Prognostication in Serious Illness

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KEYWORDS

• Prognosis • Decision making • Goals of care • Communication • Palliative care
• Patient-centered care • Palliative medicine • End-of-life care

KEY POINTS

- Prognosis, defined as the likelihood of a patient developing a particular outcome over a specific period of time, is essential to informed, patient-centered, clinical decision making.
- Prognostication involves 3 key components: formulation of the patient's prognosis; communication of the patient's prognosis; and the patient or surrogate's interpretation of the communicated prognosis.
- Prognostic indices are designed to quantify the relative contributions of prognostic variables and to assist clinicians in formulating prognostic estimates.
- A patient-oriented approach is needed when disclosing prognostic information.
- A patient or surrogate's interpretation of the communicated prognosis may be biased by optimism and the perception that the patient's attributes portend a more favorable outcome.

THE ESSENTIAL ROLE OF PROGNOSIS

> *The path forward would seem obvious if only I knew how many months or years I had left. Tell me three months, I'd just spend time with my family. Tell me one year, I'd have a plan (write that book). Give me ten years, I'd get back to treating diseases.*
>
> *—Paul Kalanithi, MD*

Of the 3 pillars of clinical medicine, diagnosis, prognosis, and treatment, one remains largely underprioritized in modern medical practice. Prognosis, the likelihood of a patient developing a particular outcome over a specific period of time, has

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Med Clin N Am 104 (2020) 391–403
https://doi.org/10.1016/j.mcna.2019.12.002
0025-7125/20/

been greatly overshadowed by a pervasive emphasis on diagnosis and treatment.[1] However, prognosis is an essential consideration in the delivery of high-quality, patient-centered care.

Prognostication involves the both the appraisal and the disclosure of a patient's prognosis as well as the interpretation of the disclosed information (Fig. 1). In essence, prognostication is the clinician's way of communicating what a patient can reasonably expect of the future with respect to a medical condition or its treatment. A dynamic skill, prognostication involves integrating clinical judgment with evidence-based patient-, disease-, and environment-related factors to make a prediction about the likelihood of a future clinical outcome. Although often equated with a prediction of survival, prognosis can refer to a range of outcomes along a patient's disease trajectory, such as a change in symptom burden, functional ability, or cognition. Given that prognosis frequently shapes a patient's priorities and alters the balance of potential benefits and burdens of a given medical intervention, prognostication is critical to informed shared decision making.[2–8]

BARRIERS TO PROGNOSTICATION

Most patients with serious illness prefer to know what to anticipate as their disease progresses. Yet clinicians are often reluctant to formulate and communicate prognostic estimates,[9–17] especially in the setting of terminal disease or serious illness, when prognostic information is likely to be most relevant. Consequently, patients or their surrogates often lack the information necessary to make informed medical decisions or to establish realistic goals of care.[8,18,19] For example, in a survey of patients with advanced breast cancer, nearly 60% of respondents incorrectly thought that their treatment was curative in intent,[20] and in a study of more than 1000 patients with incurable metastatic lung or colorectal cancer, 74% thought that the intent of chemotherapy was cure.[18] Similarly, in a multicenter study of nearly 600 patients with metastatic cancer, 71% wanted to be told their life expectancy, but only 18% had received this information.[20]

Perhaps the most significant factor limiting clinicians' willingness to engage patients in discussions about expected clinical outcomes is the misconception that prognostic inaccuracy renders such predictions clinically irrelevant.[21–23] It is not uncommon, for example, for a clinician to deflect an opportunity to engage a patient in a discussion about his or her prognosis with the reasoning that one cannot possibly predict the future.

Although it is known that, at least in terms of survival estimates among patients with cancer, clinicians tend to be overly optimistic and are frequently inaccurate, the clinical significance of this inaccuracy is unclear.[23–26] Lam[27] found a strong correlation between predicted and actual survival with an absolute difference in median survival of only 6 days (70 vs 76 days). Similarly, in a metaanalysis including more than 1500

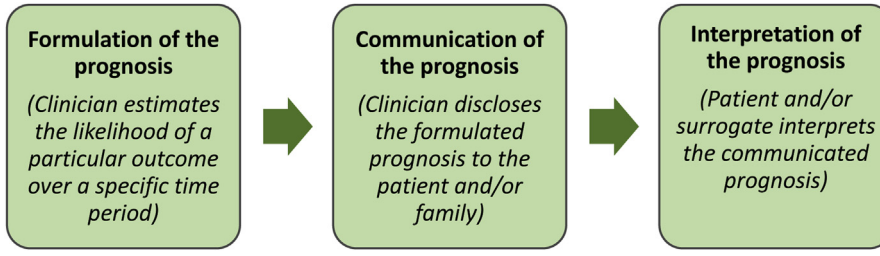

Fig. 1. Three components of prognostication.

