Medical Futility and Nursing
Carol Taylor

Defining medical futility is central to the efforts of clinicians and ethicists who seek to identify the limits of patient autonomy. This article is a critique of current efforts to define and then use policies of medical futility to justify refusing requests for treatment and care that have no perceived medical benefit. After exploring the current definitions of medical futility in the bioethics and clinical literature, comparisons of the advantages and disadvantages of the following three options are provided: allowing patients to decide all but physiologic futility, allowing clinicians to decide futility, and pursuing negotiated compromise. The third option—negotiated compromise—is recommended. A role is developed for nurses in preventing and resolving conflict about futile treatment.

[Keywords: clinical decision making; ethics; futility]

Many patients in the United States believe they can request and obtain any care they desire. Clinicians, however, are beginning to ask questions about the limits of patients' autonomy. Sensitive to the pressing need to use health-care resources in a cost-efficient manner and increasingly troubled by the need to provide care of questionable medical benefit to patients whose deaths are being painfully prolonged, clinicians are looking for a way to say no to some requests.

Under what conditions, if any, can one justifiably refuse to honor a patient's request for inappropriate care? To answer this question, one must first define "inappropriate care." It was attempts to do just this that led to the development of the idea of "medical futility." If criteria can be established for identifying medically futile care, providers will have a rationale for refusing requests for such care. Although many definitions of futility have appeared in the bioethics and health-care literature since 1988 and a number of hospitals have adopted policies to guide the withholding and withdrawing of futile care, nurses and others are beginning to question the wisdom of using a futility policy to justify refusing a request for care.

Background

Futile care is not a new problem. In its original form it was experienced most often by patients as unwanted care. Efforts to educate health-care professionals about a patient's right to be self-determining and the securing of legal protection for this right have done much to alleviate this problem. Nurse advocates who alert other providers to broad considerations of the patient good beyond mere physical well-being have also been helpful.

We thus recognize two different consequences of beneficial health care: improved physical well-being and improved overall well-being. While medicine is best equipped to determine the physical benefits of treatment, only the patient or those who know the patient best can determine if treatment is advancing the patient's overall well-being. This latter is a subjective determination. Using these distinctions treatments can be classified as follows. (a) Not futile: beneficial to both physical and overall well-being; (b) Futility: nonbeneficial to either physical or overall well-being; (c) Futility from the patient's perspective: medically indicated but not valued by the patient; and (d) Futility from the clinician's perspective: valued by the patient but not medically indicated.

Obviously the first two types of treatment are not problematic. The third, which is medically indicated treatment that is not valued by the patient, has been somewhat successfully resolved by an emphasis on patient autonomy. For example, a patient with multiple chronic illnesses who welcomes death can now refuse surgical repair of life-threatening gastrointestinal bleeding. But is patient autonomy absolute? Rephased, is professional autonomy subordinate to patient autonomy? This question leads us to the fourth type of treatment and the problem fueling the current futility debate—treatment valued and demanded by a patient that is incompatible with the aims of medical care. Whether it is antibiotics for a viral infection or aggressive treatment that merely prolongs

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dying, are physicians and nurses always obligated to accede to patient wishes?

**Concept of Medical Futility**

At issue is whether clinicians are sufficiently objective to establish that a given intervention is futile and that it therefore lies within their authority to withhold or withdraw its use (Callahan, 1991). Youngner (1988), early in the debate, identified four understandings of futility: physiologic, length of life, quality of life, and probability. This author cautioned that all, except for physiologic futility and an absolute inability to postpone death, involve value judgments. Critiquing a proposal for physicians to unilaterally limit cardio-pulmonary resuscitation (CPR) in long-term care facilities, Youngner writes, “Under the guise of medical expertise and concern for proper resource allocation, it encourages physicians to substitute their own value judgments for those of their patients” (1988, p. 2095). More recently, Miles (1992) described four perspectives of futility: physiologically implausible, nonbeneficial to the patient as a person, unlikely to work, and nonvalidated.

