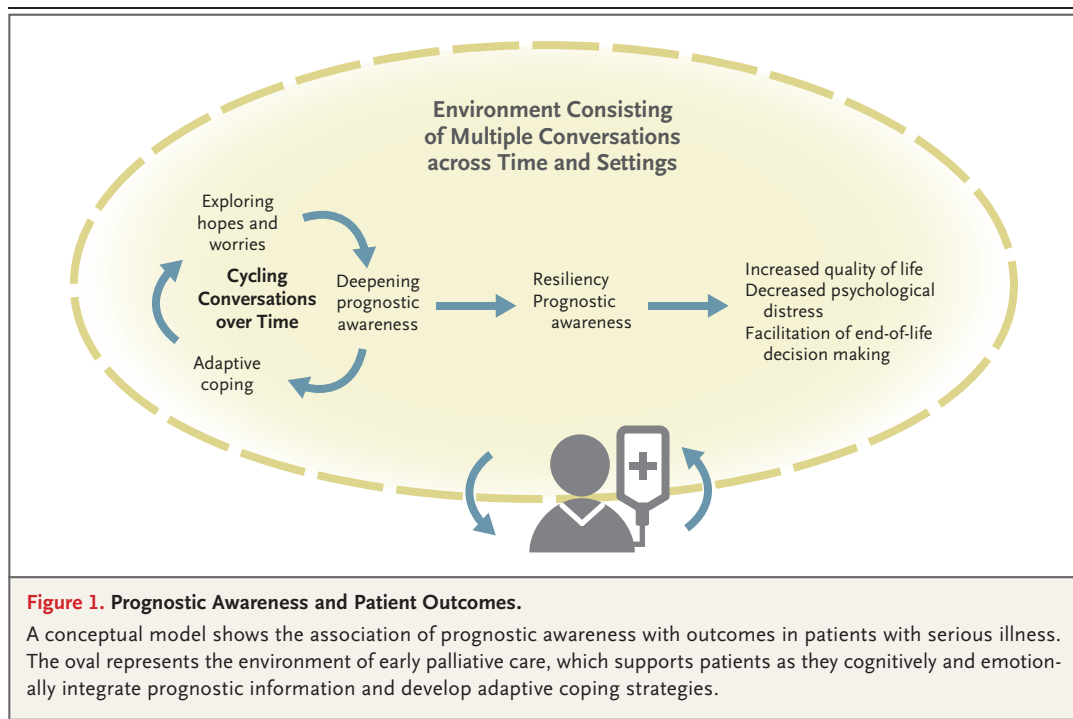
Prognostic awareness is a patient's ability to integrate the likely illness trajectory both cognitively and emotionally.⁵ Partnering with patients to deepen their understanding of their illness is an iterative process that requires several conversations over a period of months to years before the end of life. Intervention studies that have been aimed at increasing prognostic awareness have had mixed results. Some studies have shown that increased prognostic awareness was associated with lower quality of life and higher levels of psychological distress.^{10,11} We hypothesize that these poorer outcomes may occur when patients do not have enough time and support to develop adaptive coping strategies.^{8,12} Cultivating prognostic awareness entails the development of coping strategies to manage a more integrated awareness of an uncertain future.^{4,8} This process is a part of existential maturation, which is the development of integrated ways of living fully that are informed by an awareness of mortality and that allow death to be viewed as a nontraumatic

outcome.^{7,13} A patient's ability to cultivate prognostic awareness as part of the existential maturation process is critical when it comes to advance care planning, when what is most important to the patient is translated into a treatment plan, especially as it relates to end-of-life care.¹⁴