patients with cancer, predicted survival of less than 6 months was highly correlated with actual survival, although systematically overestimated.[28] Several reasons for this tendency toward overestimation have been postulated. First, because prognostication is not a routine part of clinical discourse or education, most clinicians are poorly trained in how to formulate prognostic estimates.[16,29,30] Second, most data about patients' actual survival are obtained from clinical trials, which typically select for otherwise healthy patients and are therefore limited in their generalizability.[29] Third, the culture of modern medicine discourages frank discussions of death and dying and has, in turn, fostered professional norms that devalue prognostic estimates and favor optimism over accuracy.[22,29,31]

Unfortunately, even when a clinician has a clear sense of a patient's disease trajectory, prognostic nondisclosure is exceedingly common.[7,18,20,21,31] Clinicians routinely avoid initiating discussions about expected outcomes and often knowingly communicate overly optimistic estimates of survival.[1,32,33] A survey-based study by Lamont and Christakis[23] showed that even when a patient specifically requests prognostic information, approximately two-thirds of surveyed physicians indicated that they would either refuse to disclose this information or intentionally communicate a prognosis that differs from that which they had formulated.

Clinicians cite fear of taking away patients' hope or disrupting the patient-clinician relationship as key barriers to prognostic disclosure.[11,15] There is strong evidence to suggest, however, that these barriers are not well founded. Several studies have shown that prognostic disclosure preserves, and even promotes, hope among patients and their families.[14,34–37] Furthermore, an unfavorable prognosis, when communicated skillfully and with attention to patients' individual needs, does not detract from patients' emotional well-being or weaken the patient-clinician relationship.[20,36–38] Instead, prognostic awareness has been shown to increase emotional and social functioning, reduce anxiety and spiritual distress, and improve the quality of end-of-life care.[39–44] Common barriers to prognostication are summarized in **Box 1**.

FORMULATION OF THE PROGNOSIS

Prognostication, like most aspects of clinical medicine, is both an art and a science, with increased accuracy noted when clinical judgment is combined with evidence-based tools.[45–49] Although many disease-, patient-, and environment-related factors are known to influence the likelihood of a particular clinical outcome, clinicians are often unsure of how to weigh these variables when

Box 1
Common barriers to prognostication

- Discomfort with the inherent uncertainty of forecasting
- Inaccuracy of prognostication tools
- Fear of being judged for inaccurate predictions
- Discomfort with disclosing serious news
- Inadequate communication skills training
- Fear of diminishing patients' hope
- Fear of causing patients distress or reducing their quality of life
- Fear of disrupting the patient-clinician relationship or decreasing patient satisfaction
- Guilt associated with not being able to offer curative treatments

formulating a prognostic estimate, especially for patients with noncancer diagnoses, atypical clinical presentations, and multi-comorbidities.

The most common way that clinicians estimate prognosis is through their clinical judgment and experience. Prognostication based on clinical judgment is correlated with actual survival; however, it is subject to various shortcomings that limit prognostic accuracy. In addition to the bias toward overestimation as described above, other studies have shown that clinical predictions tend to be more accurate for short-term prognosis than long-term prognosis and that the length of clinician-patient relationships also appears to increase the odds of making an erroneous prognostic prediction.

Clinician predictions may be improved by integrating within the clinician's judgment some other form of estimating prognosis, such as life tables, published studies, or prognostic indices.[50] Life tables require knowledge of only a few demographic characteristics, most commonly age and gender.[5] However, there tends to be significant variation in life expectancy based on life tables alone (**Table 1**), limiting their clinical applicability. Another method to determine prognosis is to reference published studies in which participants' diseases and demographics closely mirror those of a given patient. Importantly, because studies frequently exclude individuals who have multiple comorbidities or who are frail, prognostic estimates using published studies may often overstate survival.

Lastly, clinicians can use well-validated prognostic indices to help refine their prognostic estimates (**Table 2**). Prognostic indices are tools that use systematically selected characteristics from a particular population, such as age, comorbidities, functional status, and laboratory test results, to calculate a prognostic estimate. Use of any prognostic index requires some understanding of its accuracy, validity, and generalizability. For instance, if a prognostic index was created and tested in a community-based setting, it will likely overestimate prognosis in hospitalized adults.