Restricting futility to physiologic futility avoids the problem of value judgments but the number of cases to which it can be applied are only a small percent of the problematic cases. Unsatisfied with this approach, Schneiderman, Jecker, and Jonsen (1990) propose defining medical futility more broadly. Distinguishing the quantitative and qualitative roots of futility, they suggest that either can free a physician from the obligation to offer medical treatment. For quantitative futility, physicians conclude, either through personal experience, experiences shared with colleagues, or consideration of reported empiric data, that in the last 100 cases, a medical treatment has been useless. Qualitative futility is any treatment that merely preserves permanent unconsciousness or fails to end total dependence on intensive medical care (pp. 951-952).

Schneiderman, Jecker, and Jonsen are aware of the value judgments imbedded in their definitions and are sensitive to the potential abuses. They do, however, join a growing number of bioethicists and physicians (Koch, Meyers & Sandroni, 1992; Marsh & Staver, 1991; Murphy, 1988; Murphy & Matcher, 1990; Paris, Crone, & Reardon, 1990; Stell, 1992; Tomlinson & Brody, 1990) who believe that the merits of using a broad definition of medical futility to justify refusing treatment in select cases outweigh the potential for abuse. These proposals are generally grounded in the conviction that patients should be protected from decisions that are not in their best interests. Moreover, there ought to be a way to deter patients from making decisions that violate the best interests of society.

Concern about empowering physicians to determine futility continues to be voiced (Alpers & Lo, 1992; Brennan, 1992; Mahowald, 1993). At least two ethicists have argued that clinicians have a duty to provide some requested and equitably-funded life-prolonging treatment when they believe that such interventions will produce no net benefit (Veatch & Spicer, 1992).

If one accepts medical futility as a justification for limiting patient autonomy, these questions arise: Who ought to make decisions about futile care (Jecker & Pearlman, 1992)? What processes will ensure the best patient and societal outcomes, including the just distribution of the benefits and burdens of health care? Especially problematic are the options available to physicians when efforts to communicate with families and to mediate disagreements fail (Hacker & Hiller, 1990). Suggestions in the literature include models of shared decisionmaking (Lantos et al., 1989; Spielman, 1994) and recommendations that health care professionals defer to broad public dialogue to determine standards of futile care (Brennan, 1992; Tomlinson & Brody, 1990; Youngner, 1988). But as yet unresolved in these discussions is the weight that ought to be given to such societal concerns as the cost-efficient use of scarce resources (Wirthlin Group for Mercy Healthcare Arizona, 1993).

More recently Scheidman and colleagues (1994) called for an end to defining futility and a move to defining and implementing caring. Among those critical of the move to resort to definitions of futility to justify refusing requests for unreasonable care are Truog, Brett, and Frader (1992), who cite clinical heterogeneity, pluralistic values, and the evolutionary nature of social consensus as reasons why most clinical decisionmaking on behalf of critically ill patients defies reduction to universally applicable principles. Emphasizing that their rejection of the idea of futility does not imply an endorsement of unrestricted patient demands, these authors comment:

> When providers oppose such demands they are usually acting from a profound sense that further treatment would be fundamentally wrong. Our task is to take account of that sense of wrongness without resorting to unilateral, provider-initiated declarations of futility (p. 1562).

The unique nature of nurse-patient relationships places nurse in an excellent position to “take account of that sense of wrongness” and to help all those involved understand why each may see a different treatment option as desirable.

**Nursing and Futility**

Figure 1 illustrates the potential for futility conflicts when treatment decisions are made for critically or chronically ill patients. Once care and restoration are no longer realistic, a decision must be made to modify the treatment plan so that either stabilized functioning or a comfortable, dignified death results. Ideally, the patient, family, and health-care team are in agreement about the goal of treatment. Unfortunately, however, this is often not the case. Clinicians have three options when there is conflict about the treatment plan.

1. Allow patients or their surrogates to decide all but physiologic futility. Subordinate health-care professional autonomy to patient autonomy.
2. Allow clinicians to decide futility. Subordinate patient autonomy to health care professional autonomy.
3. Pursue negotiated compromise respecting the autonomy of health-care professionals and patients equally.

