Medical Futility in End-of-Life Care
Report of the Council on Ethical and Judicial Affairs

Use of life-sustaining or invasive interventions in patients in a persistent vegetative state or who are terminally ill may only prolong the dying process. What constitutes futile intervention remains a point of controversy in the medical literature and in clinical practice. In clinical practice, controversy arises when the patient or proxy and the physician have discrepant values or goals of care. Since definitions of futile care are value laden, universal consensus on futile care is unlikely to be achieved. Rather, the American Medical Association Council on Ethical and Judicial Affairs recommends a process-based approach to futility determinations. The process includes at least 4 steps aimed at deliberation and resolution including all involved parties, 2 steps aimed at securing alternatives in the case of irreconcilable differences, and a final step aimed at closure when all alternatives have been exhausted. The approach is placed in the context of the circumstances in which futility claims are made, the difficulties of defining medical futility, and a discussion of how best to implement a policy on futility.

CIRCUMSTANCES IN WHICH FUTILITY JUDGMENTS ARE IMPLICATED

One type of circumstance that may prompt claims of futility is discrepancy between the values or goals of the involved parties. In these situations, one party, eg, the patient or proxy, wants to pursue the goal of preserving life even if there is little or no hope of future improvement, while another party, eg, the physician, sees dying as inevitable and wishes to pursue the goal of comfort care. In such circumstances of disagreement it is likely that the physician, in complying with proxy goals, intervenes with the sense that the only reasonable expectation for the intervention is to prolong the dying process. The parties may also hold reverse goals, for example, the proxy may believe that the physician is inappropriately pursuing life-prolongation when death is inevitable.

Some conflicts are intensified by disagreements over who has decision-making authority. The case of Helga Wanglie was...
one in which a hospital went to court to
get permission to withdraw treatment from
a patient.9 However, the patient’s husband
successfully asserted that his substituted
judgment about his wife’s view of appro-
priate medical intervention should take
precedence over the medical team’s view
that intervention was nonbeneficial. In-
deed, this case, the cases holding that a
patient has a right to be free of unwanted
intervention, and the entire health care
proxy movement indicate legal endorse-
ment for a hierarchy of authority regard-
ing medical decision making. The choice
of the patient and the decision of his or
her next of kin or designated health care
proxy take precedence over the physician’s
recommendation.9

On the other hand, some cases have
upheld the prerogative of the profes-
sion to decline medical intervention that
it considered futile, such as the ruling in
Gilgunn v Massachusetts General Hospi-
tal.10 When physicians argue for profes-
sional standards, there is often a charge
that professionals are parentalistically
forcing their standards on patients.11,12
Unilateral decision making by physi-
cians feeds this reasoning and therefore
futility assessments should be imple-
mented in ways that clearly do not war-
rant such a charge.

Widely publicized court cases, such as
those of Wanglie6 and Gilgunn,10 indi-
cate that patients, families, physicians, and
others would benefit if the medical sys-
tem could handle these situations with less
need for recourse to the courts. Addition-
ally, in the rare cases that do go to court,
it would help their adjudication if a fair
professional and institutional policy on fu-
tility existed against which to judge com-
pliance or noncompliance. There is al-
ready evidence that related institutional
policies, such as those regarding do not
resuscitate orders, have been helpful in
upholding standards and in adjudicat-
ing conflicts.11

Another context in which futility ques-
tions come up is resource allocation. Some
commentators argue that elimination of
futile care is good for both patients and
allocation of resources.13 But other com-
mentators have countered that there is a
danger that judgments about futility mask
a covert motive to conserve resources. Ra-
tioning refers to the withholding of effi-
cacious treatments on a cost basis be-
cause of competing needs. Both futility
judgments and allocation decisions are
sometimes necessary, but the 2 should be
understood for what they are and not be
confused. Moreover, they should be dealt
with openly.14 Efforts to understand fu-
tility should not make use of resource-
saving criteria, and rationing needs should
not motivate declarations of futility. Al-
though cost savings that could be real-
ized if a futility standard were followed
are large by some estimates, other esti-
mates based on clinical studies suggest that
the savings would be minor.15,16 Whether
or not futility standards might realize cost
savings, they should not be used as co-
vert rationing mechanisms.