Considerations of Prognosis in Select Diseases

Cancer

Prognosis for early-stage cancer is primarily based on tumor type, disease burden, and aggressiveness suggested by clinical, imaging, laboratory, pathologic, and molecular characteristics. For more advanced cancers, functional status has consistently demonstrated an association with survival, although length of survival may depend on the underlying cancer. For example, for patients with metastatic cancer with relatively

Table 1
Life table of upper, middle, and lower quartiles of life expectancy for women and men at selected ages

	Women			Men		
Age	Top 75th Percentile	50th Percentile	Lowest 25th Percentile	Top 75th Percentile	50th Percentile	Lowest 25th Percentile
65	26.9	21.2	14.2	24.3	18.3	11.4
70	22.2	16.9	10.7	19.8	14.4	8.5
75	17.8	12.9	7.6	15.6	10.8	6
80	13.6	9.3	5.1	11.8	7.7	4
85	9.9	6.3	3.2	8.5	5.2	2.5
90	6.9	4.1	1.9	5.9	3.4	1.6
95	4.7	2.6	1.2	4.1	2.2	1

Table 2
Examples of commonly used prognostic indices

	Prognostic Index	Patient Population	Web Site
Non-disease-specific examples	Walter 1-y index	Hospitalized adults ≥70 y old	www.ePrognosis.org
	Lee 4- and 10-y index	Community-dwelling adults ≥50 y old	
	Schonberg 5- and 9-y index	Community-dwelling adults ≥65 y old	
Disease-specific examples			
Cancer	Palliative Prognostic Score	Hospice and palliative care patients with advanced solid tumors	www.ePrognosis.org
Dementia	ADEPT	Nursing home residents with advanced dementia	www.ePrognosis.org
Heart failure	Seattle Heart Failure Model	Community-based heart failure patients without significant other comorbidities	http://depts.washington.edu/shfm

good treatment options, such as prostate or breast cancer, prognosis may be considerably longer than someone with pancreatic or biliary cancers, even among patients with poorer functional status. Clinicians can refer to published studies evaluating outcomes associated with specific cancer diagnoses and their treatments. Although this is particularly helpful in cancers whereby treatment modalities are frequently changing, caution is warranted when looking at survival estimates based on published studies because most of these trials do not include patients with poor functional status, multimorbidity, or organ dysfunction.

Advanced dementia

Individuals living with dementia typically have a prolonged period of severe functional disability as the disease progresses to its advanced stages. Unfortunately, estimating short-term prognosis in this patient population is difficult. Individuals with advanced disease may survive for several years with severe functional and cognitive impairments, yet run the risk of developing sudden, life-threatening complications, such as aspiration pneumonias and urinary tract infections. These complications serve as a marker of a very poor short-term survival. In a study of individuals with advanced dementia residing in a nursing home, the 6-month mortality after the development of pneumonia, a febrile episode, or eating difficulties was 47%, 45%, and 39%, respectively.[51] In another study, individuals with advanced dementia who were admitted to the hospital with either pneumonia or a hip fracture had a median survival of approximately 6 months.[52]

Hospice eligibility guidelines for dementia state that individuals need to meet or exceed stage 7a on the Functional Assessment Stage scale (**Table 3**) and must have at least 1 dementia-related complication (aspiration, upper urinary tract infection,

sepsis, multiple stage 3–4 pressure injuries, persistent fever, weight loss >10% within 6 months). However, these criteria fail to accurately predict 6-month survival in those with advanced disease. An example of a mortality index that can be used in nursing home residents with advanced dementia is the Advanced Dementia Prognostic Tool (ADEPT), also found on ePrognosis.org. ADEPT can help identify nursing home residents with advanced dementia who are at high risk of death within 6 months, although only marginally better than current hospice eligibility guidelines.[53]

Congestive heart failure

Most deaths from advanced heart failure are preceded by a period of worsening symptoms, functional decline, and repeated hospitalizations as a result of progressive pump failure. Despite significant advances in the treatment of heart failure, the prognosis in patients who have been hospitalized for heart failure remains poor, with a 1-year mortality rate ranging from 20% to 47% after discharge. The prognosis is worse for those with multiple hospitalizations. The median survival in a study of older patients admitted for heart failure declined from 2.4 years in those with 1 hospitalization to 0.6 years for those with 4 hospitalizations.[54] Other indicators of a poor prognosis in heart failure include patient demographic factors, disease severity, comorbid conditions, physical examination findings, and laboratory values. Heart failure–specific prognostic indices often combine many of these factors to help identify patients who have a high short-term mortality.