STRATEGIES AND EVIDENCE

Advance care planning, serious illness conversations (with the use of a scripted communication guide to discussing serious illness), and palliative care interventions share the common goals of aligning medical care with patients' goals and values and improving clinical outcomes. These strategies, however, have shown varying effectiveness in achieving the intended goals. Trials that have analyzed advance care planning have shown that patient preferences regarding factors such as code status can change and that it is hard for most patients to determine an appropriate medical decision far in advance of the need for that particular decision.¹⁵⁻¹⁷ In addition, rigorous trials of advance care planning interventions have shown that simply having an advance care planning document does not result in improved patient outcomes. For instance, a large multicenter, randomized trial of advance care planning involving patients with cancer resulted in an increased number of advance directives that were completed, but investigators found no improvement in quality of life or coping strategies.¹⁸ These findings may reflect that current advance care planning models do not focus on the actual process by which patients come to understand their prognosis, share what matters most to them, and then iteratively express their preferences for medical care.¹⁹

Serious illness conversations that are con-



ducted repeatedly over a span of time expand the framework of advance care planning, and there is a growing evidence base for their effectiveness.²⁰⁻²² This approach more fully incorporates the complex, longitudinal process of planning for a patient's future health. We suggest that in order for serious illness conversations to be effective, the focus should be on the patient's ability to cognitively and emotionally integrate the likely trajectory of a known illness and the psychological processes necessary to cope with this information. Continuing, attuned conversations of this nature require more time and openness to psychological adjustment than the current norm of advance care planning, which aims for durable treatment preferences that are stated once.²³

In contrast to advance care planning trials, multiple randomized clinical trials of palliative care have shown improvements in patient-reported outcomes. Early integration of palliative care for patients with cancer improves mood, quality of life, and quality of care at the end of life.²⁴⁻²⁶ Another trial showed changes in prognostic awareness among patients who had been randomly assigned to receive early palliative care.²⁷ The improvements in quality of life and mood that were shown in trials involving palliative care are likely to be mediated by patients' increased use of adaptive coping strate-

gies.¹² Patients who see palliative care clinicians regularly and earlier are more likely to use adaptive coping strategies such as positive reframing (focusing on ways the stressor might be positive or beneficial) or gratitude (expressing appreciation for positive things in their lives) rather than avoidance or denial (refusing to acknowledge or discuss the stressor). Figure 1 shows a conceptual framework based on findings related to how the cultivation of prognostic awareness may influence patient quality of life, mood, and end-of-life decision making.

All clinicians caring for patients with serious illnesses, not only those practicing palliative care, can integrate these results into clinical practice. Here, we consider some of the factors that clinicians should understand with regard to how patients cognitively and emotionally process and integrate prognostic information. This understanding is the key to initiating end-of-life care neither too soon nor too late.

COGNITIVE INTEGRATION OF PROGNOSTIC INFORMATION

The promotion of cognitive integration of prognostic information is a complicated process. Patients report that they want honest prognostic information from their doctors and, at the same time, want their doctors to be optimistic.^{28,29}

Best practices suggest that a clinician tailor population-level data to the individual patient, acknowledging uncertainty (including uncertainty resulting from a lack of data), providing times in ranges, and respecting the patient's information preferences.³⁰

However, even when effective communication methods are used, patients often have misconceptions about their illness that affect treatment decision making. One study showed that 69% of patients with metastatic lung cancer and 81% of patients with colorectal cancer did not understand that chemotherapy was unlikely to cure their cancer,³¹ and data have confirmed misperceptions across numerous populations, including patients with hematologic cancer, congestive heart failure, and end-stage liver disease.³²⁻³⁴ Patients who overestimate the likelihood of survival are more likely to choose intensive care measures at the end of life and are less likely to discuss their end-of-life care preferences with their clinicians.³⁵ These data show that there is an opportunity for clinicians to help patients develop a more accurate understanding of the likely course of their illness. Rather than insisting that a patient immediately accept a harsh new reality, the clinician can offer support as the patient builds the capacity to come to terms with the likelihood of dying.³⁶

