

VIEWPOINT

Communication Strategies for Sharing Prognostic Information With Patients Beyond Survival Statistics

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Communicating prognosis, the anticipated course of living with an illness, is a core clinical skill and a foundation of the patient-clinician relationship. Clinicians find such communication challenging. Concerns about professional helplessness when caring for a patient with a disease with a poor prognosis and the desire to avoid difficult patient and personal emotions can lead to an understandable reluctance to share difficult news with patients and families. Clinicians also struggle to find the right words to balance hope with concern when sharing difficult news.¹ While receiving prognostic information is difficult for patients, not receiving prognostic information can create anxiety and may distance patients from their clinicians, who are often aware of the prognosis but do not share it with patients. Delaying or avoiding communication about prognosis also risks patients not having the information they need to make decisions and leads to missed opportunities to set and achieve goals that reflect what matters most to them.

Sharing prognosis with patients is about more than expected survival. The experience of serious illness includes multiple dimensions, encompassing anticipated changes to quality of life, functional abilities and activities, the possibility of unpredictable events, and patients' (and families') own hopes, worries, and

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expectations about the future. Using statistics or mortality prediction to convey prognosis (eg, median survival) may offer too narrow of a focus; both clinicians and patients could benefit from more expansive views of prognostic communication.² Approaches that enable discussion of different kinds of prognostic information offer a more holistic frame within which to face an uncertain future.

Numerous skills and techniques could help clinicians enrich discussions around prognosis, including assessing what patients think their prognosis may be, understanding the kind of details patients want to know about what may be ahead with their illness, sharing clear information about prognosis, responding to emotions, and eliciting what matters most to patients in order to recommend and formulate a care plan that matches patients' priorities.¹ In this Viewpoint, we build on the work of others and offer a framework with 3 approaches for sharing prognosis—time, function, and unpredictability—

that should help empower patients to understand the medical realities they are likely to encounter and to meet their goals in the face of uncertainties.

These 3 approaches share common principles. First, preferences for prognostic information vary among patients and families.³ That is, some people want to know how much time may be left, while others may only want to know how their daily life may change with time. Some may want to know both and others may not want to know at all. Clinicians should ask about these preferences because doing so enhances patients' control over the receipt of difficult information, avoids overwhelming them with intolerable distress, and increases the likelihood that the information will be heard and retained.⁴

Second, communication about prognosis should explicitly balance anticipated medical realities with patients' expressed hopes in the context of uncertainty. Clinicians can align with patients by using language that mirrors the concomitant hope and concern that patients and families live with in facing serious illness,¹ for example, "I hope you can see your daughter graduate from college next year and we will work toward that goal. I also worry that may not be possible if you get sicker."

Third, these approaches are not mutually exclusive. Patients desire information about their prognosis for a number of reasons, including to "make the most of life" and to inform medical and personal decisions.³ Each type of prognosis adds a dimension that may help patients prepare for the future. For example, a patient may have years to live, but information about an anticipated functional decline may help them prioritize important activities while they are still able, such as a family vacation.

Time

For some patients, knowing a time frame in which they might expect significant impairment or death can help them plan for the future. When clinicians have information that helps to predict a potentially likely time course and when patients desire that information, sharing this directly can focus patients on achieving urgent and important goals. However, communicating a single time to a given event, for example, 6 months to live, does not acknowledge the variability of treatment responses and disease trajectories. Conveying a false certainty about time can overwhelm patients emotionally and undermine trust between clinicians and patients and their families. For this reason, it is useful to consider using a range (hours to days, days to weeks, months to a year) to communicate a time-based prognosis, for example,

"I wish we were not in this situation, but I'm worried that time may be as short as months to a year, even though it could be longer or shorter than that."⁵

