

Medical Futility in End-of-Life Care

Report of the Council on Ethical and Judicial Affairs

Council on Ethical and Judicial Affairs, American Medical Association

IN THE COURSE OF CARING FOR A critically ill patient it may become apparent that further intervention will only prolong the final stages of the dying process. At this point, further intervention is often described as futile. There has been controversy in the literature and in clinical practice regarding what constitutes futile intervention.

Clinical paradigms of futile care often involve life-sustaining intervention for patients in a persistent vegetative state, or resuscitation efforts for the terminally ill.¹⁻⁴ Other paradigms include the use of aggressive therapy such as hemodialysis, chemotherapy, or surgery for advanced fatal illness without a realistic expectation of care or palliation, and also the use of less invasive treatments such as antibiotics or intravenous hydration in near-moribund conditions. Questions of futility can also arise when interventions are useless and the condition is not life-threatening. This report, however, limits itself to the use of interventions in patients with life-threatening illnesses.

The American Medical Association Council on Ethical and Judicial Affairs thus far has not defined an approach to determine what is and what is not medically futile, although it has discussed related issues concerning end-of-life care in other reports. For example, it has affirmed the ethical standing of withdrawing and withholding unwanted interventions, noted the constructive role that advance care planning can play in preempting difficult and conflicted situations, and advised the use of a range of orders not to intervene.^{5,6} The Council

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.

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has also opposed physician-assisted suicide,⁷ out of concern that recent calls from citizens and professionals for physician-assisted suicide are a response to experiences of excessive and futile intervention at the end of life.

In this report, the Council recommends a process-based approach to futility determinations. This recommendation follows from a discussion regarding various types of circumstances in which futility claims are made, an exploration of the difficulties of defining medical futility, and a deliberation on how to best 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

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one in which a hospital went to court to get permission to withdraw treatment from a patient.⁸ However, the patient's husband successfully asserted that his substituted judgment about his wife's view of appropriate medical intervention should take precedence over the medical team's view that intervention was nonbeneficial. Indeed, 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 endorsement for a hierarchy of authority regarding 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 profession to decline medical intervention that it considered futile, such as the ruling in *Gilgunn v Massachusetts General Hospital*.¹⁰ When physicians argue for professional standards, there is often a charge that professionals are parentalistically forcing their standards on patients.^{11,12} Unilateral decision making by physicians feeds this reasoning and therefore futility assessments should be implemented in ways that clearly do not warrant such a charge.

Widely publicized court cases, such as those of *Wanglie*⁸ and *Gilgunn*,¹⁰ indicate that patients, families, physicians, and others would benefit if the medical system could handle these situations with less need for recourse to the courts. Additionally, in the rare cases that do go to court, it would help their adjudication if a fair professional and institutional policy on futility existed against which to judge compliance or noncompliance. There is already evidence that related institutional policies, such as those regarding do not resuscitate orders, have been helpful in upholding standards and in adjudicating conflicts.¹¹

Another context in which futility questions 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 commentators have countered that there is a danger that judgments about futility mask

a covert motive to conserve resources. Rationing refers to the withholding of efficacious treatments on a cost basis because 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 futility should not make use of resource-saving criteria, and rationing needs should not motivate declarations of futility. Although cost savings that could be realized if a futility standard were followed are large by some estimates, other estimates 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 covert rationing mechanisms.

A final context in which futility claims may appear is when a physician believes that a patient or patient's family will not agree with the physician's assessment. In these circumstances, futility could be used as an excuse for avoiding difficult discussions. When an intervention is medically inappropriate it is justifiable to not raise the topic.^{4,6} However, there is some risk that when a physician anticipates a disagreement regarding the use of an intervention, futility claims will be used to avoid potentially unpleasant discussion. Futility claims are inappropriate under such circumstances and discussions with patients 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 realistically indispensable judgment. A fully objective and concrete definition of futility is unattainable. Webster's dictionary 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.¹⁷⁻²⁵ Claims of medical futility inherently involve a value judgment.^{26,27} 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 prolongation meaningful and worth the burden. To impose an objective definition of futility would inevitably cause some patients to receive intervention or to die according to judgments with which they disagree. Yet a workable understanding of futility is necessary. Some interventions must eventually be stopped.²⁸

