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"Medically Futile" Treatments Require More Than Going to Court

Karen Trotochaud, RN, MN

With the unrelenting development of new medical technologies and increasingly more complex treatments, health-care providers sometimes find themselves faced with requests to provide treatments they believe to be medically futile. This language and resulting argument based on it can produce an adversarial posturing on the part of providers and families that frequently anticipates or threatens a legal solution. Although our legal system will choose sides on an issue, futility cases that have ended up in the courts have generally failed to definitively answer questions about how to address future dilemmas. A more helpful process is a clear procedure for addressing both sides of the question with the ultimate decision-making remaining within the health-care setting. The ethically appropriate solution lies within the context of a shared decision-making process between patient/family and physician/health-care provider that honors the values of both parties without assuming a unilateral decision-making stance. Case managers and direct-care providers, when faced with requests for treatments deemed to be medically inappropriate or futile, are challenged to understand and pursue this shared process.

Defining Medical Futility is the Wrong Question

The dictionary defines *futile* as serving no useful purpose: ineffective.[1] For three reasons, this definition rarely is helpful when applied to a specific medical treatment: first, "useful" connotes a value judgment and is subject to interpretation; second, "purpose" would need to be specifically defined and agreed upon by all parties; and third, determining effectiveness can occur only after a treatment has been provided and its effects are known, although the value of these will be subjectively interpreted.

Because of the inability to clearly define what is meant by medical futility, numerous authors have offered more descriptive explanations for the term. For example, Schneiderman et al[2] propose that futility exists "when physicians conclude … that in the last 100 cases, a medical treatment has been useless." Although seemingly objective, this definition is hard to relate to real-life cases that commonly present with multiple and differing complications, making it difficult to clearly relate one case to another one, much less to 100 other

cases. Lacking support for statistical definitions such as "1 in 100," descriptive definitions have been proposed. However, even qualitative definitions that describe treatments resulting in certain expected outcomes as futile, such as preserving only permanent unconsciousness or being unable to end a patient's need to remain in an intensive care unit, have failed to attain universal agreement.[2] Not all physicians and health-care providers and certainly not all patients and families agree on which outcomes characterize futile treatment.

If medically futile treatments cannot be clearly defined through statistical methods or by qualitative descriptions, perhaps they can be determined by majority agreement. Numerous articles describe physicians as the decision makers for that which constitutes medically futile treatment.[3] But do physicians agree with one another? In one survey, physicians reported inconsistency in defining whether the predicted chance of survival equated with "medical futility."[4] Although most physicians believed a roughly 5% chance of survival equated to futility, the range was from 0% to 60%, with 4% of respondents reporting that a 50% to 60% predicted chance of survival equals medical futility.[4] This finding clearly demonstrates that physicians have difficulty agreeing on what constitutes medically futile treatment.

Even sophisticated scoring systems, such as the APACHE (Acute Physiology and Chronic Health Evaluation) III, have proven to be of little help in determining whether a specific treatment for an individual patient is medically futile. Although these systems can be helpful in predicting outcomes of populations of patients, they fail to be specific enough to be of significant help in predicting outcomes for an individual patient.[5]

With more than 20 years of intense scrutiny and hundreds of articles written, a consensus definition of what constitutes medically futile treatment is yet to be had. This failure to agree upon a clear definition has resulted in a change in focus from defining medical futility to addressing ways to approach cases in which a patient/family requests certain treatments that are deemed by the physician to be medically futile or medically inappropriate.[6] Several reasons support this change in focus. First, even though few treatments are clearly futile (ie, they serve absolutely no purpose and are completely ineffective), clinical cases in which a patient/family requests treatment believed by the health-care team to be medically inappropriate or futile are not uncommon. In the paradigm futility case, a family requests continued ventilation of an unconscious patient who has multiorgan failure and is unlikely to ever come off the ventilator. Continued ventilation will, in fact, keep the patient alive for some brief period and so cannot be said to be totally futile. The question of how to address this case exists, even though

Table 1. Medical Futility in End-of-Life Care (AMA Policy E-2.037*)

Health-care institutions should adopt a policy on medical futility. Policies on medical futility should follow a due process approach including the following steps:

- Earnestly attempt to negotiate a prior understanding of acceptable limits
- Maximize joint decision-making
- Attempt to negotiate disagreements with assistance of consultants
- Involve ethics committees if disagreement is unresolvable
- If process supports patient's position, transfer care to another physician within the institution
- If process supports physician, transfer to another institution may be sought if supported by the transferring and receiving institutions
- If transfer is not possible, intervention need not be offered

*American Medical Association, E-2.037: Medical Futility in End-of-Life Care. Available at www.ama-assn.org/ama/pub/category/8390.html. Accessed January 18, 2006.

the treatment cannot be said to be clearly medically futile.

