MEDICAL NARRATIVE
The Message Isn't as Mean as We May Think
Thomas W. LeBlanc, MD, MA

As medical knowledge grows in scope and complexity, so does the challenge of applying it to individual patients. This is perhaps the single most difficult task for twenty-first-century clinicians, and yet it remains among the most important to patient outcomes.

"How much time do I have, doc?" This is a question I hear almost daily as an oncologist. Although I know what the literature says about the 5-year survival for a particular disease, I struggle with how to discuss statistical predictors with my patients; it is often unclear how statistical data applies to a particular person and situation, or how a patient might use and interpret it. Along with clinical experience, statistical information is a key type of "evidence" that facilitates clinical decision making, but we are far from certain in our predictions of individual patients' outcomes. Stephen Jay Gould's remarkable story, retold in this issue of Virtual Mentor, is ultimately about this challenge. How does one "prognosticate," as physicians call this practice, and how does one do so accurately? How does prognostication help patients with their decision making and improve their lived experience?

Truthfully, there are two distinct challenges here: One is prognostication itself, and the other is communication of these predictions. As difficult it is to get the former correct, physicians are perhaps worse at the latter. For example, older patients with acute myeloid leukemia (AML) tend to grossly overestimate their likelihood of cure, despite extensive discussions with their physicians about survival. In one study, 74 percent of patients expected cure rates above 50 percent, while 89 percent of physician estimates were at 10 percent or less [1]. What remains unclear, however, is why this "prognostic discordance" between patients and their doctors persists. Is it a problem of patients' "numeracy," their ability to understand statistical and numerical information and then contextualize it with regards to their diagnosis? Or is it a problem regarding the ways in which doctors communicate this information to patients? Perhaps is it both.

To date, physicians are still learning how best to provide prognostic information to patients, at least in terms of how specific communication behaviors translate into patient understanding. Published literature does, however, offer some hints about what factors might be important, along with evidence of several shortcomings in current practice. For example, an analysis of recorded conversations about prognosis found a positive correlation between the number of pessimistic statements made by

oncologists and the likelihood of patients exhibiting prognostic concordance with them [2].

For prognoses to be understood and be useful, though, they must actually be rendered. Unfortunately, several studies suggest that physicians provide prognostic estimates less frequently than one might hope, particularly in cases of terminal disease. This has been shown in a large population-based study in Europe [3], a large survey study of U.S. oncologists [4], and a study of physicians at several Chicago hospices [5]. The latter is particularly surprising, since prognoses in the hospice setting are poor by definition; one cannot even enroll without a reasonable likelihood of dying within 6 months.

When physicians do attempt to convey prognostic information, poor numeracy and lack of statistical understanding stand as well-recognized barriers to comprehension for patients and families. One study about prognostic understanding in patients with early-stage breast cancer showed that 73 percent lacked adequate understanding of the term "median survival" and that 33 percent believed their oncologist could actually predict their individual outcome [6]. There were also significant differences in patients' preferences for information; 43 percent preferred positively framed messaging ("chance of cure") whereas 33 percent preferred negatively framed phraseology ("chance of relapse"). How should an oncologist communicate prognosis then, if many patients cannot understand our standard ways of conceptualizing it numerically, and when each person has different preferences and needs with regards to framing?

I wish I had the answers to these questions; it would make me a better oncologist and help me better address the needs of my patients.

In oncology, in particular, there is a palpable tendency to think that the role of a physician is to "maintain hope." However, many oncologists equate brutal prognostic honesty with the notion of "taking away hope." Hope is essential, no doubt. Patients' outlook and attitude is of utmost importance when facing a cancer diagnosis, as Gould so eloquently demonstrates for us in his essay. Thus, it comes as no surprise that Gould's oncologist was somewhat evasive in discussing the literature on mesothelioma.

Hope is not the only important consideration for patients, though, and the emphasis on maintaining hope raises several important questions. Does a positive outlook allow patients to live better or easier? Does it somehow result in different or better decisions? Or does it actually make things worse, leading patients to choose aggressive therapies that significantly impair quality of life, even when these treatments are overwhelmingly unlikely to result in significant benefit? Does it affect patients' decisions about transitions to palliative care? Might this result in more aggressive care at the end of life, including hospitalization, intubation, and resuscitation? I worry that prognostic avoidance as a strategy to "maintain hope" yields many of these negative results. As a palliative care fellow, I saw this happen

countless times; a well-intentioned avoidance of giving bad news can lead to much misery at the end of life.

James Tulsky, a palliative care physician who studies patient-doctor communication, encourages us to think differently about hope [7]. Our tendency is to think of hope in terms of an expectation about a specific desired outcome, such as cure. This definition creates the tension we feel between prognostic disclosure and the maintenance of hope in oncology practice. Tulsky suggests that both patients and doctors should reimagine hope in terms of "trust" and "reliance," an older definition of "hope" that can still be found in many dictionaries [8]. This conceptualization realigns the interests of the patient and oncologist such that frank prognostic disclosure is not only acceptable but also likely to facilitate more informed decision making and perhaps even better planning for the future. Indeed, this is what patients say they want.

In one survey study of patients with incurable cancer, 98 percent said they wanted their doctor to be realistic [9]. And when asked about hope, they associated hopefulness with 3 specific physician behaviors: offering the most up-to-date treatment, being very knowledgeable about their diagnosis, and providing reassurance that pain will be controlled regardless of outcome. Notice that none of these involves an expectation of cure or a desire for "false hope." These behaviors very much mirror Tulsky's conception of hope, relating to issues of trust and reliance in the patient-doctor relationship.

In this sense, the prognostic message is not as awful as we might think. Frank prognostic disclosure hardly squelches hope, if hope is about the journey and the process rather than any particular expected outcome, and it may be better for helping patients make informed choices consistent with their values and preferences.

As Gould warns, "the median isn't the message." I wholeheartedly agree. But the message isn't as mean as we may think.

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Thomas W. LeBlanc, MD, MA, is a senior fellow in medical oncology at Duke University in Durham, North Carolina. He is fellowship-trained in hospice and palliative medicine, and his clinical practice focuses on the care of patients with hematologic malignancies.

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