Definitions of futility have been proposed based on a range of possible approaches. One approach is quantitative. 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 define whether the intervention has worked in a particular case according to physiological 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 preservation of renal function should rank differently depending on the presence of cognitive functions and ability for interpersonal interaction. Similarly, one person's assessment of sufficient mental function may not be the same as another's. The quantitative standard is therefore best combined with a qualitative approach. 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 proposed criterion focuses on the intent of the physician or patient and/or proxy rather than the intervention. The difficulty here is 2-fold. First, some intentions to prolong dying are justifiable, as in preserving organs for donation or waiting for a relative to arrive. Second, the occasions when futility disputes arise usually involve disputes about both intervention 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.^{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.^{29,31-33}

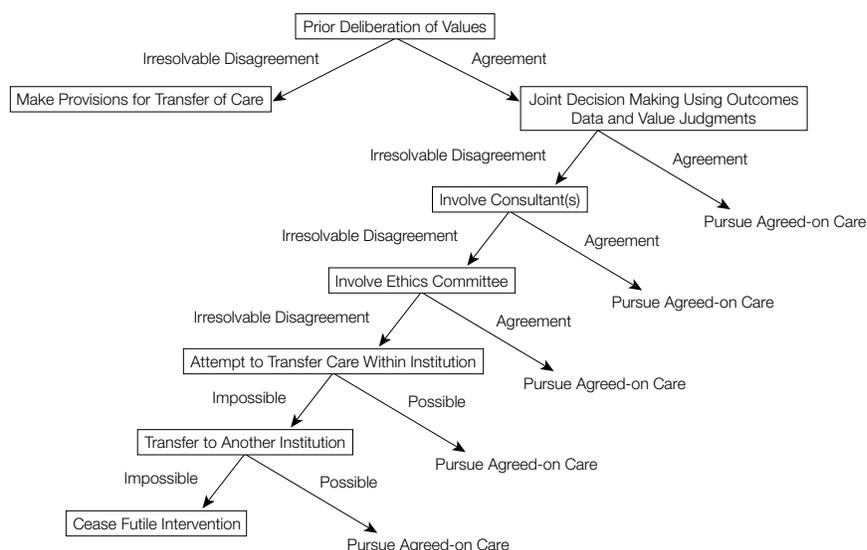
An alternative is to use institutional standards to define, proactively, what interventions are considered futile for defined circumstances. Some precedent exists for this approach in that institutions commonly have policy on do not resuscitate orders (B. Brody, PhD, A. Halevy, MD, Baylor Guidelines, 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 in-

Figure. Fair Process for Considering Futility Cases



volve 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).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 preidentified 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 irresolvable 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 signing 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

1. Paris JJ, Crone RK, Reardon F. Physicians' refusal of requested treatment: the case of Baby L. *N Engl J Med.* 1990;322:1012-1015.
2. Gray WA, Capone RJ, Most AS. Unsuccessful emergency medical resuscitation: are continued efforts in the emergency department justified? *N Engl J Med.* 1991;329:1393-1398.
3. Blackhall LJ. Must we always do CPR? *N Engl J Med.* 1987;317:1281-1285.
4. Miles SH. Informed demand for "non-beneficial" medical treatment. *N Engl J Med.* 1991;325:512-515.
5. Council on Ethical and Judicial Affairs, American Medical Association. Decision near the end of life. *JAMA.* 1992;267:2229-2233.
6. Council on Ethical and Judicial Affairs, American Medical Association. Report 5-A-97: optimal use of orders not to intervene and advance directives. In: Proceedings of the House of Delegates of the American Medical Association: 146th Annual Meeting; June 22-26, 1997; Chicago, Ill.
7. Council on Ethical and Judicial Affairs, American Medical Association. Opinion 2.211: decisions near the end of life. In: *Code of Medical Ethics: Current Opinions With Annotations.* Chicago, Ill: American Medical Association; 1996-1997.
8. Angell M. The case of Helga Wanglie: a new kind of right to die case. *N Engl J Med.* 1991;325:511-512.
9. Angell M. The legacy of Karen Ann Quinlan. *Trends in Health Care Law & Ethics.* 1993;8:17-19.