Second, the term "futile" creates difficulty in analyzing and resolving these problems because the unspoken assumption is that if a treatment is futile, then it should not be provided. Thus, the term "futile" can itself dictate a treatment plan without any real discussion or analysis of what ought to be done. Third, the real question is not whether the treatment serves a useful purpose or is effective but whether the treatment should be provided. Rather than struggling with a definition for medically futile treatment, the more appropriate question is, "How do we ethically decide what to do when a patient/family demands treatment that the physician believes to be medically inappropriate or futile?"

Legal Cases Provide Little Help on Medical Futility

On the basis of review of prior cases, litigation has not been particularly helpful in addressing futility questions. Here are three cases that illustrate this point. Although going to court has resulted in a resolution of each case, no clear process for resolving future cases has evolved.

Case 1

Catherine Gilgunn, 71 years old, was admitted to Massachusetts General Hospital after a fall that injured her hip. She was in poor health, with a history of diabetes, heart disease, chronic urinary tract infections, Parkinson's disease, stroke, and a mastectomy for breast cancer. After admission, she developed seizures that resulted in brain damage and coma. Joan, her daughter and surrogate decision maker, reported that her mother wanted everything possible done, including resuscitation should she arrest. After several weeks with no improvement, the doctors believed continued treatment to be futile and recommended writing a Do Not Resuscitate (DNR) order. When Joan protested this decision, they consulted the hospital's Optimum Care Committee, which supported the physicians. Over the daughter's clear objections, a DNR order was written, and when Mrs. Gilgunn subsequently arrested, she was not resuscitated and died. Joan sued the hospital and the doctors for withdrawing the ventilator against her mother's wishes. A jury found that the conduct of the care providers met the accepted standard of care and hence could not be found negligent. The court did not address the question of the requirement to provide treatment deemed futile when requested.[7]

Case 2

Helga Wanglie, 86 years old, was permanently dependent on a ventilator and unconscious after a hip fracture. While in the hospital, she also experienced a cardiorespiratory arrest, resulting in severe anoxic encephalopathy and a persistent vegetative state. Her physicians wished to remove the ventilator, stating that it was "nonbeneficial." Her husband, daughter, and son insisted that the ventilator be continued. In an attempt to resolve the difference of opinion, the hospital went to court, asking to have Mr. Wanglie removed as the legal decision maker. The court found no reason to support that decision. In this case the court did not address the question of the medical futility of continued ventilator support for Mrs. Wanglie. Rather they stated that, as Mr. Wanglie had been Mrs. Wanglie's husband for over 50 years and impressed the court with his concern for his wife, he retained the right to make the decision to keep her on the ventilator.[8]

Case 3

Baby K was born with anencephaly, a congenital defect in which the cerebrum, which constitutes a majority of the brain, fails to develop. Because her brainstem was functional, she was able to breathe but she had no cognitive ability, was permanently unconscious, and was unable to see, hear, or interact with her environment. Even though babies with this diagnosis are usually made comfortable and allowed to die a natural death from their disease process, Baby K was provided aggressive support and kept alive by her mother's request and her refusal to agree to a DNR order. Once stable, she was transferred to a nursing home for long-term care. When she began having respiratory difficulty, however, she was transferred to the emergency room (ER) for treatment, including ventilator support. After this had occurred twice, the hospital went to court to request a declaration that the hospital not be required to provide respiratory support because it was deemed medically futile. The hospital argued that a Virginia state statute allowed physicians to withhold treatment they believed to be ethically or medically inappropriate. Ruling against this argument, the court found that the Emergency Medical Treatment and Active Labor Act (EMTALA) requires that hospitals provide emergency treatment, including intubation and ventilation, for patients in respiratory distress. As a federal statute, EMTALA would preempt state law, and under EMTALA, ERs are required to provide stabilizing treatment. The court ruled that EMTALA does not allow exceptions, even when the physicians believe intubation is medically inappropriate or futile, as in the case of Baby K.[8]

Table 2. Texas Advance Directives Act: Procedure If Not Effectuating a Directive or Treatment Decision (Texas Statute 166.046)

- If physician refuses to honor patient/family wishes for treatment, case is to be reviewed by ethics or medical committee
- Patient/family is given written description of ethics or medical committee review process and registry list of alternative providers
- Patient/family is given at least 48 hours' notice of and invited to attend committee review process
- Written explanation of committee decision is provided to family and placed in the chart
- If no agreement is reached, reasonable effort is made to transfer patient to another physician and/or institution
- If after 10 days no transfer is possible, hospital and physician may withhold or withdraw treatment determined to be futile
- Court-ordered extension of this time may be granted if reasonable likelihood of finding a willing provider

*American Medical Association, E-2.037: Medical Futility in End-of-Life Care. Available at *http://www.capitol.state.tx.us/statutes/docs/HS/content/htm/hs.002.00.000166.00.html*. Accessed January 18, 2006.

These legal cases have provided limited and confusing guidance on how to address the question of medically inappropriate or futile treatments. On the basis of their outcomes, one might conclude that if a patient/family requests a treatment that the physician deems to be medically inappropriate or futile, the law will require that it be provided. However, that is not the finding in these cases because the specific question about the futility of the treatment was neither asked nor answered. Rather, other questions were answered. Does withholding of treatment from Mrs. Gilgunn constitute negligent care? Who can speak for Mrs. Wanglie? Is emergency treatment required for Baby K? It is unclear how the courts will answer a question on the request to provide treatment the physician believes to be medically inappropriate or futile.