A final context in which futility claims
may appear is when a physician be-
lieves that a patient or patient’s family will
not agree with the physician’s assess-
ment. In these circumstances, futility
could be used as an excuse for avoiding
difficult discussions. When an interven-
tion is medically inappropriate it is jus-
tifiable to not raise the topic.4,6 How-
ever, there is some risk that when a
physician anticipates a disagreement re-
arding the use of an intervention, fu-
tility claims will be used to avoid poten-
tially unpleasant discussion. Futility
claims are inappropriate under such cir-
cumstances and discussions with pa-
ients and families and shared decision
making should be encouraged.

**EXISTING EFFORTS TO DEFINE
AND IMPLEMENT A POLICY ON FUTILITY**

Futility is an essentially subjective but re-
alistically indispensable judgment. A fully
objective and concrete definition of fu-
tility is unattainable. Webster’s dictio-
nary defines the term futile as serving no
useful purpose: completely ineffective.
However, people differ on judgments of
usefulness, purpose, and ineffectiveness
and how the 3 balance out, whether
in medical or other affairs.17–23 Claims of
medical futility inherently involve a value
judgment.24–27 For example, 1 patient may
consider the physical, emotional, prac-
tical, or financial burden of aggressive
intervention not worth the purpose of
prolonging seemingly meaningless life.
Another may find even short prolonga-
tion meaningful and worth the burden.
To impose an objective definition of
futility would inevitably cause some pa-
sients to receive intervention or to die
according to judgments with which they
disagree. Yet a workable understanding
of futility is necessary. Some interven-
tions must eventually be stopped.28

Definitions of futility have been pro-
posed based on a range of possible ap-
proaches. One approach is quantita-
tive. The best known proposal in this
category is by Schneiderman et al17 that
asserts that if the intervention does not
work in more than 1% of attempts, it
should be considered futile. They de-
define whether the intervention has worked
in a particular case according to physi-
ological outcome. The problem here is
the same one that gave rise to the need
for a concept of futility in the first place.
Individuals do not judge the worth of an
intervention by physiological outcomes
alone; for instance, successful preserva-
tion of renal function should rank dif-
ferently depending on the presence of
cognitive functions and ability for inter-
personal interaction. Similarly, one per-
son’s assessment of sufficient mental
function may not be the same as anoth-
er’s. The quantitative standard is there-
fore best combined with a qualitative ap-
proach. This functional assessment
usually concerns what constitutes a
worth-the-effort quality of life.

Another possible definition of futility
requires physicians and patients and/or
proxies to decline intervention that has
the intent of prolonging dying. This pro-
posed criterion focuses on the intent of
the physician or patient and/or proxy
rather than the intervention. The diffi-
culty here is 2-fold. First, some inten-
tions to prolong dying are justifiable, as
in preserving organs for donation or wait-
ning for a relative to arrive. Second, the
occasions when futility disputes arise
usually involve disputes about both in-
tervention and intent.

A third possibility in defining futility
is to use community standards to ascer-
tain which interventions will be provided. This controversial approach has already been debated in current literature, and, therefore, will not be reexamined in detail here.\textsuperscript{29,30} Using community standards has the merit of allowing different communities to define for themselves what interventions they consider to be worthwhile for a full panoply of illness circumstances. However, the problems of this approach involve defining the relevant community, securing valid prior decisions by that community, accommodating a range of different opinions within the community, allowing suitable exceptions, and maintaining periodic updates of the standards to keep pace of changes.\textsuperscript{29,31-33}

An alternative is to use institutional standards to define, proactively, what interventions are considered futile for defined circumstances. Some precedent exists for this approach in that institutions commonly have policy on do not resuscitate orders (B. Brody, PhD, A. Halevy, MD, Baylor Guidelines, 1995). In the sense that an institution can draw from members of or be used to define the community, this standard could be the same as community standards, and therefore is subject to some of the same problems.