10. *Gilgunn v Massachusetts General Hospital*, Mass Super Ct (1995). No 92-4820, verdict 21.
11. Schneiderman LJ, Jecker N, Jonsen A. Medical futility: its meaning and ethical implications. *Ann Intern Med*. 1990;112:949-954.
12. Capron AM. Abandoning a waning life. *Hastings Cent Rep*. 1995;24:6.
13. Murphy DJ, Finnecane TE. New do-not-resuscitate policies: a first step in cost control. *Arch Intern Med*. 1993;153:1641-1648.
14. Jecker NS, Schneiderman LJ. Futility and rationing. *Am J Med*. 1992;92:189-196.
15. Lundberg GD. National health care reform: the aura of inevitability intensifies. *JAMA*. 1992;267:2521-2524.
16. Teno JM, Murphy D, Lynn J, et al, for the SUPPORT Investigators. Prognosis-based futility guidelines: does anyone win? *J Am Geriatr Soc*. 1994;42:1202-1207.
17. Schneiderman LJ, Faber-Langendoen K, Jecker NS. Beyond futility to an ethic of care. *Am J Med*. 1994; 86:110-114.
18. Brody BA, Halevy A. Is futility a futile concept? *J Med Philos*. 1995;20:123-144.
19. Lantos JD, Singer PA, Walker RM, et al. The illusion of futility in clinical practice. *Am J Med*. 1989; 87:81-84.
20. Trough RD, Brett AS, Frader J. The problem with futility. *N Engl J Med*. 1992;326:1560-1564.
21. Murphy DJ. Lessons from communities in conversation: the Colorado experience. *N C Med J*. 1995; 56:428-430.
22. Kelly B. A social worker's view of futility policy issues. *N C Med J*. 1995;56:427.
23. Emanuel L. Structured deliberation to improve decision-making for the seriously ill. *Hastings Cent Rep*. 1995;6(suppl):S14-S18.
24. Emanuel L. Structured advance planning: is it finally time for physician action and reimbursement? *JAMA*. 1995;274:501-503.
25. Zawacki BE. The "futility debate" and the management of Gordian knots. *J Clin Ethics*. 1995;6:112-128.
26. Schneiderman LJ. The futility debate: effective v beneficial intervention. *J Am Geriatr Soc*. 1994;42: 883-886.
27. Council on Ethical and Judicial Affairs, American Medical Association. Opinion 2.035: futile care. In: *Code of Medical Ethics: Current Opinions With Annotations*. Chicago, Ill: American Medical Association; 1996-1997.
28. Board of Trustees, American Medical Association. Report 48-1-95: quality care at the end of life. In: Proceedings of the House of Delegates of the American Medical Association; 144th Annual Meeting; December 3-6, 1995; Chicago, Ill.
29. Emanuel LL, Emanuel EJ. Decisions at the end of life: guided by communities of patients. *Hastings Cent Rep*. 1993;23:6-14.
30. Special edition on medical futility and a community policy. *N C Med J*. 1995;56:412-472.
31. Callahan D. Medical futility, medical necessity: the problem without a name. *Hastings Cent Rep*. 1991; 21:30-35.
32. Sugarman J. A community policy on futility? a conversation of the North Carolina community. *N C Med J*. 1995;56:415-417.
33. Halevy A, Brody B. Multi-institution collaborative policy on medical futility. *JAMA*. 1996;267:571-574.
34. Tomlinson T, Czlonka D. Futility and hospital policy. *Hastings Cent Rep*. 1995;25:28-35.
35. Emanuel EJ, Emanuel LL. Four models of the physician-patient relationship. *JAMA*. 1992;267:2221-2226.
36. Appelbaum P, Meisel A, Lidz C. *Informed Consent*. New York, NY: Oxford University Press Inc; 1986.
37. Fletcher JC, Siegler M. What are the goals of ethics consultation? a consensus statement. *J Clin Ethics*. 1996;7:122-136.
38. *In the matter of Baby K*, 16 F3d 590 (4th Cir 1994).

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