

Bioethics for clinicians:

16. Dealing with demands for inappropriate treatment



Education

Éducation

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Abstract

DEMANDS BY PATIENTS OR THEIR FAMILIES for treatment thought to be inappropriate by health care providers constitute an important set of moral problems in clinical practice. A variety of approaches to such cases have been described in the literature, including medical futility, standard of care and negotiation. Medical futility fails because it confounds morally distinct cases: demand for an ineffective treatment and demand for an effective treatment that supports a controversial end (e.g., permanent unconsciousness). Medical futility is not necessary in the first case and is harmful in the second. Ineffective treatment falls outside the standard of care, and thus health care workers have no obligation to provide it. Demands for treatment that supports controversial ends are difficult cases best addressed through open communication, negotiation and the use of conflict-resolution techniques. Institutions should ensure that fair and unambiguous procedures for dealing with such cases are laid out in policy statements.

Résumé

LES DEMANDES D'UN TRAITEMENT JUGÉ INAPPROPRIÉ par les prestataires de soins de santé faites par les patients ou les membres de leur famille posent d'importants problèmes moraux en pratique clinique. On a décrit dans les textes toutes sortes de façons d'aborder de tels cas, y compris la futilité médicale, les normes de soins et la négociation. La futilité médicale est un échec parce qu'elle confond des cas distincts sur le plan moral : demande d'un traitement inefficace et demande d'un traitement efficace qui appuie une fin controversée (p. ex., inconscience permanente). La futilité médicale n'est pas nécessaire dans le premier cas et elle est nuisible dans le deuxième. Le traitement inefficace se situe en dehors de la norme de soin et les travailleurs de la santé ne sont donc pas tenus de le fournir. Les exigences relatives à un traitement qui appuie des fins controversées sont des cas difficiles qu'il est préférable d'aborder par la communication ouverte, la négociation et le recours à des techniques de résolution de conflit. Les établissements devraient s'assurer que des énoncés de principe exposent clairement des façons équitables et sans ambiguïté de faire face à de tels cas.

Mr. A, a 58-year-old man with metastatic cancer, is admitted to hospital because of sepsis. When his physician discusses a do-not-resuscitate order with him, the patient is adamant that he wants to be resuscitated in the event of cardiac arrest.

Mrs. B is a 43-year-old woman in a persistent vegetative state secondary to head trauma suffered in a motor vehicle accident 13 months ago. She and her family are Orthodox Jews. When pneumonia develops, the family insists that "everything be done" for her, including, if necessary, treatment in the intensive care unit.

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What are demands for inappropriate treatment?

The right of the patient to refuse an unwanted medical intervention, even a life-saving treatment, is a well-established ethical and legal dictum in medicine. The limits of patient autonomy, however, have been challenged recently by demands from patients and families for medical interventions felt by the health care team to be inappropriate. Although treatment demanded by patients runs the gamut of medical interventions, the most pressing cases involve appeals for life-sustaining treatment. Must clinicians always accede to the wishes of patients and families? Are all such cases more or less similar, or are important moral distinctions among cases to be drawn?

A number of approaches to the problem have been proposed. Perhaps best known is that of “medical futility.” The concept was devised to take “precedence over patient autonomy and [permit] physicians to withhold or withdraw care deemed to be inappropriate without subjecting such a decision to patient approval.”¹ According to this view, a treatment is quantitatively futile “when 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.”² A treatment is qualitatively futile if it “merely preserves permanent unconsciousness or . . . fails to end total dependence on intensive medical care.”² Futile treatment need neither be offered to patients nor be provided if demanded.

Critics of medical futility have argued that it confounds morally distinct cases: demand for treatment unlikely to work, and demand for effective treatment supporting a controversial end (e.g., permanent unconsciousness). They point out that the concept of medical futility is unnecessary in the first case and harmful in the second. Appeals for ineffective treatment can be dismissed because such treatment falls outside the bounds of standard medical care.² Cases in which care is effective but the end supported is controversial typically involve substantial value disagreements. An optimal approach to such cases will rest on open communication and negotiation between the health care team and the patient or family.

Why are demands for inappropriate treatment important?

Demands for inappropriate treatment, although infrequent, cause substantial emotional and moral distress for patients, families and health care workers. In a few cases conflict may be so severe that legal action is taken by either the hospital or the patient.

