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# End-of-Life Care: Conversations and Opportunities

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## INTRODUCTION

Any discussion about end-of-life care is likely to address several points. Most people would agree that end-of-life conversations should occur, but there is likely to be divergence regarding *who* should convene and be involved in such discussions. The next question might address what should be the topic of the conversation. In this issue of *JCE*, Stump, Klugman, and Thornton chose to focus on the time immediately preceding death, asking how a patient wants to die. An expansion of the question and the context may result in even greater opportunities to improve how people live with, and die from, many diseases.

## EVOLUTION OF END-OF-LIFE CARE

Healthcare providers' discomfort in caring for patients and families at the end of life is relatively new, resulting in large part from advances in healthcare technologies. This change of attitude began in the second half of the twentieth century.

At the end of the nineteenth and beginning of the twentieth centuries, people died differently than they do now. The paucity of means to forestall death meant that options for patients and families around the time of death were limited. The standard of care at that time was to create a calming environment, and to use those medicines that were available to manage symptoms.<sup>1</sup>

In 1900 life expectancy was shorter; causes of death were more likely to be from acute illness, infection, trauma, and childbirth. Gender disparity was actually less than it is today (women were likely to live just two years longer than men).<sup>2</sup> The time between diagnosis and death was estimated in days in 1900, as opposed to years in 2000. In 1900, the median age of death in the United States was 58 years; only 87.6 percent of infants survived the first year of life.<sup>3</sup> In 1900, the life expectancy of Whites was 14.6 years longer than Blacks (see table 1).<sup>4</sup>

Most importantly, though, in 1900 clinical tools to forestall death were far fewer than today, whereas, in the twenty-first century, it is presumed that death can be delayed. Myriad interventions (medications, surgery, radiation, or other technological interventions) have changed the implications of certain diagnoses. Treatments might allow cure, but more often modern medicine promotes longer life, albeit with disability.

As a result, often the slightest chance of cure limits discussion about other likely or inevitable outcomes. Patients, families, and providers may focus on cure as the only option. This singular vision extends beyond

the healthcare environment. The Race for the Cure or the Armstrong Foundation's "Live Strong" campaign have made significant inroads towards cures by increasing funding for research and knowledge about diseases. The emphasis on cure or survivorship, though, can leave others for whom cure is not possible with a notion of failure. ("The patient failed a trial of [X medication or therapy]." "She lost her battle with the disease.") If death or the absence of cure is seen as a failure, a reluctance to engage in conversations about the end of life is understandable.

### COMMUNICATION: TIMING AND RESPONSIBILITIES

Providers often believe that not only are patients unwilling to discuss the end stage of their lives, but further, providers worry that an introduction of the topic sends the message that "We've done everything we can; there's nothing else we can do," and engenders fear that the patient is being abandoned by the physician. Stump and colleagues suggested that discussions about end-of-life care in group situations (presumably similar to the sessions they conducted), or in clinical encounters, are likely to be met with resistance.

Perhaps the question, "How do you want to die?" isn't the discussion patients want to have about the end of their lives. Perhaps patients and families are more focused, not on the minutes immediately preceding death, but on how they will live the days, weeks, months, or years they have left.

Even if a patient is aware of his or her impending death (as the vast majority are), the patient is unlikely to initiate the discussion.<sup>5</sup> In fact, most patients *do* want to discuss end-of-life issues with their physicians, although they expect that the physician will initiate the discussion.<sup>6</sup>

Opportunities for conversations with patients and families about the end of life are common in certain specialties. Heart disease, cancer, cerebrovascular disease or respiratory illnesses, diabetes, Alzheimer's, and kidney diseases are most often chronic, their trajectories predictable. Providers caring for people with these diseases can make specific predictions about prognosis, timing, and quality of life.

#### Structuring the Discussion

Conversations about the end of life may be roughly dichotomized to two situations: in the context (proximal reality) of illness, and without the context (no immediacy or proximal reality) of illness. While the context changes the urgency of one's responses, broadly construed, the questions that should be asked do not change.

In their new version of the tool, Stump and colleagues ask whether the respondent has an advance directive. This is an important question, although there are several challenges. Patients and families may not

**Table 1.** Causes of Death in the United States, 1900 and 2004

Rank	Causes of Death, 1900	Causes of Death, 2004
1	Pneumonia and influenza	Heart disease
2	Tuberculosis	Malignant neoplasm
3	Diarrhea, enteritis, and ulceration of the intestine	Cerebrovascular disease
4	Heart disease	Chronic lower respiratory disease
5	"Intracranial lesions of vascular origin"	Accidents (unintentional injuries)
6	Nephritis	Diabetes mellitus
7	All accidents	Alzheimer's disease
8	Cancer and other malignant tumors	Influenza and pneumonia
9	"Senility"	Nephritis, nephritic syndrome, and nephrosis
10	Diphtheria	Septicemia

Data extracted from M.P. Heron, "Deaths: Leading Causes for 2004," *National Vital Statistics Reports* 56, no. 5 (2007) and E. Arias, "United States Life Tables, 2003," *National Vital Statistics Reports* 54, no. 14 (2007).

know what the term means. Even if the patient has designated, for example, a durable power of attorney for healthcare (DPA-HC), too often there are disconnects. The respondent may not realize that a DPA-HC is one component of an advance directive. Additionally, the person who is designated may not know of the designation, may be unable to complete the duties (for example, the sister with Alzheimer's, the brother who has been out of touch for 20 years), or may have no idea of the patient's preferences.

