



# The Uncertain Science of Predicting Death

Laura Van Metre Baum, MD; Debra Friedman, MD

With their study, Seow et al<sup>1</sup> call attention to the complementary role that patients play in shaping end-of-life (EOL) care and the potential utility of a patient-oriented prognostic tool in influencing their experience. The investigators sought to develop a prognostic tool that is geared toward patients and families, making excellent use of a large and representative data set from Ontario, Canada, that is unique for its longitudinal measurement of patient-reported outcomes and symptom scores that are not available in most other cancer registries. Using the Edmonton Symptom Assessment Scale and Palliative Performance Scale to predict mortality, along with various other clinical factors, the investigators created a novel model for predicting mortality among patients with cancer irrespective of cancer type and laboratory values.

Despite increased attention to quality of EOL care, patients with cancer continue to receive aggressive care near death and experience poor EOL outcomes.<sup>2</sup> Although 80% of patients prefer to die at home, most die in hospitals and without a prior goals-of-care conversation,<sup>3,4</sup> and nearly 25% of patients with cancer receive chemotherapy within 2 weeks of death.<sup>2</sup> Outcomes are shaped by multiple factors, including poor physician prognostic awareness and optimism bias. With advances in therapeutics, patients and practitioners may anchor on the explanation of advanced cancer as treatable but not curable but neglect the harder discussions of how declining functional status and the biological limits of late-line therapies will inevitably limit the value of additional treatments. Therefore, physicians have been the focus of recent attempts to improve prognostication and palliative care implementation through electronic health record automation and machine learning methods.<sup>3,4</sup>

Efforts to develop and standardize patient-facing prognostic tools to help patients understand their own mortality and disease trajectory, as well as tools to empower patients and families to advocate for care consistent with their goals and values, are also necessary. Patients substantially overestimate their own likely survival, and discordance between physician and patient understanding is substantial, including on fundamental issues, such as whether cure is likely.<sup>5</sup> Furthermore, heterogeneity of physician practice, as opposed to relevant clinical factors, often determines the timing and likelihood of EOL discussions.<sup>6</sup>

A prognosis framework based on functional decline and symptoms is intuitive and conceptually useful in orienting patients and practitioners toward linking the day-to-day changes that patients and families experience to their larger prognostic significance. Of note, the study's finding that any change in appetite is predictive of mortality is an important one, highlighting the critical need for further research into cancer-related cachexia. Although some of the other metrics used in the model are circular, such as receiving EOL home care, this not an inherent weakness in a patient-oriented model. As discussed, many patients are unaware of even basic prognostic significance. The significance of EOL home care noted in the article may also reflect a difference in the Canadian health system, in which there is no distinct hospice service with prognosis and therapy requirements for enrollment.

Although the analysis is comprehensive, the model's widespread implementation and dissemination as a patient-facing tool will require further study, particularly in implementation for patients with varying levels of health literacy. Although the numeric probability of survival in days may be of interest to some patients, a discussion with a practitioner of what this means—in hours to days, days to weeks, weeks to months, or months to years—will be needed to assist patients in appropriate legacy planning, EOL preparedness, and medical decision-making. Fundamentally, the

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model provides information, with the eventual goal to empower patients to speak with practitioners about palliative care. The translation of knowledge to behavior and of information to empowerment and activation requires further intervention for successful implementation.

Like most behavioral change, improving EOL outcomes has proven to be a complex problem that requires multilevel interventions with careful study of barriers and facilitators for stakeholders. Patient prognostic awareness is one of many necessary components toward achieving EOL outcomes that align with patient goals and values. As physicians, we must prioritize discussing prognosis and medical decision-making within a framework of overarching, values-driven patient goals and realistic treatment expectations. Shared decision-making is critical in the evolving determination of the value of medical therapy in the context of expected toxic effects, quality of life, and prognosis. Of importance, patients' perspectives change over time: some bargain down to accommodate acceptance of previously intolerable debility, whereas others no longer bear increasing burdens of disease as they experience an increasing realization of their own mortality.

Although cancer is associated with high mortality, death remains remarkably unpredictable. As we strive to improve tools to predict mortality, we must also strive to improve our management of the uncertainty of disease. When access to palliative and quality EOL care are dependent on a predictable course of illness and certain death, we miss the opportunity to help patients with an unpredictable disease trajectory. As treatments continue to improve, the EOL trajectories of many cancers are changing to mimic the longer, less predictable EOL courses traditionally seen in nonmalignant advanced chronic conditions.<sup>7</sup> In the changing and complex landscape of oncology care, including novel therapeutics, targeted and personalized medicine, evolving care delivery and payment models, and quality metrics, early and accurate predictors of mortality and morbidity will become even more important.

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#### ARTICLE INFORMATION

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**Corresponding Author:** Laura Van Metre Baum, MD, Division of Hematology and Oncology, Vanderbilt University Medical Center, 2220 Pierce Ave, Nashville, TN 37232-6307 ([laura.baum@vumc.org](mailto:laura.baum@vumc.org)).

**Author Affiliations:** Division of Hematology and Oncology, Vanderbilt University School of Medicine, Nashville, Tennessee (Baum); Division of Pediatric Hematology/Oncology, Vanderbilt University School of Medicine, Nashville, Tennessee (Friedman).

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