Function

Patients with serious illness have priorities besides living longer. Among these are maintaining the myriad functions that allow them to live well, whatever their version of doing so may involve. Patients commonly desire to maintain their independence,⁶ to continue core personal activities such as gardening or painting, and not to "burden" others with their care. How an illness is likely to affect functional ability may be far more important to a patient and family than understanding how much time may be left. Preparation for an undesired functional state also could help patients cope and may empower patients to act on goals while still possible to do so. For example, patients with Parkinson disease or amyotrophic lateral sclerosis experience predictable functional decline over time. Discussing this possibility can help patients, families, and clinicians make plans to maximize the patient's independence as much as possible while also preparing for future changes. Clinicians might use the following language: "I hope that you can maintain as much independence as possible and we will work toward that goal. I'm also worried that you may get weaker over time and may not be able to live on your own as your disease progresses."⁵

Unpredictability

Patients with serious illnesses characterized by end-stage organ disease can live for years and can experience unpredictable acute events that result in serious debility or death. To help patients begin to consider this possibility and prepare for an event without

undermining their hope for ongoing survival and quality of life, the following language can be helpful: "It can be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time and we will keep working toward that goal. I'm also worried that you could get very sick suddenly, and I think it is important for us to prepare for that possibility."⁵ Sharing this possibility in advance could give patients time to think about what would be important to them. It also could promote discussions to prepare patients, care teams, and caregivers for sudden changes, when urgent or consequential medical decisions may need to be made by the patient or caregiver if the patient is unable to express his or her wishes. The burden of decision-making during acute crises creates distress for patients and families that may be reduced by preparation and planning.⁷

Conclusions

Communicating prognosis is difficult for patients, families, and clinicians. Yet high-quality communication for people living with serious illness includes sharing information using patient-centered approaches. Reconceptualizing prognosis beyond just survival provides a more comprehensive (and perhaps more acceptable) frame for planning and decision-making that empowers patients with serious illness and families to adjust to changes in their lives. Sharing prognosis can also close the distance that is created when a clinician has prognostic estimates that are not shared with the patient, even if the intention is protective. These conversations may serve to strengthen the patient-clinician relationship by creating space to hold the feelings and uncertainties experienced by patients and by building the security and trust needed to plan together for this challenging experience.

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REFERENCES

1. Jackson VA, Jacobsen J, Greer JA, Pirl WF, Temel JS, Back AL. The cultivation of prognostic

awareness through the provision of early palliative care in the ambulatory setting: a communication guide. *J Palliat Med.* 2013;16(8):894-900. doi:10.1089/jpm.2012.0547

2. Thomas JM, Cooney LM Jr, Fried TR. Prognosis reconsidered in light of ancient insights: from Hippocrates to modern medicine. *JAMA Intern Med.* 2019;179(6):820-823. doi:10.1001/jamainternmed.2019.0302

3. Ahalt C, Walter LC, Yourman L, Eng C, Pérez-Stable EJ, Smith AK. "Knowing is better": preferences of diverse older adults for discussing prognosis. *J Gen Intern Med.* 2012;27(5):568-575. doi:10.1007/s11606-011-1933-0

4. Bernacki RE, Block SD; American College of Physicians High Value Care Task Force. Communication about serious illness care goals: a review and synthesis of best practices. *JAMA*

Intern Med. 2014;174(12):1994-2003. doi:10.1001/jamainternmed.2014.5271

5. Ariadne Labs. Serious Illness Conversation Guide. <https://www.ariadnelabs.org/wp-content/uploads/sites/2/2018/04/Serious-Illness-Conversation-Guide.2017-04-18CC2pg.pdf>. Accessed August 8, 2019.

6. Fried TR, Tinetti ME, Iannone L, O'Leary JR, Towle V, Van Ness PH. Health outcome prioritization as a tool for decision making among older persons with multiple chronic conditions. *Arch Intern Med.* 2011;171(20):1854-1856. doi:10.1001/archinternmed.2011.424

7. Sudore RL, Fried TR. Redefining the "planning" in advance care planning: preparing for end-of-life decision making. *Ann Intern Med.* 2010;153(4):256-261. doi:10.7326/0003-4819-153-4-201008170-00008