

MEDICAL FUTILITY

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Issue:

What is medical futility and who decides? Recent news events illustrate the difficulty of presuming to answer ethical dilemmas using legal methodologies and court systems.

When Michelle Finn requested that her severely brain-damaged husband's feeding tube be removed, she was expecting this to be the family's final, private, and personal stage of grieving. Her husband, Hugh, a successful television anchorman until his car crash more than three years before, was unable to eat, provide for any of his personal needs or communicate in any way. But when her husband's brother, followed by Virginia Governor Jim Gilmore, went to court to prevent the removal of the tube, her private nightmare became very public. Eventually siding with the patient's wife and physician, Virginia courts allowed the tube to be removed. Hugh Finn died peacefully in a nursing home eight days later.²

As this story illustrates, there are many pitfalls encountered in cases of medical futility, namely, the definition of futile care; the emotionally charged debate; the responsibility of a physician to his patient; the role of the surrogate decision maker; and who decides what futile care is. The genesis of this paper was a discussion within our Hospital Bioethics Committee as we set about revising our DNR related regulation. As I put more research and thought into the seemingly innocent question of how to define medical futility for the purposes of regulation, it became more apparent how "futile" the attempt. That is not to say there has not been much debate and writing on the topic over the last five years; but rather, there is little agreement or comfort level with the topic.

The only consensus on the definition of medical futility is that there is no consensus. The problem with formulating a standard clinical definition of medical futility is that the concept contains value judgments about the quality of the patient's life. As a consequence, what may be considered by one physician to be futile may not be

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²Associated Press, Richmond, Byline: Larry O'Dell, "Approval of Finn Payment does not Put Issue to Rest," March 29, 1999.

to the patient or even another physician. The difficulty with agreeing on a futility definition was readily apparent at the Washington Hospital Center's Seventh Annual Bioethics Conference in 1993. During one part of the conference, attendees were asked to develop a process for determining medical futility. A mix of physicians, nurses, social workers, clergy, legislators, attorneys, administrators, psychologists, and clinical staff noted much debate in coming to an agreement on a working definition of futility, or even what criteria should go into a determination of futility in the clinical setting. Sound familiar? It should if you have served on your hospital's bioethical committee.

Generally, literature divides medical futility definitions into two types. The qualitative definition stipulates that if a treatment merely preserves permanent unconsciousness or cannot end dependence on intensive care, it should be considered futile. By this definition, Hugh Finn's feeding tube would be considered futile, since it merely preserved his chronic vegetative state more than three years after his head injury.

The quantitative definition looks to whether an intervention is deemed futile if the empirical data show that the treatment has less than a one percent chance of benefiting the patient. An example of this type of "futility" is providing CPR to an inpatient with advanced, end stage cancer.³ As this definition looks to the statistical probability of a desirable outcome, it almost begs for argument. The statistical cutoff point chosen in this definition as the threshold for determining futility is relative to opinion. Why not, three percent, or five percent (as is customarily adopted in scientific research)? No matter what point is selected, there is always a potential survivor not predicted to survive, prompting the public and the courts to spend vast quantities of scarce resources to avoid the possibility of that survivor expiring. Even if there was agreement on a statistical cutoff point for determining futility, physicians are often highly unreliable in estimating the likelihood of success of a therapeutic intervention. Even in theory, statistical inferences about what might happen to groups of patients do not permit accurate predictions of what might happen to the next patient.

³Schneiderman, L.J., Jecker, N.S., Wrong Medicine (1995).

While there was apparent agreement that futile endeavors should not be carried out,⁴ there does not appear to be much guidance addressing what is actually futile. Currently, there are few statutory guidelines on making futility decisions other than state-level "do not resuscitate order" or "advance medical directive" legislation. Both New York and Georgia attempted to define the term medically futile in respect to do not resuscitate statutes. Both define the term as "meaning that cardiopulmonary resuscitation will be unsuccessful in restoring cardiac and respiratory function or that the patient will experience repeated arrest in a short time period before death occurs." Neither statute provides a definition that is helpful for more generalized use.

Court derived definitions are even less helpful. Currently, only a few cases of health care providers seeking to withhold medical care contrary to patients' demands have reached the courtrooms. The most illuminating case involved what treatment physicians were obligated to provide to Baby K. Baby K was born with an anencephalic condition but, in response to emergent respiratory distress, she was provided with mechanical ventilator treatment. After a few days, physicians recommended that the mother allow ventilator treatment to be stopped and a DNR order to be issued on the basis that such treatment was "medically unnecessary and inappropriate." The mother refused the recommendation.

The physicians and the hospital decided to refer the matter to the hospital ethics committee which concluded that the treatment should end because "such care is futile" and if the family insisted on treatment recommended that the hospital should go to court. The hospital also sought appointment of a guardian ad litem, who concluded that treatment should be withheld. The Federal District Court and ultimately, the Appeals Court for the 4th Circuit, held that to withhold ventilator treatment to Baby K violated the Americans with Disabilities Act (ADA) of 1990.⁵ The Court's reasoning was that Baby K is disabled because of the anencephalic condition, and that denying the benefits of ventilator services to anencephalic babies as a class of disabled individuals is not permitted. The Court compared

⁴This concept of futile medical treatment goes back to the time of Hippocrates who advised physicians "to refuse to treat those who are overmastered by their diseases, realizing that in such cases medicine is powerless." See also *AMA Code of Medical Ethics*, 1997, "Physicians are not ethically obligated to deliver care that, in their best professional judgment, will not have a reasonable chance of benefiting patients."