Ethics

Medical care is governed by a number of ethical principles, including respect for persons, beneficence, non-maleficence and justice.³ These principles find expression in the CMA's *Code of Ethics*.⁴ When caring for patients, including those who are receiving (or who may receive) life-prolonging treatments, physicians have an obligation to “[a]scertain wherever possible and recognize [the] patient's wishes about the initiation, continuation or cessation of life-sustaining treatment” and, if the patient is unable to speak for herself, to respect wishes expressed in an advance directive or by a proxy decision-maker (usually a family member).⁴ Obligations to respect the wishes of patients, however, must be tempered by duties to “consider first the well-being of the patient” and to provide “appropriate care.”⁴ Finally, physicians must not discriminate against patients on such grounds as medical condition, disability or religion.⁴ Demands for ineffective treatment and demands for effective treatment that supports a controversial end must be considered separately.⁵

Demands for ineffective treatment

It is uncontroversial that clinicians have no obligation to provide a treatment that cannot work or is very unlikely to work (e.g., an antibiotic to treat a common cold, or mechanical ventilation in the presence of massive tumour deposits in the chest).^{5,6} Such treatment falls outside the bounds of “appropriate care.” But what of demands for experimental treatment (treatment with an unknown chance of success) when proven treatment exists or treatment is effective but outdated (the success rate is known to be less than that of standard treatment but greater than 1%)? Medical futility provides no basis to refuse these *prima facie* unreasonable requests from patients. Clearly, then, we require a more robust ethical concept.

“Appropriate care” is most productively understood as treatment that falls within the bounds of standard medical practice, that is, medical interventions used by at least a “respectable minority” of expert practitioners.^{7,8} Standard of care is a well-established concept rooted in the physician-patient relationship:

[The] health care professional has an obligation to allow a patient to choose from among medically acceptable treatment options . . . or to reject all options. No one, however, has an obligation to provide interventions that would, in his or her judgement, be countertherapeutic.⁹

Thus, on the basis of standard of care alone, and without appeal to medical futility, clinicians have a sound basis for refusing to provide ineffective, experimental or outdated treatment.



Demands for effective treatment that supports a controversial end

Disagreements about so-called qualitatively futile treatment are not about probabilities — they are about values. Often the question “What sort of life is worth preserving?” is at their core. Although most patients and their families would not choose to prolong life in a profoundly diminished state, some have very good reasons for doing so. For example, members of a variety of religions, including Orthodox Judaism, fundamentalist Protestantism, fundamentalist Islam and conservative Catholicism, believe that the sanctity of human life implies a religious obligation to seek out and obtain life-prolonging medical treatment.¹⁰ The concept of medical futility wrongly tries to

redefine a debate about conflicting values as a debate about medical probabilities. And given that physicians are generally the sole arbiters of medical probability, this amounts to saying to families, “Your values don’t count.”¹¹

A unilateral decision to withhold or withdraw care in such cases violates the obligation to respect the wishes and values of the patient and may constitute discrimination on grounds of physical or mental disability, or religion. Within the constraints of available resources, clinicians must try to deal with such conflicts through open communication and negotiation.

Cases at the boundary

Our analysis implicitly rests on the determination of whether a particular treatment falls within the bounds of standard medical care. A variety of factors may be used to argue for a treatment being considered appropriate: the prevalence of its use by expert clinicians (the threshold being its use by at least a “respectable minority”), licensure by Health Canada’s Therapeutic Products Directorate for a specific use, and the existence of high-quality scientific evidence of its safety and efficacy.

The gap between scientific evidence and clinical practice is closing because of initiatives in evidence-based medicine, including clinical practice guidelines. Although the correspondence between evidence and practice is currently less than perfect, high-quality evidence of the effectiveness of a treatment may be sufficient to establish that it falls within the bounds of standard care, assuming adequate resources. *A fortiori*, clear evidence that a prevalent treatment is positively harmful or ineffective establishes that the treatment is not appropriate medical care.

Law

Although the physician has a legal duty to treat a pa-

tient once the physician–patient relationship has been established,¹² this does not imply that the physician must provide any treatment demanded by the patient. Picard and Robertson,¹³ in their authoritative book *Legal Liability of Doctors and Hospitals in Canada*, conclude that there is no obligation to inform patients of or to provide them with treatment that is completely ineffective.