The potential advantages and disadvantages of these options are summarized in Table 1. Obviously, negotiated compromise may precede either of the first two options. Unfortunately, it is increasingly overlooked in practice and members of no one profession seem to be assuming responsibility for leading the health
team to resolve futility conflicts through negotiation. Being too ready to accept either of the initial options may irreparably damage the clinician-patient relationship by negating the need for continuing dialogue among all the participants in a conflict about futility. I recommend that nurses play a leading role in effecting the third

Table 1: Advantages and Disadvantages of Competing Options.

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<tr>
<th>Potential Advantages</th>
<th>Potential Disadvantages</th>
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<tr>
<td>I. Patient or surrogate decides all but physiologic futility</td>
<td>• Ultimate control is with patients or their legally valid surrogates</td>
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<td>• Compromises professional autonomy</td>
<td>• Compromises professional autonomy</td>
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<td>• In some cases, surrogates may not speak in a patient’s best interests</td>
<td>• May result in an unjust allocation of scarce resources</td>
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<td>II. Clinicians decide futility.</td>
<td>• Impairs professional-patient/surrogate communication</td>
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<td>• Resolves difficult cases</td>
<td>• May evolve into a new form of paternalism where professionals make decisions for</td>
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<td>• Resolves difficult cases</td>
<td>patients—based on what is in the best interest of society (individual patient’s</td>
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<td>• Preserves integrity of health care disciplines and moral integrity of</td>
<td>interests are factored into decisionmaking but are no longer central.)</td>
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<td>individual health care professionals.</td>
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<td>• Facilitates better allocation of scarce resources</td>
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<td>• In some cases, clinicians may be better able to serve a patient’s best interests</td>
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<td>than can surrogates</td>
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<td>III. Shared decisionmaking: Mediated compromise.</td>
<td>• Prevents, and in some cases resolves, conflict between patient/surrogate and</td>
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<td>professionals, regarding treatment options.</td>
<td>• Preserves the integrity of health care disciplines and the moral integrity of</td>
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<td>• Facilitates the trust between professionals and patient/surrogate.</td>
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option by identifying patients, families, and health-care teams at high risk for experiencing conflict about futile care and then initiating the dialogue that may prevent or resolve the conflict. The focus in negotiation should be on everyone working together to obtain the best possible outcome for a particular patient, not on any person or group asserting their primacy of authority.

High Risk Patients

Nurses have historically placed patients and their values at the center of care. The debate about futility determinations underscores the urgent need for some professional to bring to ethical discourse about treatment decisions a sense of who the patient is and the values that underlie the patient’s and surrogates’ demands for treatment. Equally needed is a willingness to honestly appraise the values influencing determinations of when a given treatment justifies the risk of suffering and expense. Table 2 lists common factors underlying patient and surrogate requests for medically futile care. Table 3 shows several factors contributing to the popularity of medical futility as a means to refuse requests for unreasonable care.

As nurses learn more about the constellation of patient and caregiver variables associated with intractable conflicts about futile treatment, high-risk patients and caregivers can be identified and strategies can be initiated to prevent adversarial relationships from developing. Ideally much conflict can be avoided by early intervention. The North American Nursing Diagnosis Association

Table 2: Factors Underlying Patient/Surrogate Requests for Medically Futile Care.

- Faulty reasoning. Belief that doing the “loving” or “right” thing for the patient means doing “everything that is medically possible”
- Psychological factors such as denial and guilt
- Unrealistic expectations
- Inability to trust professionals to act in the patient’s best interests
- Religious conviction that life is to be preserved at all costs
- Economic considerations
- Entitlement mentality

Table 3: Factors Contributing to the Popularity of Medical Futility Among Professionals Seeking a Means to Refuse Requests for Unreasonable Care.