⁵*In re Baby "K"*, 16 F.3d 590 (4th Cir. 1994), cert. denied, 1994 U.S. Lexis 5641 (1994).

anencephalic infants to AIDS patients, stating that because an AIDS patient may receive ear surgery "despite poor long term prospects of living," an anencephalic infant is similarly entitled to ventilator treatment.

This logic is, I believe, faulty - while anencephaly falls into a category of disabled or handicapped, the condition cannot be compared to AIDS. An AIDS patient may have a shorter than expected life span, but it is generally a fully conscious life. Further, there remains hope that a treatment of a suppressed immune system is possible. In contrast, Baby K was not able to hear, see, think, or interact with others. There is no cure that could have replaced her missing brain to provide a chance of any sort of conscious life. This does not mean that anencephalic infants should be denied medical treatment. On the contrary, the point is that perhaps a standard of care that dissuades aggressive technological intervention for anencephalic infants should have been recognized by the courts. Editorially, I have to wonder if a different initial presentation to the mother than one using terms of "medical necessity or appropriateness" would have been more successful.

It's not surprising that the courts fell back on a statutory construction or legal standard when determining the appropriateness of care rather than applying medical standards or ethical principles. In "end of life" cases, it's unlikely that courts will tread where legislatures have failed to act.

The significance of this analysis is that where a tension exists between physicians making medical judgments and patients or their representatives demanding treatment, the patient apparently will prevail. As the Baby K opinion suggests, courts are compelled to favor individual rights under current federal statutes and case law. In addition, while courts were willing under limited circumstances to let individuals refuse life-sustaining medical treatment, judges were not willing to let physicians refuse to provide treatment contrary to the patient's or surrogate's wishes.

If we examine and find wanting the statistical, or legislative, or court-derived definitions, perhaps it would be useful to look at how futility should not be defined. Withholding or withdrawing futile care is different from rationing care. Rationing refers to limiting disbursement of medical care, typically based on resource availability and cost considerations. Futility, however, addresses the question of effectiveness and benefit. As the patient's

advocate, the physician is ethically bound to provide care despite costs. But if the intervention is futile, regardless of cost, the physician is not bound to continue with that treatment.

Distinguishing between futile and palliative care is also important. Palliative care improves the quality of a patient's life, even if the intervention may not prolong the length of survival. An example would be palliative radiation therapy for a patient with incurable metastatic cancer who develops a painful isolated bony metastasis.⁶ Certainly hospice care with its focus on symptom management, pain control and relief of suffering in terminally ill patients constitutes palliative care. Conversely, the repeated rounds of chemotherapy in a progressively weakening person with widely metastatic bladder cancer is futile care. A patient receiving yet another round of chemotherapy for incurable cancer, particularly if the cancer is at the end stage of a long, predictable decline, represents a classic presentation of medical futility. But what if the patient or patient's surrogate wants more treatment than the palliative measures? That is the most likely scenario to be presented to your ethics committee.

If the committee rejects futility as a useful concept, it does not imply that we endorse patients' unrestricted demands for intervention. On the contrary, when providers oppose such demands they are usually acting from a profound sense that further treatment would be fundamentally wrong. The task is then to take account of that sense of "wrongness" without resorting to unilateral, provider-initiated declarations of futility.

In many of the situations in which questions of futility arise, providers believe that the treatment in question would not be in the patient's interests, even from the patient's perspective, and that any insistence by the patient or the patient's surrogate on further interventions is based on faulty reasoning, unrealistic expectations, or psychological factors such as denial or guilt. In these circumstances, providers are obligated to make every effort to clarify precisely what the patient intends to achieve with continued treatment. If the patient's goals appear to reflect unrealistic expectations about the probable effect of medical interventions, providers should attempt to correct those impressions. Although this appeal to the

⁶ "Medical Futility: Ethical Principles in Theory and in Practice," Continuing Medical Education Workshop, October 15, 1998.

patient's interests may seem to contain some of the same ambiguities as arguments using the concept of futility, there is a subtle but important distinction between the two. Judgments about what is in the patient's interests are properly grounded in the patient's perspective, whereas judgments cast in the language of futility falsely assume that there is an objective and dispassionate standard for determining benefits and burdens.

Does this mean that as an institution we must oblige our patients by providing unlimited medical interventions? I do not believe so; in many cases such unrestrained deference to the wishes of the patient or surrogate conflicts with two other values that do not require a unilateral judgment of the futility of treatment: professional ideals and social consensus.

The ideals of medical professionals include respect for patients' wishes, to be sure, but they also include other values, such as compassionate action and the minimization of suffering. Healthcare professionals should not be required to take part in care that violates their own morals; however, the law in this area remains uncertain. On the one hand, courts have upheld a state interest in protecting the ethical integrity of the medical profession. This may provide some basis for protecting doctors who wish to refrain from cruel or inhumane treatment despite the wishes of the patient or surrogate. On the other hand, the judges have upheld the surrogates' decision-making authority. Clearly this area of the law remains to be defined.

In conclusion, the construction of a formula for resolving conflicts over interventions frequently regarded as futile may itself prove futile. The notion of futility generally fails to provide an ethically coherent ground for limiting life-sustaining treatment. Perhaps as the community standard evolves, much as the DNR discussions of the 1970's and 1980's, there will be consensus on effective rules for the use of high technology medical resources and interventions. In the meantime, I would urge an approach based on patient benefit and interests and not on "futility."

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