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Uncertainty: The Other Side of Prognosis

Alexander K Smith, M.D., M.S., M.P.H., **Douglas B. White, M.D., M.A.S.**, and **Robert M. Arnold, M.D.**
Department of Medicine, Division of Geriatrics, University of California, San Francisco, and the San Francisco Veterans Affairs Medical Center — both in San Francisco (A.K.S.); and the Department of Critical Care Medicine (D.B.W.) and the Division of General Internal Medicine (R.M.A.), University of Pittsburgh, Pittsburgh

Recently, there has been a resurgence of interest in prognosis. This interest has been driven by a recognition that prognosis plays a central role in medical decision making, from counseling outpatients about stopping cancer screening to making decisions with patients' surrogates about withdrawal of life support in intensive care units.[1,2] Patients say that understanding prognosis is important for making life choices, such as engaging in financial planning, arranging custodial care, and deciding when it's important for long-distance family members to visit.[2]

Despite a proliferation of data about prognosis and life expectancy, our best estimates still carry a high degree of uncertainty.[3] First, 95% confidence intervals express variation in the survival of people with similar health conditions and limitations in sample sizes. Second, most prognostic indices have not been tested in heterogeneous clinical settings.[3] Third, in clinical practice, clinicians must extrapolate from population-level estimates to make judgments with or for individual patients. Even if a risk estimate is very precise — say a 25% risk of death within 6 months — it is not clear whether the patient is one of the 25 out of 100 who will die or one of the 75 who will live.

Some people believe that the best approach to this problem is to generate and analyze more data, so that we can "know" what the future will bring. Improving the accuracy of our prognostic estimates is indeed critically important — reducing uncertainty is helpful for clinicians and patients alike.[2] On the other hand, the quest for prognostic certainty has been described, by our colleague Dr. Faith Fitzgerald, as the "punctilious quantification of the amorphous." In other words, no matter what we do, there will always be some uncertainty in prognosis.

This uncertainty is difficult for patients and their families. For patients, not knowing what the future will bring is psychologically difficult. Worrying about the future may impede their ability to enjoy the present. They may be consumed by trying to figure out whether things are getting better and therefore become hyperaware of any physical changes that occur. Families may spend a great deal of time acquiring information in an effort to learn more about what the future will bring and may focus excessively on the medical details. For both patients and family members, anxiety may increase.

We believe that at least as much attention should be paid to clinicians' communication about the uncertainty associated with prognostication as to the search for better prognostic models. We propose a framework of three central tasks that clinicians can perform to help patients and families manage uncertainty. Physicians should tailor this framework to the core values

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of the patient. Some patients will value quality of life more than quantity of life, and for these patients uncertainty about future well-being may be of more concern than life expectancy.

The first task is to normalize the uncertainty of prognosis. This step is important because it seeks to reset expectations. Patients are bombarded in the lay media with the notion that high-tech advances in imaging and genomics have resulted in definitive answers to clinical questions such as prognosis. Clinicians should be honest with patients about the boundaries of knowledge, saying, for example, “I understand that you want more accurate information about the future. The reality is that it’s like predicting the weather — we can never be absolutely certain about the future. I wish I could be more certain.”

The second task is to address patients’ and surrogates’ emotions about uncertainty, acknowledging how difficult it may be for them not to know. Responding to emotional distress is an important goal in itself, but it may also have important consequences for medical decision making. Studies suggest that patients make poor decisions when they are anxious or experiencing strong emotions.[4] Clinicians can invite patients to discuss these emotional reactions, saying for example, “It is tough not knowing what the future is going to bring.”

The third task is to help patients and families manage the effect of uncertainty on their ability to live in the here and now. The search for certainty may impede the ability of patients and family caregivers to live in the present. They may believe that if they only knew what the future would bring, their decision making would be easier — they wouldn’t make mistakes or have to worry about regret. Patients and families may feel trapped ruminating about a future they cannot predict with complete accuracy or control. Continually asking and worrying about that future inhibits their ability to enjoy the time they have now. Rather than view uncertainty as part of the human condition, they view it — and therefore their life — as terrifying.

Clinicians may be complicit in encouraging patients and families to dwell on an uncertain future rather than the here and now. Clinicians often say, “We need more time to be sure.” Although more time brings greater prognostic certainty in some cases, in other cases the hoped-for clarity never emerges and decisions are pushed off to an ever-more-distant future. The time spent waiting may be dear to patients and their families. Patients may miss important opportunities to spend time with family because they’re focused on the future and unable to enjoy the present. To help a patient refocus on the here and now, the clinician might ask, “What can we do to help you now, given that we are unsure of exactly what the future will bring?”

To be sure, the present may not be a comfortable place for some. Living with anxiety, pain, or the support of a mechanical ventilator are reasons to focus on the future. Uncertainty may thus represent hope for some, an escape from the present for others. Clinicians can offer brief counseling sessions to help patients cope with the reality of the present, or refer patients to experts who can help them grapple with the emotional and psychological strain that comes with facing death.

Prognosis, and prognostic uncertainty, has a profound influence on physicians, as well as patients and families. Physician’s generally optimistic bias is well-documented. In one study physicians overestimated survival of terminally ill patients by a factor of five, and longer the longer the duration of the patient-physician relationship, the more optimistic the estimate.[5] Clinicians also may have trouble with prognostic uncertainty. Some react by not being willing to talk to the patient about the future at all (commonly expressed as “we have to wait and see” or “no one can tell”). Others, ignoring the uncertainty built into prognostication, do

more and more tests in a futile hope of being able to better predict the future. Physicians need to recognize their reaction to uncertainty and how these reactions may influence their conversations with patients.

In many respects, the primary communication task of clinicians is the management of uncertainty, and perhaps in no realm is this clearer than in communication about prognosis. By normalizing uncertainty and attending to the affective response to living in the face of an uncertain future, we may help our patients and their families enjoy the time they have now.

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