COMMUNICATION OF THE PROGNOSIS

There are few tasks in clinical medicine that are as challenging, or as important, as skillfully communicating a patient's prognosis. Unfortunately, few clinicians receive formal training in how to effectively communicate prognostic information. To address this need, several communication aids have been developed to guide clinicians through the process of prognostic disclosure and to promote patient-centered communication. Ask-Tell-Ask is a simplified model that highlights the importance of assessing a patient's understanding before and after disclosing important information (**Table 4**). Similarly, the SPIKES (**Box 2**) and NURSE (**Table 5**) frameworks can help lead clinicians through the key considerations when disclosing prognostic information.[55] **Table 6** highlights additional resources related to communicating prognosis.

Table 3
Summary of functional assessment staging

Stage 1	No subjective or objective impairments in cognition
Stage 2	Mainly subject complains of forgetting names and misplacing objects
Stage 3	Objective evidence of memory impairment; impairment beginning to affect work performance
Stage 4	Moderate cognitive decline with impairments in instrumental activities of daily living
Stage 5	Difficulty with naming current aspects of their lives with some disorientation
Stage 6 (a-e)	Difficulty dressing, bathing, toileting without assistance. Experiences urinary and fecal incontinence in stage 6d and 6e
Stage 7 (a-f)	Speech declines from <6 intelligible words per day (7a) to one or less (7b). Progressive loss of ability to ambulate (7c), sit up (7d), smile (7e), and hold head up (7f)

Table 4
Ask-tell-ask

		Example Statement
Ask	Clarify what prognostic information the patient wants to know and ask for permission to disclose this information.	"What questions do you have about how your symptoms may change over the next few weeks?"
Tell	Disclose the requested information using simple clear language.	"Your shortness of breath will continue to worsen as your disease progresses."
Ask	Clarify the patient's understanding and interpretation of the disclosed information as well as how this may inform future decisions or goals.	"How does this information impact your preferences about your treatment options?"

Data from Back AL, Arnold RM, Baile WF, et al. Approaching Difficult Communication Tasks in Oncology. CA Cancer J Clin 2005;55(3):164-177.

Setting

Clinicians should prepare for prognostic disclosure. Conversations should ideally be held in a private setting and without disruption. Clinicians should ensure that they are familiar with the case and have reviewed the relevant information ahead of time.

Perception

A key step before prognostic disclosure is evaluating the patient's current understanding of his or her medical condition. Often, a clinician can best assess a patient's understanding through the use of open-ended, exploratory questions; however, for some patients, directed questioning may be required.

Invitation

Clinicians should gauge the patient's desire for prognostic disclosure. Although most patients want to discuss their prognosis with their clinicians, those who prefer not to should have the opportunity to communicate this preference. Clinicians should similarly clarify which outcomes their patients find most relevant and want disclosed. For example, a patient may prefer to not discuss how much time he has left but may want to know what changes in his functional independence he can reasonably expect. Clinicians should also assess patients' preferences regarding how and

Box 2
SPIKES framework for delivering serious news

*S*etting (eg, ensuring a private location, minimizing interruptions)

*P*erception (eg, assessing the patient's understanding)

*I*nvitation (eg, clarifying what information the patient wants to know)

*K*nowledge (eg, stating the information clearly)

*E*motion (eg, identifying and responding to patient's emotion with empathy)

*S*ummarize/*s*trategize (eg, determining next steps, closing the encounter)

Adapted from Back AL, Arnold RM, Baile WF, et al. Approaching Difficult Communication Tasks in Oncology. CA Cancer J Clin 2005;55(3):169; with permission.

Table 5
NURSE mnemonic for responding to emotion

	Example Statement
*N*ame the emotion	"This news seems like it's a big surprise for you."
*U*nderstand the emotion	"It sounds like you are afraid of what's to come. Is that right?"
*R*espect/praise the patient/family	"I'm so impressed with the strength you have shown through all of this."
*S*upport	"We're going to make a plan together."
*E*xplore	"What's the most difficult part of this for you?"

Data from Back AL, Arnold RM, Baile WF, et al. Approaching Difficult Communication Tasks in Oncology. CA Cancer J Clin 2005;55(3):164-177.

when they want prognostic information communicated. Attentive listening is key to ensure that the clinician best understands the information needs of each patient.