Since none of these previous attempts at defining futility is truly adequate, the challenge now is to find a suitable approach that allows for quality decision making when there is a possibility of futility.

**A PROPOSAL FOR A FAIR PROCESS IN FUTILITY CASES**

An option that integrates features of all the above proposals and respects the reality that objectivity is unattainable is to use a fair process approach. In circumstances in which pressing dilemmas cannot be resolved by establishing an absolute rule or overriding principle, justice dictates that a fair process for resolution be followed. For instance, a due process standard is implemented in the judicial system. Since a perfect and objective reconstruction of a case can be impossible, the outcome of a fair process of hearings is adopted as the best available option. When medical cases involving futility judgments, case-by-case evaluations using a fair process approach may well be the best available option; it acknowledges both the impossibility of attaining objective assurance and the necessity of proceeding fairly (B. Brody, PhD, A. Halevy, MD, Baylor Guidelines, 1995).\textsuperscript{34}

In medicine, and for futility policies, fair process approaches would likely be adopted at the institutional level for use in individual cases, but could be adopted for larger communities of, say, religious institutions or even states. The emphasis of the approach is on fair process between parties rather than on having a definition that is externally imposed on the parties. Professional standards including use of clinical outcome measures, patient rights, intent standards, and family or community involvement usually should be accommodated in the process of deliberation. For this reason, the Council favors the fair process approach.

The fair process approach for declaring futility in a particular case would be defined within parameters set by a regulatory body of the institution or the community. The regulatory body would itself have an appropriate legitimizing composition and mechanisms to establish its authority. The body would, for instance, likely have a composition or structure to allow patient/public representation as well as professional and expert guidance. To foster ownership by those who must adhere to it, the fashion of its development, as well as the fair process adopted, should be openly published and accessible to members of the community and enrolled patients.

An important advantage to having a fair process approach is that arbitration can occur in a setting that is usually more convenient, more knowledgeable in medicine, more rapidly responsive, and less expensive in financial and emotional terms than court action.

**FEATURES OF FAIR PROCESS FOR CONSIDERING FUTILITY CASES**

Ideally, a fair process approach to futility would include at least 4 distinguishable steps aimed at deliberation and resolution, 2 steps aimed at securing alternatives in case of irresolvable differences, and a final step aimed at closure when all alternatives have been exhausted (Figure).

**Deliberation and Resolution**

First, earnest attempts should be made to deliberate over and negotiate a prior understanding between patient, proxy,
and physician about what constitutes futile care for the patient and what falls within acceptable limits for the physician, family, and possibly also the institution. This prior understanding is best achieved before critical illness occurs. If serious disagreement is unresolvable, provisions can be made for a sensitive and orderly transfer of care at such a time that it can preempt later conflicts.

Second, joint decision making should also be made at the bedside between patient or proxy and physician. This joint decision making should make use of outcomes data whenever possible, should incorporate the physician and patient and/or proxy intent or goals for treatment, and should abide by established standards of deliberation and informed consent.35,36

Third, the assistance of an individual consultant and/or a patient representative is a further step that is often helpful to reach resolution within all parties’ acceptable limits. The role of this individual consultant is not to single-handedly resolve the conflict but rather to facilitate discussions that would help reach that end.

Fourth, an institutional committee such as an ethics committee may be involved if disagreements are irresolvable. Institutional consultation services, as opposed to individual consultants, may involve a chairperson assembling an ad hoc team, a predefined subgroup, or a whole committee review.37 Regardless of the institution’s consultation model, such a committee should be structured to provide for full voice for the patient or proxy perspective, whether by having a lay representative on the committee, by having a full hearing from the patient or proxy or advocate/representative, by ensuring that the patient or proxy can call for ethics committee involvement, or by all of the above.

