



Recently, End-of-Life Issues Have Become an Increasingly Common and Prominent Part of Healthcare

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Perspective

Among other things, there is an emerging specialty of palliative care, which deals with some of these issues in a comprehensive manner, and seeks to ease pain and improve quality of life. As an infectious-disease specialist primarily involved in inpatient care, with many seriously ill patients, I have had the opportunity to observe firsthand the role of palliative-care specialists. Some of their contributions are extremely helpful, but their involvement can sometimes be problematic. For example, they may stray from their primary mission and seek to impose their own values on patients and their families, who are in extreme distress and extremely vulnerable. This phenomenon is also evident in the growing literature in the field of palliative care. Another problem in the practice of palliative care is the general lack of any relationship between those specialists and the family of the patient prior to the time of the serious illness. Both of these problems may lead to unfavorable consequences for families with seriously ill loved ones.

When patients become seriously ill and death looms as an imminent possibility, those patients and, more often, their family members (surrogates), are thrust into the position of making decisions with regard to treatment. Often the decision is whether to administer some form of treatment, whether it is fluid replacement; providing nourishment; administration of antibiotics for infections; administration of medications to maintain blood pressure (pressors); mechanical ventilation assistance; dialysis; or even surgery.

A common element in making these decisions relates to certain value judgments. Often, these value judgments are based on religious or cultural beliefs. I do not presume to offer my opinion as to what general view is correct with regard to certain end-of-life decisions. While certain actions, such as murder, rape, and robbery, are universally held to be unacceptable and not subject to individual value judgments, other decisions, such as whether to prolong life or help end it to prevent suffering, are and should be left to the individual's system of belief and/or value judgment.

However, as an Orthodox Jew, I will share some beliefs held by those who follow the Jewish traditions handed down from generation to generation for thousands of years. The two basic beliefs that have the greatest impact on most end-of-life decisions are: 1) the physical human body houses a spiritual soul which returns to heaven at the end of life. 2) There is an afterlife, in which reward and punishment are determined by the level of one's adherence to Jewish laws, pertaining to relationships between man and man and between man and his Creator. Hence, "quality of life" is determined by one's fulfillment of G-d's commandments, and not by how physically comfortable a person is.

Of course, other religions and cultures have other viewpoints which would influence their end-of-life decisions, but I leave the details of such viewpoints to experts in such religions and cultures.

Many patients, and their surrogates, hold personal feelings that are independent of religious and cultural values and which influence their decision-making. For example, I recently was caring for a 90-year-old man who was deteriorating over several months. Prior to that, he had been functioning quite well. I was discussing his condition and prognosis with his daughter on an almost daily basis. Finally, the palliative-care team (who had never met the patient before) came in and tried to convince her to let her father "go." She told me that they had no idea how much she loved her father and how she was not ready for him to leave her yet. She was in tears and told me how they had made her feel so bad for having such feelings.

Two years ago I attended a conference devoted to Jewish law and medical ethics. A palliative-care specialist presented a case of a patient with Amyotrophic Lateral Sclerosis (Lou Gehrig's disease), who was getting to the point of requiring a ventilator. The specialist described vividly the

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scene of the wife and children gathering around in a "happy death," as the physician assisted in his dying as comfortable as possible, avoiding having to live the rest of his life dependent on a ventilator. Following that case description, a neurologist presented the account of a patient with the same disease who ended up completely paralyzed and ventilator-dependent, but able to move his eyes. With the aid of computers, he lived a productive life, publishing a number of books in this state. This patient was appreciative of every moment of life that he had.

Rather than being respectful of whatever decisions the family makes, especially when those decisions involve prolonging life, the palliative-care specialists, to my observation, often have difficulty in accepting such decisions and appear to try to impose their own values of ending life rather than prolonging suffering, when they feel that there is little hope of restoring what they consider a reasonable "quality of life." In speaking to families and reading the clinical notes, it is clear that these specialists stress the suffering of the patients and how compassionate it would be to relieve them of their suffering and helping in ending their lives. I was struck recently by a change in terminology in the palliative-care chart entries. The expression for removing a patient from a ventilator with the expectation of death was changed from "terminal extubation," to "ventilator liberation." This change of expression is a clear manifestation of the effort to influence families in viewing assistance in ending life.