Knowledge

Prognostic estimates should be communicated clearly and without the use of jargon. Prognostic disclosure is best done through a brief statement that addresses the expected outcome most relevant to the patient while incorporating the patient's communication preferences. For some patients, visual aids may be helpful in conveying information about the likelihood of a particular outcome (**Fig. 2**).

Emotion

Upon disclosing prognostic information, clinicians should anticipate that patients may have an acute emotional response. Although somewhat counterintuitive, a strong emotional reaction often indicates that the information was communicated effectively. Clinicians should allow patients time to process the new information while remaining attentive to their emotional experience. Attending to emotion can be accomplished through therapeutic silence or responding with empathic statements. The mnemonic NURSE highlights ways of responding to patients' emotional cues.[55]

Table 6
Selected resources for communicating prognostic information

Resource	Description	Web Site
VitalTalk	Communication skills training with modules on prognostication	https://www.vitaltalk.org
Serious Illness Care Program	A multifaceted program aimed at improving communication between clinicians and patients with serious illness	https://www.ariadnelabs.org/areas-of-work/serious-illness-care
Palliative Care Fast Facts	Concise, evidence-based, peer-reviewed summaries covering a variety of palliative care topics, including prognostication	http://www.mypcnow.org/fast-facts
Center to Advance Palliative Care	Online courses in prognostication	https://www.capc.org

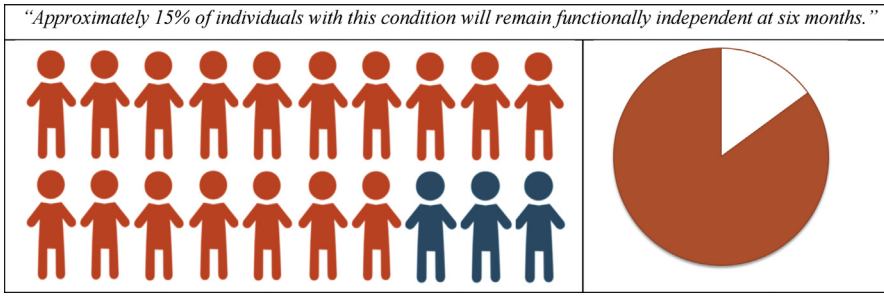

Fig. 2. Visual aids can assist in communicating the likelihood of specific clinical outcomes.

Summarize/Strategize

After responding to the patient's emotion, the clinician should assess the patient's understanding of the disclosed information and should address questions that arise. An effort should be made to delineate next steps because this can alleviate uncertainty or trepidation about the immediate plan of care.

INTERPRETATION AND INTEGRATION OF THE PROGNOSIS

The third, yet frequently underacknowledged, component of prognostication is the patient or surrogate's interpretation of the communicated prognosis. Take, for example, a patient with decompensated end-stage liver failure on maximum vasopressor support in the intensive care unit. The patient is not a transplant candidate and is actively dying. The patient's family, however, insists that the patient remains "full code" despite a communicated prognosis of hours to days. A clinician may be tempted to label the family as "in denial" or "unwilling to accept the truth." Alternatively, the clinician may assume that the patient's prognosis was not adequately communicated and therefore may repeatedly attempt to convince the family of the inevitability of the patient's impending death.

However, studies indicate that surrogates rarely base their view of a loved one's prognosis solely on the clinician's prognostic estimate. Instead, these studies suggest that surrogates attempt to balance the clinician's judgment with other factors, including their belief of the patient's intrinsic qualities and will to live; their observations of the patient; their belief in the power of their support and presence; and their optimism, intuition, and faith.[56–58] Furthermore, even in the face of poor prognostic information, patients and surrogates remain optimistic and overestimate survival. Given these findings, it can be helpful to communicate the specific factors influencing the clinician's prognostic estimate because these may also influence the patient or surrogate's interpretation of this information. It is also valuable to ask the patient or surrogate to share how they interpret the communicated prognosis and what other factors influence their beliefs because this can help guide further discussions.

SUMMARY

Prognostication is a key component in clinical decision making and is a fundamental skill for all practicing clinicians. Accurate prognostication allows for clinicians to provide patients and families with realistic options for care given current medical circumstances and aids in determining which interventions offer little chance of benefit because of competing risks of morbidity and mortality. The use of communication

aids such as Ask-Tell-Ask and SPIKES can help in delivering prognostic estimates in an effective and empathic manner.

DISCLOSURE

The authors have nothing to disclose.

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