Nor is there a duty to provide treatment contrary to the patient’s best interests. Manitoba’s Court of Appeal recently ruled on a case involving a do-not-resuscitate (DNR) order being challenged by the parents of a 1-year-old child in a persistent vegetative state.¹⁴ The child had been savagely attacked at 3 months of age and afterward had been taken by the Child and Family Services of Central Manitoba. Justice J.A. Twaddle, upholding the lower court’s decision to grant the DNR order, commented:

[I]t is in no one’s interest to artificially maintain the life of a . . . patient who is in an irreversible vegetative state. That is unless those responsible for the patient being in that state have an interest in prolonging life to avoid criminal responsibility for the death.¹⁴

That is, the judge found that the parents were not deciding in the best interests of the child.

A case involving demand for life-prolonging treatment based on deeply rooted cultural or religious beliefs has yet to be considered by Canadian courts, and so the issue remains undecided. Defendant doctors and hospitals are likely to be confronted with a number of well-known cases in the US courts that have sided with families and supported the provision of life-sustaining treatment, but Canadian courts are not necessarily influenced by these decisions.¹⁵ The US cases of Helga Wanglie and Baby K are particularly well known. Both cases involved demands for continued life-prolonging treatments for patients in a persistent vegetative state. In the Wanglie case, the court refused an attempt to have the husband replaced as the decision-maker for his wife.^{16,17} In the Baby K case, the court ordered physicians to provide life-prolonging interventions to the child.¹⁸

In other US cases courts have sided with clinicians. In the Gilgunn case, a jury found that clinicians were not negligent for the death of a patient when they removed mechanical ventilation despite the objections of the patient’s daughter.¹⁹ Commentators have questioned whether the court would have sided against the family if the patient were still alive and the continued provision of life-sustaining care were at issue.²⁰ The decision by the Court of Appeal of Manitoba is consistent with many others in common-law jurisdictions. In a leading English case, for instance, Lord Keith noted the following:

[A] medical practitioner is under no duty to continue to treat . . . a patient where a large body of informed and responsible medical opinion is to the effect that no benefit would be conferred by continuance.²¹



Policy

Issues raised by demands for inappropriate treatment have been dealt with in a number of policy statements.²²⁻²⁶ All of these policies acknowledge the patient's right to refuse unwanted medical treatment, even life-prolonging treatment. Some of these policies assert that the physician has a right to unilaterally withhold or withdraw treatment that she or he deems futile. For example, the CMA's "Joint statement on resuscitative interventions (update 1995)" states that "[t]here is no obligation to offer a person futile or nonbeneficial treatment"; that is, the treatment "offers no reasonable hope of recovery or improvement or . . . the person is permanently unable to experience any benefit."²⁴ The policy was recently criticized on the basis that families of people in a persistent vegetative state may have morally and legally enforceable reasons to demand CPR.¹¹

At least one recent policy initiative has shifted away from attempts to define "futility" and has instead focused on the establishment of fair procedures for dealing with demands for inappropriate treatment. This initiative involves a staged approach to such conflicts currently in use in a number of hospitals in Texas.²⁷ The procedure emphasizes clear communication, negotiation and, if needed, impartial arbitration. The University of Toronto Critical Care Program and Joint Centre for Bioethics have developed a model policy on appropriate use of life-sustaining treatment (www.utoronto.ca/jcb [under "end of life"]).

Empirical studies

Decisions to withhold or withdraw life-sustaining treatment are common in modern health care.²⁸⁻³⁰ Disagreements over withdrawing life support, a kind of demand for inappropriate treatment, are relatively uncommon and many resolve over time.²⁸⁻³⁰ Demands for inappropriate treatment are nonetheless a source of substantial moral and emotional distress for health care workers and patients' families.^{31,32} Such requests and the distress they incite arise from a variety of causes, including unrealistic expectations of the family, failure of the clinician to be realistic, lack of clear explanation of the implications of continued treatment and fear of litigation.³³

How should I approach demands for inappropriate treatment in practice?

If the proposed treatment clearly falls outside the bounds of standard medical care, the physician has no obligation to offer or provide it. However, if substantial medical controversy as to the beneficial effect of the treatment exists, the law on this issue is unclear. Furthermore,

this assertion does not address the emotions surrounding a case, so a clinician should proceed with caution.