- Conviction that at times aggressive care is not in the best interest of patients/families and may even be cruel and inhumane
- Concern to preserve the moral integrity of the disciplines of medicine and nursing
- Concern to preserve the moral integrity of the individual caregivers
- Escalating health care costs and justice considerations
- Conviction that harm to identifiable third parties constitutes a justifiable limitation to the autonomy of patients/surrogates
- Conviction that new standards of care are needed; for example, once persistent vegetative state is definitively diagnosed, life-sustaining medical therapies should be withdrawn in the absence of a directive to the contrary
accepted as a nursing diagnosis, "Decisional Conflict: The state of uncertainty about the course of action to be taken when choice among competing actions involves risk, loss, or challenge to personal life values" (1989, p. 68). Unfortunately, one rarely reads this diagnosis in a plan of care. Part of the reluctance that nurses express about documenting decisional conflict results from fear about them becoming accountable for a problem they feel ill equipped to solve.

Prevention of Conflict

The following case illustrates the need for communication that is patient-centered, personal, initiated by a trusted individual, ongoing, and consistent. Parents of a small, premature infant who had spent the first 6 months of his life in a neonatal intensive care unit were understandably outraged when they received a letter from their son's neonatologist explaining in four lengthy typewritten pages why aggressive care should be discontinued. The information in the letter was factual and eloquently expressed that continued aggressive treatment was cruel and inhumane given the remote possibility of it benefiting the infant. What caught and held the parents' interest, however, was a paragraph explaining that the health-care resources being consumed by their son would be better invested if directed to another infant more likely to benefit from treatment. As the parents explained to their attorney, "They [health care professionals] don't think our son deserves the care he is getting. Who are they to decide who's worthy of care?" Had the parents received this information in person and from someone whom they trusted, misunderstandings might have been clarified and the parents might not have sought legal counsel. Had the neonatologist focused on why terminating aggressive treatment was in the infant's best interests rather than citing societal benefits, the parents may not have questioned the loyalty to their son. And finally, if periodic meetings between the parents and interdisciplinary team took place during the 6 months of the infant's life, during which time the goals of treatment were explored and treatment priorities were reassessed, the news in the letter might not have been so shocking. When interacting with high-risk families, nurses should: (a) keep all conversations focused on securing the patient's good; (b) identify the caregiver who is most trusted by the patient and family and allow this person to be present at all conversations about treatment options; (c) ensure that caregivers make ongoing and consistent recommendations to the family; and (d) communicate person-to-person.

Mediation

In a practical guide to mediating bioethical disputes, Dubler and Marcus (1994) define mediation as a “voluntary process that uses an unbiased neutral party to facilitate negotiation and conflict resolution between disputing parties” (p. 80). They identify the following responsibilities of people mediating bioethical disputes.

• Identifying and clarifying the relevant medical facts and the logic of moral arguments.
• Facilitating the reflective process.
• Comparing the moral consequences of alternative solutions.
• Playing a role in seeking resolution.

Advocacy

It is essential for nurses to develop the interpersonal competence and group process skills that can successfully effect mediated compromise. Both the American Nurses Association Code of Ethics (1985) and the Standards of Clinical Nursing Practice (ANA, 1991) obligate nurses to be patient advocates. Being a patient advocate when conflicts develop between patients and professionals, means standing in the middle of the conflict and doing the hard work of uncovering exactly what it is that underlies the patient's and surrogates' demands as well as the factors that are making professionals uncomfortable about these demands. Often there can be no satisfactory resolution of the conflict until these factors are identified.

To play the mediator role successfully, nurses must know the patient and surrogates; nurses cannot be effective advocates for patients without this knowledge. At the heart of nursing excellence and nurses' contribution to the interdisciplinary team is the nurse-patient relationship. This relationship enables nurses to speak authoritatively to the effects of the patient's illness on the patient. It is this three-pronged assessment of current health state, the influence of this state on a person, and the influence on a person's ability to achieve meaningful life goals, that in part distinguishes nursing from medicine. Faithful to this assessment and the relationships that make it possible, nurses will be able to bring to a discussion about futility a clear sense of why some patients and their surrogates are demanding care that professionals deem inappropriate or futile and suggest strategies for clarifying unrealistic expectations, correcting faulty reasoning, or addressing the source of emotional conflict.