I have also overheard palliative-care specialists in "private" conversations, mocking family members who do not give in to the pressure to end life but rather seek to prolong the life of their loved ones as long as possible. I have heard their frustration expressed verbally and in body language when family members "just don't get it."

The general lack of respect among palliative-care specialists for decisions favoring prolonging life is evident in the literature. There was a recent article [1] analyzing "discordance about prognosis between physicians and surrogate decision-makers of critically ill patients." In this particular study, 43% of surrogates were more optimistic than physicians and 10% were more pessimistic. In their opening paragraph, the authors discussed this discordance and stated that numerous studies have shown that "surrogates of patients with advanced illness often have optimistic expectations about prognosis." The authors continued, "This is problematic because optimistic expectations are associated with more use of invasive treatments in the dying patients and delayed integration of palliative care. Clinicians cite unrealistic expectations by surrogates as one of the most important barriers to high-quality end-of-life care in seriously ill patients."

The negative reaction of the authors to the optimistic view of the surrogates, which generally leads to decisions to prolong life, is evident. It is also clear that, to the authors, "high-quality" end-of-life care means avoiding any life-prolonging measures.

The authors also noted that there were several reasons that the surrogates were more optimistic than the physicians: "surrogates' religious beliefs, a need to maintain hope, and skepticism about physicians' prognostic accuracy." The authors concluded that interventions are needed to "improve the comprehensibility of prognostic information...and to attend to the emotional and psychological factors that influence surrogates' prognostic expectations." It is again obvious that the authors are unhappy with the more optimistic view of the surrogates and suggest doing more to

minimize such views, which would lead the surrogates to decisions more compatible with those favored by the palliative care providers.

In another recently published article [2], another group of authors note that "the resulting discordance between the expectations of clinicians and families can adversely affect the quality of family surrogate decision-making and thus the treatment of patients with chronic critical illness." Once again, it is clear that the authors harbor a negative opinion of decision-making that leans towards prolonging of life.

Another major flaw in palliative care, as generally practiced, is the lack of any contact between the patients and families and the palliative-care specialists prior to the onset of the serious illness. Although I do not have studies to confirm this, it seems reasonable to believe that a physician who has cared for a patient for years would be much more easily believed and trusted than a physician or provider who has never seen the patient prior to the illness. Certainly, having a close relationship with the patient and family prior to the acute event would give the palliative-care specialists needed information which would relate to the actual prognosis and which would also enhance their communication with the patient's family, as there are intangible factors that don't relate to clinical data that affect the prognosis.

As a result of these factors, palliative-care meetings with families are now often more harmful than helpful. The study above [2] concluded that "The use of palliative care-led informational and emotional support meetings compared with usual care did not reduce anxiety or depression symptoms and may have increased posttraumatic stress disorder symptoms."

It is evident that at times palliative-care specialists have formed their own value judgment on end-of-life decisions, and are sometimes intolerant of judgments that don't conform to their view. This may sometimes be the result of their ignorance of religious and cultural views. Some of this may be related to how successful they are viewed in the environment in which they work. It appears that in the specialty of palliative care, to convince a family that was reluctant to "let go" finally to do so appears to be a success and even a "victory" to take pride in.

Palliative care can potentially serve an extremely valuable role. It can certainly make the end-of-life much less difficult in many situations. The specialty is in an infant stage and some modifications need to be made. I am not familiar with the palliative-care curriculum training, but certainly familiarity with religious and cultural views with some specific details should be included. Tolerance of views that palliative-care specialists do not share must be emphasized. Religious views regarding the value and purpose of life must be respected. Providers should be trained to take pride in helping patients are comfortable in whatever decision is made, and not to measure success by their ability to change the minds of surrogates.

Finally, palliative-care specialists should understand that their predictions of the course of the patient's illness are limited by a number of factors, especially their lack of any contact with the patient beforehand. I have observed many times and heard many anecdotes of patients who were "written off" by their physicians and went on to recover and have significant "meaningful" time. Palliative-care specialists also need to understand that there are certain intangibles in determining prognosis that cannot be evaluated without previous knowledge of the patient. Perhaps by openly communicating the limitations of their prognosis, the families will come to trust them

more, which will enable the palliative-care specialists to use their expertise to alleviate the pain and suffering of patients and families in these situations.

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