End-of-Life Discussions With Patients

Timing and Truth-Telling

In the context of caring for terminally or critically ill patients, determining the limits of patient autonomy has been a contentious problem.12 Who determines whether a patient is competent, and how is this determination made? If the patient is not competent, how do we determine what he or she would have wanted? Whom do we allow to speak or make decisions for the patient? How strictly do we interpret advance directives? In order for patients to make meaningful decisions about their health care, they require honest, objective, and complete information about their state of health, their prognosis, and the likely outcome of any proposed interventions. After patients decide what treatments they will or will not accept, they then depend upon their physicians to respect these decisions.

These various problems defy easy resolution, but there are two steps that can simplify matters considerably. First, physicians can elicit patients’ views on life support and other aggressive interventions when the patients are in their normal state of health and mental functioning. Unfortunately, the failure to discuss life support and resuscitation issues with patients before they become critically ill remains a common problem. Studies indicate that a pronounced majority of patients undergoing the withdrawal of life support do not participate in the withdrawal decision because they are not mentally competent at the time.3,5 Advance directives address this problem, and the Patient Self-Determination Act of 1990 (PSDA) was enacted to ensure that all hospitalized patients would be aware of their right to prepare such a document. However, the implementation and effects of the PSDA have been disappointing, and studies have found at most a marginal increase in advance directives attributable to the law.6,7 The bottom line is that advance directives can only work if patients prepare one; physicians can help by encouraging them to do so.

Second, physicians can give their patients clear, unbiased information, and thus, empower them to participate fully in making health-care decisions. We believe that the principle of patient autonomy dictates that physicians separate their respective responsibilities to inform and to counsel their patients; most patients want their doctor’s advice on how to treat their illness, but they also need objective information on the facts of their illness and on the range of options available to them. If physicians bias the information they give patients so as to manipulate the patients into choosing a recommended course of action, then the patients are never in a position to make up their own mind.

Several studies have found that physicians’ personal characteristics and values appear to influence their decision-making regarding the withholding or withdrawal of life support from the critically ill.8–11 Influen
tial characteristics include age, religion, geographic locale, and type of hospital. Quite simply, the studies imply that factors entirely independent of the patient’s personal preferences and clinical condition influence physicians’ medical decisions. One would have to be naive to be surprised by such findings. Nonetheless, it is partly because these nonrational biases apparently influence physicians’ professional decision-making that patients need an objective assessment of their medical condition and therapeutic options in addition to and separate from their physician’s recommendations.

In this issue of CHEST (see page 258), we learn from a Canadian study that problems remain in the manner in which physicians discuss life-support issues with terminally ill patients. Sullivan and her colleagues interviewed 15 respiratoryists in Ottawa to elicit information about what they told their end-stage COPD patients about intubation and mechanical ventilation. Their study consisted of semistructured interviews which probed the physicians’ perception of the deci-
ision-making process regarding DNR/DNI status. Physicians also were asked to describe and to give an example of how they conducted discussions of intubation and mechanical ventilation with these patients. The small sample size makes it hard to generalize from the results, but the findings are interesting. All 15 pulmonologists indicated that they discussed intubation and mechanical ventilation with their end-stage COPD patients, yet half (7) felt that their discussions of intubation and ventilators generally took place too late in the disease process. COPD is by definition a chronic disease, so physicians should have plenty of opportunity to discuss life-support issues before these patients end up in critical condition. In addition, all but one physician indicated that they commonly framed their discussions in order to influence the patient's decisions. We agree with the study's authors that framing medical information, whether positively or negatively, interferes with the patient's ability to participate fully in the decision-making process.

As the US population ages, end-of-life care will become an increasingly large part of medicine. We suspect that the difficulties that persist in discussing this issue with patients stem both from physician discomfort and from a failure to value the difference between a good death and a bad death. If we can accept that helping our terminally ill patients to have a good death represents an important part of our professional responsibility, then perhaps we can become less reticent about discussing code status and other life-support issues early in the course of chronic disease.

Refraining from biasing the information we give to patients poses a more subtle problem. As physicians, we generally have a greater understanding of disease than do patients. Thus, we may conclude that we know better than the patient what would be the best medical therapy. If the patient makes what we perceive to be a bad decision, we may feel that we did not perform our job properly. Further complicating the matter, it is impossible to present a completely objective account of a serious illness. Physicians will always have to choose which details to emphasize, which studies to believe. Moreover, bias can be communicated as much by body language or tone of voice as by the specific words chosen. Nonetheless, one can aim for a balanced presentation.

In talking to patients about health problems, it is important to identify three separate issues: the facts of their condition, the medical options available to them, and our professional recommendation. If the relevant scientific evidence is cut and dry, then the patient is likely to agree with our advice. If a patient chooses a different course of action, we have no choice but to respect that decision. We all know from experience that even well-informed physicians can vigorously disagree about medical decisions. Moreover, an individual's health-care decisions are based not only on science but also on personal characteristics and values. To frame — ie, to bias — medical information in order to lead patients to agree with our recommendations violates the bioethical principle of truth-telling. Once patients have a fair understanding of their illness and the available treatment options, they will be in a position to evaluate for themselves whether or not they agree with their doctor's advice.

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