To play this mediating role, nurses must also be sensitive to professional and societal factors that contribute to conflict. Bias and discrimination can always influence clinical decision making. More difficult still may be separating caretaker suffering from patient suffering to ensure that treatment decisions are based on a patient's interests rather than those of caretakers.

Accountability

Once conflict has been identified, either proactively while there is still time to intervene to prevent adversarial relationships from developing, or later, all involved parties must assume responsibility for resolving the conflict. Too frequently no one takes responsibility for the difficult work of mediating the conflict so the conflict escalates. Establishing that it falls within the domain of each profession and the authority of each caregiver to prevent and resolve ethical conflict is a critical first step. Nurses can play an important role in bringing the interdisciplinary care team together to explore a conflict and
prepare for a patient care conference. Should unbiased people be needed to facilitate negotiation and conflict resolution, nurses are well-prepared to serve in that role.

**Patient Care Conference**

If patient care conferences that include patients and families are not routinely scheduled for critically ill patients, a nurse's first task is to convene such a conference. Physicians who may initially view such meetings as a waste of time are often surprised to discover the confusion that exists among the family and caregivers about the goal of medical treatment. As a patient's condition changes, it may be necessary to rethink the goal of treatment and which may change from restoration and cure to stabilization of function or preparation for a comfortable and dignified death. Families who are consistently apprised of changes in a patient's condition and assisted to explore what these changes mean are less likely to be distrustful of the care team in the event a recommendation is made to withdraw or withhold further aggressive treatment. An effective strategy in these meetings, when it is difficult to predict the benefits of treatment, is to describe limits. Say, for example, "We will attempt a trial of ventilatory assistance for 2 weeks and reassess our decision at the end of that time."

Once a futility conflict arises, nurses should keep conversation focused on securing the best outcome for the patient and encourage all present to discuss what they take to be the best course of action and why. A discussion of the frustrations experienced on all sides of the conflict may be helpful. Because families are increasingly seeking legal counsel and might bring an attorney to these meetings, the presence of hospital counsel might also be indicated. It is critical, however, for caregivers not to be intimidated by attorneys nor to relinquish control of the meeting to those with a legal agenda.

One of the functions of patient care conference is to enable the care team to present the family with a unified position and rationale. Even if the care team is split 6 to 4 on a particular treatment option it is easier for the family to hear this along with reasons for the differences, than to be approached by 10 different caregivers each offering a personal recommendation.

When the best attempts to effect mediation fail, caregivers are thrown back into the position of having to accede to what they take to be unreasonable patient or family requests or to deny these requests. When caregivers honestly believe that a patient is being seriously harmed by unreasonable requests, legal solutions to the conflict should be pursued. The greater clarity we have in explaining why the surrogate's request is incompatible with the aims of medicine or nursing, the greater the potential that caregiver autonomy will be preserved.

**Role of the Courts, Media, and Bioethics in Creating Acceptance for Futility as a Decision-making Tool**

More than caregiver frustration is driving the popularity of medical futility as a clinical decision-making tool. Precedent-setting legal cases, the media, and the discipline of bioethics itself, are all legitimizing futility and facilitating its acceptance. Nurses participating in each of these activities can keep attention focused on the human needs of the participants involved.