EMOTIONAL INTEGRATION OF PROGNOSTIC INFORMATION

The process of emotional integration of difficult prognostic information necessitates that the patient grieve losses, reimagine hopes, and manage fears and worries in order to tolerate and effectively cope with the distress related to their prognosis. It is often a bumpy, oscillating developmental process that involves conflicting, intense emotions. Patients oscillate between expressions of extreme hopefulness (“I know I will beat this. I don’t believe the oncologist.”) and realism (“I don’t know what the future holds. I hope I feel well enough to take a trip with my family this summer.”) Oscillation between conflicting states of mind is a fundamental part of normal emotional processing and development and is well-established in psychological theories that have been applied to processing the realities of serious illness.³⁷⁻³⁹ With the benefit of time and the opportunity to explore hopes and worries in a trusted environment, patients tend to

progress toward prognostic awareness and existential maturation.^{3,5,7,13}

EVOLUTION OF INTEGRATED AWARENESS

Studies have shown that deeper prognostic awareness happens over time, often across a continuum of conversations.^{40,41} Patients and clinicians often “cycle” through short portions of this ongoing conversation over periods of weeks, months, or years, depending on the patient and the cadence of the illness.

Clinicians can align with patients in these vacillations, not only accepting patients' hopes but exploring them in order to better understand what is most important to the patient. Additional factors that may facilitate this interaction include showing empathy; normalizing patient reactions; slowly exploring the sadness, grief, and loss; and maintaining a reliable and accessible partnership to help the patient cope and live as fully as possible in this final phase of life, however long it may be.⁴²

The cycling of these conversations over time and in different settings (e.g., palliative care, oncology, and primary care) and with different disciplines (e.g., social work, psychology, and chaplaincy) allows the patient to develop a language for discussions about the possibility of dying and the adaptive coping skills to participate in those discussions. Crucial conversations about these matters also involve families and loved ones. Some conversations with family and loved ones entail divergent hopes and worries that affect the patient's process of integrating the prognostic information and may need to be discussed with the clinician. Throughout the course of all these conversations, patients increasingly link a cognitive and emotionally integrated understanding of the illness to their expression of what is most important, and they are able to make more fully informed decisions (Fig. 1).

Despite effective communication and partnership with their clinicians, some patients may continue to struggle to cognitively and emotionally integrate prognostic information. This lack of integration may result in the clinician facing a situation in which a patient is requesting a treatment that is unlikely to be of benefit. The competing precepts of autonomy and nonmaleficence can be difficult to balance. Continued attuned conversations and, perhaps, a time-limited trial of treatment may be helpful.⁴³

AREAS OF UNCERTAINTY

Clinicians and researchers need to be able to measure the degree to which patients have cognitively and emotionally integrated key prognostic information and how well they are adaptively coping.⁴⁴ We need a better understanding of which domains of patient concern are germane to medical decisions — such as relationships and thresholds regarding disability, physical suffering, and invasiveness of treatment — and how these factors relate to the oscillations of hopes and worries.^{45,46} More research is needed to better understand the ideal timing, content, and structure of these conversations and how these elements might vary with factors such as a patient's baseline coping strategies, cultural preferences, lack of trust in the medical system (including concerns about systemic racism), physical or spiritual suffering, and the patient's ability to develop trusting relationships.^{45,47} We also know very little about how factors that affect clinicians, such as self-awareness, burnout, existential maturity, and capacity to tolerate uncertainty, influence their abilities in this area.

In addition, research needs to produce a better understanding of the ways in which well-studied psychotherapy interventions could be helpful to patients with serious illness, not only in mitigating psychological symptoms such as anxiety and depression but also in cultivating prognostic awareness, coping, and the quality of decisions.^{6,48} Reconsideration of how best to conduct the research and the clinical process of advance care planning is under way.^{17,23,45,46,49,50} Because palliative care specialists cannot be the sole orchestrators of these conversations, more research is needed to guide not only clinicians' acquisition of primary palliative-care skills but also the way serious illness conversations — and the documentation of those conversations — are integrated into their workflow. Finally, clinicians need methods to easily and visibly document in the medical record an assessment of patients' illness understanding, coping abilities, and the elements of what matters most to them.^{45,46}

GUIDELINES

Professional societies have not promulgated guidelines regarding the ways clinicians can help patients integrate prognostic information.

