The New Frontier: Prognosis and End-of-Life Care

Daniel Callahan*

Three points can, I believe, be reliably made about the end-of-life discussion and debate that have gone on for over fifty years now. First, end-of-life care has focused on improved palliative care, better physician training, and superior patient education to understand end-of-life decisions. The second is that, while there has been much concern about the costs of care at the end of life, it has not directly confronted a major background issue in the context of that care: chronic illness, which is now both the leading cause of death and of high national health care costs. The third is that a new ingredient is being added to the end-of-life discussion, that of the role of prognosis, bearing on the quality of that care and on costs.

I want to contend that the time has come to more closely examine that last development. The sign that this is happening can already be discerned in recent research on patient prognosis, and in some proposals for different ways of talking with patients who have serious life-threatening illnesses but are not necessarily dying. The aim of that examination would be to push the end-of-life discussion back into the chronic illness context in order to find ways of stopping aggressive life-sustaining treatment earlier for individual patients, thus leading to better deaths, but no less helping to reduce the costs of care of the chronically ill. One important result of expanding that new frontier would be that more chronically ill patients would die earlier than is presently the case, a benefit for them and for the economics of health care.

But are we not already well along on that road? Over a million people every year are dying in hospice programs, a trend that continues to rise, as do the number of those who have living wills. But completion rates for living wills for various patient age groups range from four-percent to twenty-five percent and have risen only slowly over the years, despite intense educational efforts. Moreover it has been well recognized for

* Daniel Callahan, Ph.D., is the Research Scholar and President Emeritus of The Hastings Center. He received his B.A. from Yale and a Ph.D. in philosophy from Harvard. He is the co-
years that a large percentage of terminally ill patients go into hospice care much later than they should. While there has been some progress in recent years, from a national average of 12.4 to 18.3 days in hospice, there is also enormous—and inexplicable—variation in different parts of the country (6.1 days for Elmira, New York and 35.2 days for Lubbock, Texas). Moreover, patients seeing ten or more doctors during the previous six months of life increased between 2003 and 2007, reflecting the complications of multi-organ failure from chronic disease. Even if the costs of their dying, once that has been determined, can be reduced, it does not mean inexpensive care prior to that last phase. On the contrary, the odds are good that costly care was provided. It is exactly that combination, of care prior to the dying phase and during it that is heavily responsible for the twenty-percent of health care costs incurred by only twenty-one percent of the population.

We now have a fairly good picture why the costs of those critically ill with chronic disease are so expensive. They include a tradition in medicine of all-out treatment of the critically ill with medical technologies, considerable difficulty in discerning the line between living and dying (a function of the capacity of technologies to almost always make possible further life-sustaining treatment), hesitation on the part of physicians and patients to face the coming of death, and a strong and an enduring tradition of hope inspired by physicians and desired by patients. On the latter point, an important commentary by Allan S. Detsky found that “even if patients are in a health state for which cure is exceedingly unlikely, they want to have hope and be offered options that might help . . . as well, patients and their families feel guilty if they do not try to get better.” In sum, almost everything in the culture of medicine, and imbibed by patients, pushes toward more, not fewer, curative life-sustaining efforts.

---

Almost everyone, it seems, acts as if it is better to be treated for too long a time than too short a time. And that is probably why, after all these years working to improve end-of-life care, sad stories about poor deaths are readily at hand. Atul Gawande noted a conversation with a critical care physician, who said “I’m running a warehouse for the dying.”\(^5\) Out of some ten patients, only two were likely to leave the hospital for any length of time.\(^6\) Why, one must ask, were they even in an Intensive Care Unit, and were they given a chance to discuss their prognosis before being admitted?

A 2012 study reported in *The Journal of the American Medical Society* ("JAMA"), by Dr. Lindsey C. Yourman, et al., “Prognostic Indices for Older Adults: A Systematic Review,” directly addressed questions of that kind. “Failure to consider prognosis in the context of clinical decision-making can lead to poor care . . . guidelines increasingly incorporate life expectancy as a central factor in weighing the benefits and burdens of tests and treatments.”\(^7\) Their own study, its authors reported, reviewed a large number of such studies, aiming to “assess the quality and limitations of prognostic indices for mortality in older adults through systematic review.”\(^8\) They identified “some 16 validated non-disease specific indices,” but immediately noted their limitations, concluding that “there is insufficient evidence at this time to recommend the widespread use of prognostic indices in clinical practice.”\(^9\) They note, however, that clinical decision-making is most likely to be most influenced by a “very high or very low mortality risk . . . [and that] midrange probabilities may still be useful in clinical decisions in which life expectancy plays a role, allowing patient preferences to drive the physician’s recommendation.”\(^10\)

A number of commentators responded with some skepticism, picking up on the limitations noted by the authors of the study.\(^11\) One comment said that physicians already rely too heavily on technological tests and strategies to deal with sick patients, opting for improved overall care of the terminally ill.\(^12\) Others thought the indices could

---

6 *Id.*
8 *Id.*
9 *Id.* at 190.
10 *Id.*
11 See infra notes 12-14 and accompanying text.
be useful for hospital patients or elderly patients in nursing homes or at home. A website, designed by the authors of the JAMA article, eprognosis.org, drew a wary response, partly because the public could access it, but also out of a suspicion that patients may not be helped a great deal or may not know how to apply the data to their own lives.