**Role of Courts**

Other examples of futility are some recent court cases in which physicians attempted to withdraw treatment they believed to be medically inappropriate against the wishes of surrogates. In a Minnesota case, physicians believed that continued use of mechanical ventilation and intensive care were futile for 86-year-old Helga Wanglie who had been in a persistent vegetative state for over a year (In Re. Conservatorship of Wanglie, 1991). Her husband maintained that his wife would have wanted her life maintained at all costs. In an Atlanta case in 1991 (Annes, 1991), caregivers at the Scottish Rite Hospital for Crippled Children argued that continuing life-sustaining efforts for a near-comatose 13-year-old with an irreversible degenerative brain disorder would be "abusive and inhumane." Complicating this case was the mother's ambivalence about what was in her daughter's best interests and the father's persistent refusal to withdraw treatment, calm in his faith that a miracle would save his daughter. In New England (Paris, Crone, & Reardon, 1990), parents resisted physician efforts to withdraw treatment from an infant with severe brain damage. Even more recently, the Virginia courts (In Re. Baby K, 1994); Annas, 1994, denied a hospital request to withhold ventilator treatment from an anencephalic infant.

Reported in the medical and popular literature, these cases did much to popularize the need for the courts to recognize medical futility as a clinical decision-making tool. Unfortunately, in each of the four cases the courts focused exclusively on who had the authority to make the decision in question. All verdicts affirmed the family's authority to decide on behalf of the patient, even in the face of physician argument that the treatment requested was an inappropriate use of medical resources and not in the patient's best interests. Nurse attorneys and nurse witnesses should be helpful in the future by directing the court's attention to the good of the patient for whom decisions are being made.

**Role of the Media**

The media has also played a significant role in popularizing medical futility. To illustrate the different roles the media plays one need only examine three major stories that appeared in the Washington Post in 1991-1992. A June 1991 story about a family who wanted to withdraw consent for life-sustaining treatment for a patient who spent 102 days in critical care following heart surgery highlighted how difficult it is to determine what constitutes futile care and who should make that decision (Okie, 1991). The article alerted the public to the practical consequences of family-physician conflict about futility and corresponding treatment options. It emphasized the family's struggle against the medical establishment to secure the care they wanted for their father.

The following month a two-part article appeared in the
Washington Post detailing the frustration of caregivers who firmly believed that continued mechanical ventilation and aggressive treatment were no longer benefiting—and were in fact harming—18-month-old Baby Rena who was dying of AIDS and heart disease (Weiser, 1991). This article eloquently detailed the frustrations of caregivers who were unable to persuade the child’s obviously caring foster parents to consent to removing the ventilator. The article makes a strong case for society to accept futility policies.

Finally, in March 1992, a two-part article in the Washington Post health section questioned the benefits “machines, monitors, and medicine” secured for Crystal Pinkett, a child with short-gut syndrome who died the day before her first birthday after a year of hospitalization and painful surgeries and treatment (Colburn, 1992). The article sensitively details the struggles of both Crystal’s mother and her caregivers to discern what was in the child’s interests, and points to the need to wisely decide when “enough is enough.”

What each of these cases illustrates is the media’s ability to dramatize the futility conflict for the public and to influence public opinion. Nurses need to be conscious that patient and family trust may be influenced by these and similar stories. Finally, nurses caring for patients whose stories are being told publicly should consent to interviews so that a nursing perspective will become part of the public record.

Conclusion

While bioethics is a relatively new discipline, its practitioners play a powerful role in legitimating new medical technologies and new processes of decisionmaking. Bioethicists articulate compelling arguments for and against futility policies. Nurses can best advocate for patients by weighing the respective merits of these arguments in light of the effects they achieve for patients.

Nurses are beginning to question reliance on medical futility policies to resolve conflict about treatment preferences. While policies that guide the withholding and withdrawal of futile care seem to offer a way out of morally distressing clinical situations, they also legitimate the substitution of caregiver values for patient values at a time when the rights of vulnerable patients are increasingly jeopardized.

Increased sensitivity to the reasons for patient and surrogate requests for inappropriate care and the willingness to attempt to mediate conflict may prevent many of these situations. Nurses should re-examine their commitment to the kinds of nurse-patient relationships that make this mediation possible. Increased sensitivity to the courts, the media, and the discipline of bioethics in securing acceptance of futility as legitimate, will enable nurses to intervene effectively.

References


In Re Baby K, 832 F. Supp. 1022 (E.D. Virginia, 93-68-A); aff’d 16 F.3d 590 (4th Cir. 1994).