Table 1. Key Concepts and Examples of Communication Strategies.

Concept	Communication
Assess the patient's prognostic awareness while eliciting and exploring hopes and worries.	"What is your understanding of your illness? When you think about what lies ahead, what are you hoping for? What are you most worried about?"
Respond to prognostic questions with your best understanding, even if there is uncertainty.	"I hope your health will steadily improve, and I am worried that you may have a continued decline in your health."
Respond to emotions.	"This is so sad." "I can only imagine how hard this is."
Include loved ones in conversations exploring illness understanding.	"Who else might be helpful to include in our conversation?"
Help patients discern what matters most to them.	"If your health does worsen, what is most important to you?"
Recommend clinical care that is based on what matters most to the patient.	"It sounds like _____ is most important to you. Given this priority, I'd recommend _____."

CONCLUSIONS AND RECOMMENDATIONS

To guide patients such as the 71-year-old man described in the vignette, clinicians first must effectively communicate prognostic information.³⁰ Next, clinicians need to partner with patients as they integrate prognostic information while their states of mind oscillate normally between intense hopefulness and more realistic aspirations. By exploring their hopes and worries, patients may begin to grieve the life they had expected and to integrate and cope with the likely course of the illness. As a patient gains an integrated awareness that life may be short, clinicians should be ready to discuss what is possible, with regard both to decisions about medical treatments and to decisions about how the patient may choose to live this last phase of life, given the illness trajectory. By means of these discussions, clinicians must be able to help their patients to discern what now matters most to them. With that knowledge, clinicians can incorporate the patient's informed goals and values into a recommendation about care at the end of life, such as hospice or life-sustaining treatment and the limitations of such therapy (Table 1).

For the patient described in the vignette, we would initiate a plan to treat his pain, build a strong therapeutic relationship, and then assess his prognostic awareness. If he continued to express a belief that he could live several more

years, we would explore his hopes and worries regarding that next period of time. In this exploration, clinicians and patients often find common ground and goals for their work together. If the patient's hopes and worries were centered on the care of his wife, we would acknowledge the patient's loving support, normalize his desire to care for her and attend to his emotions related to the thought of leaving her, and engage in practical planning for her care.

Over the course of several visits, we typically find that a patient gradually oscillates less widely and becomes more open to discussions of prognosis. As the patient's prognostic awareness deepens, the patient is better able to understand the implications of changes in physical function, such as intense fatigue or anorexia. If the patient described in the vignette states that he would like to be at home surrounded by his family at the end of his life, we would recognize his possible readiness for a recommendation for hospice care. Finally, we would document the serious illness conversation in the medical record, including the patient's prognostic awareness, coping, and what is most important to him, so that the information is accessible to all the clinicians who care for him (Table 2).

Partnering with patients who have a serious illness to help them live and die well requires

Table 2. Key Elements to Document in the Medical Record.

Prognostic awareness
Illness understanding
Patient's hopes and worries
Prognostic information that was shared (e.g., curable or not curable); continued decline in patient's condition; a time-based prognosis of days to weeks, weeks to months, or months to years
Assessment of how the patient is coping, including strategies used by the patient and family
What is most important to the patient and family, including relationships, disability, suffering, and invasiveness of treatment
Recommendations made to the patient and family

iterative conversations about their illness understanding, prognostic awareness, hopes and worries, and what matters most to them as the trajectory of the illness becomes clear. These conversations must take place over the course of the illness, in the context of trusted relationships in which the clinician is attuned to the patient's psychological coping and ability to cognitively and emotionally adapt to the reality of their mortality.

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