The Patient’s Response to Medical Futility

Despite years of debate by bioethicists about the concept of medical futility, until now no one has tried to assess the reactions of patients with serious illness to its application. One reason may be that this type of study is technically difficult to perform. Outcome variables are hard to define, consistent data difficult to gather, and interview questionnaires hard to validate. Another reason is difficulty with the definition of futility. Withholding futile treatments supports the ethical principles of both nonmaleficence (do no harm) and beneficence (relieve suffering).

Some ethicists argue that invoking the principle of futility is in direct conflict with the principle of patient autonomy. During the past decade, patients and their families have become increasingly involved in end-of-life decisions, both in hospitals and in the courts. The courts have usually ruled in favor of the patient’s right to autonomy, especially in cases regarding withholding or withdrawing unwanted life support. However, there is no clear legal precedent about withholding futile care against a patient’s wishes.

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The difficulty in defining futility itself compounds such concerns. The term medical futility has been used to describe life-or-death situations in which proposed treatments will fail to prolong quality life, achieve the patient’s key goals for medical care, achieve a critical physiologic effect on the body, or result in a therapeutic benefit for the patient. Another definition of futility states that “if a treatment merely preserves permanent unconsciousness or cannot end dependence on intensive medical care, the treatment should be considered futile.” In an attempt to give a quantitative definition of futility, some have suggested that treatments with less than a 1% chance of benefiting patients should be considered futile.

In practice, however, the concept of futility is applied broadly and often incorrectly. Many fear that insurers may use it as an excuse to deny payment for costly but beneficial treatments. Furthermore, some believe physicians might use it as a reason to justify their failure to deliver all treatments requested of them by patients and their families.

The consensus statement of the Society of Critical Care Medicine’s Ethics Committee attempted to clarify the concept of futility. The committee proposed that a treatment be defined as futile only when it will not accomplish the intended goal. The committee further stated that futility should not apply to several types of treatment often mislabeled as futile: those that are extremely unlikely to be beneficial, those that have beneficial effects but are extremely costly, and those that are of uncertain or controversial benefit. These treatments may be inadvisable, costly, or a poor use of health care dollars, but they are not medically futile.

In spite of these attempts at providing a useful definition of futility, the concept of futility is often difficult to apply in clinical practice. Decisions about which treatments are futile almost always need to be based on a patient’s goals for medical care. Only in the strictest interpretation of futility, treatments that do not offer any physiological benefit, can we apply it broadly without regard for the variability of patients’ values. Performing cardiopulmonary resuscitation on a patient who has a massively ruptured left ventricle is an often-cited example of a universally futile treatment. No matter what the patient’s values, cardiopulmonary resuscitation would offer no physiological benefit. However, in most other situations, the goals of care will impact decisions about which treatments are futile. For instance, a 40-year-old woman with metastatic breast cancer who wants to live to see her daughter graduate from high school might not agree that an extra cycle of chemotherapy is futile if it offers her a 1 in 150 chance of living during those 4 months until graduation.

In this issue of the Archives, Curtis et al publish an analysis of the attitudes of 57 patients toward the use of the “medical futility rationale.” All 57 patients had advanced (category C3) acquired immunodeficiency syndrome (AIDS), defined as having a prior AIDS-defining illness and a past CD4 cell count of less than 100/µL. In a structured interview setting, the authors assessed the responses of the patients to questions about a hypothetical situation in which they had less than 3 months to live and had developed severe pneumonia. The patients were told that their physicians thought that initiating life support, such as mechanical ventilation, would be futile (the patient would be unlikely to survive to get off of life-support machines). Patients then were asked whether it would be acceptable for their physicians to make them comfortable without offering life support. Sixty-one percent of patients answered that it would definitely be acceptable for their physicians to withhold life support, and 26% answered that it would probably be acceptable. However, a significant proportion disagreed. Thirteen percent answered that it would definitely not or probably not be acceptable for their physicians to withhold life support under these circumstances.
The authors checked for a correlation between these responses and the patients' preferences regarding mechanical ventilation in 4 hypothetical health states related to end-stage human immunodeficiency virus (HIV) infection. They also sought to correlate the patients' responses with their overall satisfaction with care, health-related quality of life, and patient-clinician communication about end-of-life decisions. Not surprisingly, the patients' preferences regarding mechanical ventilation in a variety of health states correlated significantly with whether they thought it would be acceptable for their physicians to withhold life support. Patients who wanted mechanical ventilation in a variety of health states were significantly more likely to answer that withholding life support was unacceptable. Patient satisfaction with care, health-related quality of life, and communication about end-of-life decisions were not significantly correlated with responses about withholding support.

The authors conclude that the majority of patients with advanced AIDS accepted the medical futility rationale. Although technically the concept of futility does apply to this situation since offering life support would be inconsistent with the patients' goals of care, the patients' opinions about futility itself were not assessed.

Some patients desired aggressive care. Many of these patients stated that it would not be acceptable for their physicians to withhold life support without discussing it with them. These patients rejected the medical futility rationale; withholding life support would contradict their goals. Furthermore, providing life support can have potential physiological benefits for patients with advanced AIDS and pneumonia, and may not be futile. Two studies7,8 conducted on mechanical ventilator support for patients with AIDS and severe Pneumocystis carinii pneumonia reported survival rates of 30% and 36%. Another study9 of 29 patients with AIDS and a mean CD4 cell count of 110/µL reported that 28% of patients who required mechanical ventilator support survived.

The variability of patient responses is not surprising. Many different factors contribute to the development of a patient's goals for medical care. It would be interesting to know what factors might have been involved in the choices of answers given by the patients in the study by Curtis et al. A qualitative study would be interesting in this setting. How many of the patients have outlived the original survival estimates given to them along with their diagnosis of HIV infection? How many of the patients trust their physicians' estimates of how many months they have left to live? Which patients have cared for friends who died of respiratory failure despite receiving maximal life support? What is the most important thing the patients want to do before they die? How do the patients define futility?

It is common for physicians to be unaware of their patients' opinions about end-of-life issues. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT)10 showed that most US physicians surveyed did not know the wishes of their patients regarding do not resuscitate orders. The current study by Curtis and colleagues is important because it adds to our understanding of the wishes about end-of-life care of patients with AIDS. It also contributes needed information to the debate about the application of the concept of medical futility. This study supports our belief that most treatments can be considered futile only within the context of an individual's goals for care. If a patient desires aggressive care, the patient is unlikely to consider many treatments futile, even treatments the physician believes are extremely unlikely to be beneficial.

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