Securing Desired Care

A fifth step may occur if the outcome of the institutional process coincides with the patient’s desires but the physician remains unpersuaded. In such a case, arrangement may be made for transfer to another physician within the institution. Alternatively, if the outcome of the deliberation process coincides with the physician’s position but the patient and/or proxy remains unpersuaded, arrangements for transfer to another institution may be sought. If this path is taken, the transferring institution should be supportive and helpful in the process and the accepting institution and physicians should be comfortable honoring the patient’s and/or proxy’s wishes.

Finally, if transfer is not possible because no physician and no institution can be found to follow the patient’s and/or proxy’s wishes it may be because the request is considered offensive to medical ethics and professional standards in the eyes of a majority of the health care profession. In such a case, by ethics standards, the intervention in question need not be provided, although the legal ramifications of this course of action are uncertain.38

OPEN DISCLOSURE OF AND EXEMPTION FROM INSTITUTIONAL POLICY

This fair process approach insists on full and fair deference to the patient’s wishes, placing limits on this patient-centered approach only when the harm to the patient is so unseemly that, even after reasonable attempts to find another institution, a willing provider of the service was not found. The approach has the further advantage of being open, allowing for a sense of fairness and accountability for all parties in an era when cost containment and other driving forces compromise trust.

If a patient enters an institution’s care, perhaps on an emergency basis, but disagrees with the futility policy, cases may arise of irreconcilable disagreement without options for a full, fair process and transfer. Some institutions may allow patients and/or proxies to opt out of the policy, but other institutions may insist on the eventual option to cease unseemly intervention even if it leads to court action to arbitrate.

RECOMMENDATIONS

The Council finds great difficulty in assigning an absolute definition to the term futility since it is inherently a value-laden determination. Thus, the Council favors a fair process approach for determining, and subsequently withholding or withdrawing, what is felt to be futile care. The fair process approach that the Council proposes insists on giving priority to patient or proxy assessments of worthwhile outcome. It can accommodate community and institutional standards, and the perspectives offered by the quantitative, functional, and interest approaches that involved parties may bring. When the physician’s primary purpose of the treatment seems to be to prolong the dying process without much benefit to the patient or others with legitimate interest, this will be taken into account among fairly heard perspectives, and may become determinative but only if all available physicians in all institutions share this perspective. The fair process approach also provides a system for addressing the ethical dilemmas regarding end-of-life care without need for recourse to the court system. The Council, therefore, recommends that health care institutions, whether large or small, adopt a policy on medical futility, and that policies on medical futility follow a fair process approach such as that presented above.

REFERENCES

The Key and Critical Objectives of JAMA

Key Objective: To promote the science and art of medicine and the betterment of the public health

Critical Objectives:
1. To publish original, important, well-documented, peer-reviewed clinical and laboratory articles on a diverse range of medical topics
2. To provide physicians with continuing education in basic and clinical science to support informed clinical decisions
3. To enable physicians to remain informed in multiple areas of medicine, including developments in fields other than their own
4. To improve public health internationally by elevating the quality of medical care, disease prevention, and research provided by an informed readership
5. To foster responsible and balanced debate on controversial issues that affect medicine and health care
6. To forecast important issues and trends in medicine and health care
7. To inform readers about nonclinical aspects of medicine and public health, including the political, philosophic, ethical, legal, environmental, economic, historical, and cultural
8. To recognize that, in addition to these specific objectives, the JOURNAL has a social responsibility to improve the total human condition and to promote the integrity of science
9. To report American Medical Association policy, as appropriate, while maintaining editorial independence, objectivity, and responsibility
10. To achieve the highest level of ethical medical journalism and to produce a publication that is timely, credible, and enjoyable to read