Thus, conversations about end-of-life care should address the two dimensions that are a part of most advance directives: "If you are unable or choose not to participate in decision making, who should represent your wishes?" and "What factors should we consider in making decisions about your care?" Stump and colleagues described their tool as a vehicle for conversations with healthcare providers or within families. That is certainly important. Another tool for guiding these discussions is Five Wishes (<http://www.agingwithdignity.org/5wishes.html>).

The other questions in these conversations should be disease-specific. Good decisions can be made only with an understanding of the facts and of what realistic options are. It is incumbent on healthcare providers first and foremost to ensure that the patient understands the current state of the disease. Based on that, options for treatment (including symptom management) are constructed. These first two rely on the expertise of the healthcare team, most often the physicians. Autonomous decisions can be made (and thus respected) only in the context of knowledge of the biology of the disease.

Asking patients, or especially families, about specific treatments, though, is likely to engender discomfort. Before focusing on a specific decision, it can be extremely helpful to focus on the goals of care. What are the overall goals for this patient at this time? What is the goal of this treatment? "If this treatment does not accomplish that goal, then we can and should stop it."

### **The Proximity of Death**

The proximity of death does narrow the focus of conversations. The focus should still be on physiologic realities, on goals, and on the patient's wishes.

Stump and colleagues found that respondents' concerns about their final hours of living had to do with their environment, their loved ones, and their personal well-being. Thankfully, all of these things can be addressed. With the exception of symptom management, initially addressing these questions within hours of death limits the likelihood of accomplishing the goals of patient or family, so the discussion should be held earlier, both within families and with providers.

In an attempt to increase communication between provider and patient, providers may have relinquished some responsibilities. Under the guise of sharing control due to considerations of patient and family autonomy, providers have failed to consider how the facts of a patient's illness frame the clinical options for a specific clinical situation. Instead, we ask the amorphous question, "What do you want us to do?" Very few patients or families have the clinical expertise to provide informed input to that specific way of delineating options for decision making.

Another difference between the early twentieth century and the twenty-first is that death is now most likely to occur away from home. As a result, there can be a poignant awkwardness that surrounds the patient's bedside as death approaches. Whereas in prior centuries, families were likely to abide with the dying person, to sit at the bedside, to be present, many families have no experience being with someone whose death will be soon (though a majority of Stump and colleagues' respondents wanted to die at home, consistent with prior research).

Again, there are opportunities. Saying to family members, "Six months from now, I don't want you to have any 'what ifs . . . ?' or 'I wish I had. . . .'" Although this is a very sad time, it's a chance for you to tell him what you want to make sure he knows," gives them ideas, and perhaps even permission. We sometimes even have to model how to sit with, to talk to the person who is dying. Asking family members about who should be present, about what environment the patient would want, or if they see something that providers have missed, validates the value of the family members' presence and their more intimate knowledge of the person who is dying.

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Stump and colleagues were surprised that "so few participants would want a healthcare provider by their deathbed." The job of providers is to provide an environment and symptom management that allows the person who is dying to be with those who have been a part of their living, not necessarily of their dying.

## CONCLUSION

To provide care at the end of life remains a challenge. How could it be otherwise, when those most involved with it on a regular basis are often reluctant to discuss it? Healthcare providers have a responsibility to be good at it. Physicians must be involved, but they do not have to be alone. There are frequently differences between health team members' perceptions of the adequacy and completeness of the decision-making process.<sup>7</sup> An interdisciplinary team will provide complementary skills and knowledge.

The clinical situation is similar to other situations in which one party is ethically opposed to being involved. The reluctant participant is not forced to be involved. The responsibility does not end there, though. If one provider is unwilling to address the implications of serious illness, then someone who does it well must be brought in. This may mean a consultation with a palliative care team or an ethics consultation service. Neither of these options allows the primary provider to withdraw. Rather, consultations can allow the building of a team that will result in better patient care. Involvement of a palliative care team is likely to increase a patient's understanding of the disease and its implications.<sup>8</sup>

Healthcare providers who are involved in the care of patients with potentially life-threatening diseases should be prepared to discuss difficult issues across the course of each patient's illness. These conversations must be (1) specific, (2) structured by the provider, (3) amenable to input from the patient, and (4) most importantly, based on *this patient's condition*.

Asking how a person wants to die gives important consideration about people's concerns about the end of life. These data can provide important reminders about what should be addressed. Even absent these data, though, healthcare providers have a responsibility to manage symptoms aggressively, and to address physical and other issues at the end of life.

## NOTES

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