Some of the most difficult cases occur at the boundary of appropriate medical care, when it is unclear whether demanded treatment falls within the standard of care. A treatment may have little evidence to support its safety and efficacy, it may be advocated by a very small group of physicians, or new evidence may have arisen questioning established use. Because patients and their families have increased access to uncontrolled sources of medical information on the Internet, demands for treatment of this sort may increase. In such cases, the physician ought to consult with colleagues within and outside of her institution: How prevalent is the treatment? How respected are those advocating it? Is there evidence for efficacy and safety? Beyond these obvious questions, others will need to be asked by the physician: Am I competent to administer the treatment? Does its provision violate my own conscience or the mission of my institution? A negative response to these last 2 questions calls for the patient to be transferred to the care of another physician or another institution.

Misunderstandings, emotional anguish and disagreements about fundamental values often lie at the heart of cases in which seemingly inappropriate care is demanded. Therefore, the health care team should take a patient, supportive, empathic and open approach in attempting to resolve these cases. Effective communication skills are essential. The physician should ask: Why has the conflict over treatment arisen? What are the deeper issues at stake (e.g., a need for more information, denial, trust, differing values)? Such cases often also lead to conflicts among members of the health care team, and these too should be addressed in an open and constructive manner.

When disagreement among health care providers, patient and family persists, the physician should conceptualize this as a situation of conflict in which the goal is to seek a negotiated solution.³⁴ If necessary, the physician should seek the services of someone trained in conflict mediation, such as a clinical bioethicist, psychiatrist, psychologist or social worker.

If the conflict cannot be resolved through mediation, arbitration may be necessary. Consultation with a lawyer is important at this stage. Some provinces have provisions in their consent laws for arbitration through boards. For example, the Consent and Capacity Board in Ontario has the power to replace a substitute decision-maker who is not making decisions according to the patient's wishes or best interests.³⁵ As a final recourse, the courts may be appealed to by either party, but this step runs the risk of increasing both the emotional anguish of patients, family and health care providers, and the conflict among them. Ideally, the health care institution will have a policy on dealing with demands for inappropriate treatment. The



policy should describe a clear and nonarbitrary process to address such cases in the institution.²⁷

The cases

Mr. A has advanced cancer and demands cardiopulmonary resuscitation (CPR). There is good evidence that CPR is very unlikely to be effective for patients with metastatic cancer or sepsis, let alone a patient who has both; therefore, such treatment falls outside the bounds of standard care.³⁶⁻³⁹ We have said that, in general, there is no obligation to offer or provide such treatment. Should the decision to withhold CPR be communicated to the patient? We think so. First, the expectation on the part of the patient that CPR will be provided may create an obligation to disclose the fact that it will not be provided and the reasons why.¹³ Second, it furthers the end of honesty and open communication with the patient. Third, and perhaps most important, it provides the physician with the opportunity to explore the motivations for the demand. If denial is a factor, counselling may be offered. If control is an issue, the clinician should help the patient focus on the various options that exist regarding his care. Clinicians should remain open to the possibility of compassionate exceptions to withholding CPR. For example, if the patient is motivated by the wish to survive to see a relative who will arrive shortly, a time-limited order to attempt resuscitation may be written.

Mrs. B is in a persistent vegetative state, and her family demands aggressive medical treatment. The disagreement is not about the efficacy of the interventions, but whether they should be used to prolong a state of permanent unconsciousness. Health care workers should not unilaterally refuse to provide treatment in this case. Compromise should be sought through open communication and negotiation. The scarcity of resources, particularly beds in the intensive care unit, is undoubtedly an issue that must be dealt with in this case (and similar cases). An attempt at compromise may include the provision of a variety of treatments outside of the intensive care unit, perhaps including fluids, nutrition, physiotherapy, supplemental oxygen and antibiotics.