Procedural Guidelines Come Closer to Addressing Treatment Decisions

A more appropriate question is how to address decision making when a patient/family requests treatment that the physician believes to be medically inappropriate or futile. In the early 1990s the Houston City-Wide Task Force on Medical Futility drafted a set of guidelines. Choosing not to categorically define medical futility but rather to use the language of medically inappropriate treatment, they proposed a procedural approach that supported specific steps toward conflict resolution. Ultimately, the goal of these guidelines was to provide institutional support to withhold and/or withdraw specific medical treatments deemed to be medically inappropriate or futile by the physician but specifically requested by a patient/family. Several hospitals in the Houston area adopted these guidelines and created policies that supported them.[9]

The American Medical Association (AMA) Council on Ethical and Judicial Affairs also approved and published similar guidelines on Medical Futility in End-of-Life Care (Table 1). Choosing to use the term "futility" but offering no clear definition, these guidelines proposed "a due process approach."[10] Following a series of seven clearly defined steps, the guidelines recommended that treatments found to be futile "need not be offered."[10]

In 1999 the Texas legislature revised its laws on end-of-life treatment under the Texas Advance Directives Act and included a mechanism for dispute resolution when a physician is asked for a treatment believed to be inappropriate. Similar to the Houston and AMA guidelines, the Texas law established a series of steps to be followed on the part of the family and the hospital for resolving futility disputes (Table 2). If these steps are followed, "The hospital and physician may unilaterally withhold or withdraw therapy that has been determined to be futile."[11] As such, the statute provides civil and criminal immunity from liability to both the hospital and the physician.

Another approach to addressing these cases is the preventive-ethics approach. In this approach primary care physicians "take responsibility for discussing decisions about futile treatment with patients before clinical circumstances call for such decisions."[6] This approach rests on the primary value of open, honest communication on both sides and a concerted development of trust. A preventive-ethics approach also dictates that institutions and professional provider groups base their treatment approaches, especially for more frequent diagnoses, on professional standards of care and evidence-based outcomes.

Initial Outcome from Procedural Approach to Futility Cases

Initial outcomes after enactment of the Texas statute, although limited, seem to indicate some positive results. Baylor University Medical Center reviewed the 24 months of documentation after its implementation. Of 47 futility consultations, four requests were deemed nonfutile and the treatments were provided. Joint agreement between physician and family resulted in withdrawal of treatment in 37 cases. Of the six cases deemed futile by the full process, three families ultimately agreed to treatment withdrawal. In the final three cases, the patients died during the process of identification of and transferring to an alternative provider. To date, no family member from any of these cases has pursued legal action.[11] These results demonstrate a successful procedure for addressing questions about medically futile treatments.

These professional and legislative guidelines come close to answering the question of how to address medically inappropriate or futile treatment by defining steps that support involvement of both patient/family and physician/health-care provider in the decision-making process. Although the guidelines represent a good start, they are

problematic in that they fail to address certain ethical issues. First, none of the guidelines gives any direction on how ethics committees are to make a determination as to whether a treatment should be provided. Although this lack of specific direction can support addressing each case individually within the full context of the case, it also can allow for prejudicial thinking and decision making that lacks principled ethical analysis. Clearer directions including a requirement to support decisions on the basis of accepted ethical principles would strengthen these guidelines.

Second, these guidelines assume from the outset some level of adversarial relationship between the patient/family and physician/health-care provider and, in the end, support a decision for one side or the other. Certainly a shared decision is encouraged and can be reached as both sides move through the defined steps, as demonstrated by the Baylor study, but if that is not the case, ultimately one side wins while the other loses. In the end there may be no way to totally overcome this problem, but a worthwhile goal may be to reduce unilateral decision making to a minimum. Procedural steps that support this outcome, through the use of mediation techniques and other methods of shared decision making, would be helpful.

Conclusion

If solutions to futility dilemmas in clinical practice are to be addressed and resolved in an ethically appropriate manner, the answers are unlikely to come from further clarification of definitions or judicial precedent. They will more likely come from practiced approaches as suggested by professional or legislative guidelines whose goals strive to arrive at shared decisions that respect and honor the values and integrity of parties on all sides. The acceptance of a shared decision-making model is key to the development of a moral decision in these cases. For this to occur, communication and deliberation must be explicit, open, and more than just the exchange of information.[12]

Professional guidelines and legislative statutes that support process-based, ethical approaches can help teach health-care providers how to work with patients/families requesting treatments that they believe are medically inappropriate or futile. Along with these guidelines, it is necessary that physicians and other health-care providers develop and practice an approach to requests for medically inappropriate or futile treatment that honors each other's values and that seeks a shared decision. ❑

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Karen Trotochaud, RN, MN, is a senior program associate at the Emory University Center for Ethics in Atlanta, Georgia.

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