My own reaction was to immediately recall the debate that emerged in the health reform debate about comparative effectiveness research that became part of the final ACA legislation, and the 2009 argument that ensued when the United States Preventive Services Task Force determined that physicians should no longer routinely order mammographies for women under the age of fifty. In both cases, a major line of criticism was that general probability data, often mockingly called “one size fits all,” should be rejected. Physical variability, on the one hand, and psychological variability, on the other, militates against an uncritical use of such data. Even to have a solid probability that a sick patient has an eighty to ninety-percent prognosis of death within a short time is no predictor of how his physician, his family, and the patient, will want to be treated. A ten to twenty-percent possibility of survival will seem well worth the struggle to stay alive for some. It is axiomatic in my field of ethics, that an “ought” cannot be derived from an “is”; that is, data on life expectancy does not entail how that life ought to be treated. Of course one might reply that if a patient has a one-percent likelihood of survival at the cost of a miserable death that would not be a wise choice. But for some patients a one-percent chance of survival is better than zero-percent.

The combination of statistical uncertainty and the problem of what do with solid prognostic data, even when one has it, serves to underscore the importance of the doctor-patient relationship. Just about the time the JAMA article was published, quite coincidentally some other articles appeared about the importance of sick patients discussing their prognosis with their physician. One article in The New England Journal of Medicine (“NEJM”), by Dr. Alexander K. Smith, et al., contended that:

---

13 See Paula Span, Plain Speaking at the End of Life, N.Y. TIMES, December 14, 2011.
To improve the quality of decision making for the very old, we believe we should radically alter the paradigm of clinician-patient communication: offering to discuss overall prognosis with very elderly patients should be the norm, not the exception . . . we would suggest that clinicians should routinely offer to discuss the overall prognosis for elderly patients with a life expectancy of less than 10 years, or at least by the time a patient reaches 85 years of age [in light of the fact that at that age,] the average life expectancy in the United States is six years.16

Another physician, Dr. S. R. Workman of Halifax, Nova Scotia, wrote that “asking permission to talk about prognosis can facilitate discussion while respecting patient autonomy.”17 In an interview Dr. Workman said that physicians should avoid circumlocutions and evasions, saying instead to a patient “We’re not winning. The treatment’s not working. She’s dying despite our best efforts.”18

Neither article displays the kind of skepticism about the use of prognosis data found in response to the JAMA article, much less the reservations conceded by the authors of that article themselves.19 In fact, the NEJM article suggests a kind of middle ground:

[T]o explain the patient’s overall prognosis, the physician might say “people in their mid-80s with health similar to yours live about 6 more years, on average. Some people live more than 6 years, others less.” In this way the physician would acknowledge uncertainty. He could then assess how the patient received and processed this information.20

But that six-year figure does not, it appears, derive from prognosis studies about the course of a particular illness; it is a figure that applies to all persons in their mid-eighties.21 If that is correct, then it might seem that the physician has not told the patient with any kind of precision the actual prognosis.

18 See Span, supra note 13.
19 Supra notes 12-14 and accompanying text.
20 Smith et al., supra note 16, at 2151.
21 Id.
Clearly, Dr. Yourman, et al., seem to believe that much better prognosis data is necessary in order for it to be used effectively with large numbers of patients with different medical conditions in a reliable and fully useful way. Dr. Smith, et al., appear willing to settle for far less specificity. Patient surveys, they note, show that they are open to talking about prognosis, and they conclude their article by saying “we believe we should start talking about overall prognosis now, even as we carry out more research on patient preferences and ways of improving such discussions.” Not mentioned at all is the need for more and better prognosis data before initiating such discussion, something that Dr. Workman does not deal with either. Let me call this the “relaxed way” of using data.

Three questions emerge. Is the relaxed way of using prognosis data sufficient to inform a patient with enough information to make a meaningful choice and should a physician be willing to use such data? If research on prognosis continues, as it should, what level of specificity will be necessary to give a patient and his doctor enough information to act responsibly? And, to further complicate matters, how can such research be kept up to date in the face of new treatments or improved old treatments, shifting the prognosis? Comparative effectiveness research, if it is any good, could constantly change the prognosis-effective treatment equation.

I can offer no good answers to those questions. They can only be answered with more research, with the informal physician probably demanding less than the severe. Once again, then, we have a common enough situation these days: we need more good research and data to act responsibly, and that will take much time, perhaps years to be forthcoming. In the meantime, the advice of the NEJM authors will probably be the best we have for the short run. Moreover, in light of the high costs of critical care for chronic illness and the possibility of increased costs in the years ahead, I would opt for the informal method, adding that those so inclined should at least look at the more specific data now available for patients with certain maladies. Whichever way one goes, the physician should openly and candidly inform the patient and family just what the criteria is for presenting information to patients. Uncertainty will always be part of the process, however good the data—if only because patient and doctors can respond differently to the same information. It has ever been so with medicine.

---

22 Yourman et al., supra note 7, at 182-91.  
24 Id.  
25 See generally Workman, supra note 17.  
26 See generally Smith, supra note 16.
Let me end by mentioning a way I have tried to think about whether I would risk treating ending to early rather than going on too long. I have heard too many stories and have seen some cases myself where the life-sustaining treatment went on too long, leading to a far worse death than optimal. I have heard of practically none where a conscious, informed case was made to stop at a stage when life could have been sustained longer, even for a significant period of time. Not only are some patients willing to give up the struggle to live earlier than others, some want to avoid the struggle altogether (by ignoring symptoms and staying away from doctors). I tend to fall into the latter category—but then I have not been pushed to the test, so we will see.