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References

- Schneiderman LJ, Jecker NS, Jonsen AR. Medical futility: its meaning and ethical implications. *Ann Intern Med* 1990;112:949-54.
- Weijer C, Elliott C. Pulling the plug on futility. *BMJ* 1995;310:683-4.
- Beauchamp TL, Childress JF. *Principles of biomedical ethics*. 4th ed. New York: Oxford University Press; 1994.
- Canadian Medical Association. *Code of ethics*. Ottawa: The Association; 1996.
- Truog RD, Brett AS, Frader J. The problem with futility. *N Engl J Med*

- 1992;326:1560-4.
6. *Of life and death. Report of the Special Senate Committee on Euthanasia and Assisted Suicide*. Ottawa: Supply and Services Canada; 1995. Cat no YC2-351/1-OIE.
7. Freedman B, McGill/Boston Research Group. Nonvalidated therapies and HIV disease. *Hastings Cent Rep* 1989;19(3):14-20.
8. Brett AS, McCullough LB. When patients request specific interventions: defining the limits of the physician's obligation. *N Engl J Med* 1986;315:1347-51.
9. US President's Commission for the Study of Ethical Problems in Medicine and Biomedical Research. *Deciding to forgo life-sustaining treatment: a report on the ethical, medical and legal issues in treatment decisions*. Washington: The Commission; 1983.
10. Post SG, Baby K: medical futility and the free exercise of religion. *J Law Med Ethics* 1995;23:20-6.
11. Weijer C. Cardiopulmonary resuscitation for patients in a persistent vegetative state: Futile or acceptable? *CMAJ* 1998;158(4):491-3.
12. Picard EI, Robertson GB. *Legal liability of doctors and hospitals in Canada*. 3rd ed. Scarborough (ON): Carswell; 1996. p. 235-69.
13. Picard EI, Robertson GB. *Legal liability of doctors and hospitals in Canada*. 3rd ed. Scarborough (ON): Carswell; 1996. p. 264-5.
14. *Child and Family Services of Central Manitoba v. Lavallee* (14 Nov 1997), (Man. C.A.) [unreported].
15. Daar JF. Medical futility and implications for physician autonomy. *Am J Law Med* 1995;21:221-40.
16. Angell M. The case of Helga Wanglie: a new kind of "right to die" case. *N Engl J Med* 1991;325:511-2.
17. Capron AM. In re Helga Wanglie. *Hastings Cent Rep* 1991;21(5):26-8.
18. Annas GJ. Asking the courts to set the standard of emergency care — the case of Baby K. *N Engl J Med* 1994;330:1542-5.
19. *Gilgum v. Massachusetts General Hospital*. No 92-4820 (Mass. Sup. Ct. Civ. Action Suffolk Co. 22 Apr 1995).
20. Prip W, Moretti A. Medical futility: a legal perspective. In: Zucker MB, Zucker HD, editors. *Medical futility and the evaluation of life-sustaining interventions*. Cambridge (MA): Cambridge University Press; 1997. p. 136-54.
21. *Airedale N.H.S. Trust v. Bland* [1993] 1 All E.R. 821 at 861.
22. American Thoracic Society Bioethics Task Force. Withholding and withdrawing life-sustaining therapy. *Am Rev Respir Dis* 1991;144:726-31.
23. Society of Critical Care Medicine Ethics Committee. Consensus statement on the triage of critically ill patients. *JAMA* 1994;271:1200-3.
24. Joint statement on resuscitative interventions (update 1995). *CMAJ* 1995;153(11):1652A-C.
25. Murphy DJ, Barbour E. GUIDe (Guidelines for the Use of Intensive care in Denver): a community effort to define futile and inappropriate care. *New Horiz* 1994;2:326-30.
26. Task Force on Ethics of the Society of Critical Care Medicine. Consensus on the ethics of forgoing life-sustaining treatments in the critically ill. *Crit Care Med* 1990;18:1435-9.
27. Halevy A, Brody BA. A multi-institution collaborative policy on medical futility. *JAMA* 1996;276:571-4.
28. Wood GG, Martin E. Withholding and withdrawing life-sustaining therapy in a Canadian intensive care unit. *Can J Anaesth* 1995;42:186-91.
29. Prendergast TJ, Luce JM. Increasing incidence of withholding and withdrawal of life support from the critically ill. *Am J Respir Crit Care Med* 1997;155:15-20.
30. Corley MC. Moral distress of critical care nurses. *Am J Crit Care* 1995;4:280-5.
31. Solomon MZ. How physicians talk about futility: making words mean too many things. *J Clin Ethics* 1993;21:231-7.
32. Simmonds A. Decision-making by default: experiences of physicians and nurses with dying patients in intensive care. *Humane Health Care Int* 1996;12:168-72.
33. McCrary SV, Swanson JW, Younger SJ, Perkins HS, Winslade WJ. Physicians' quantitative assessments of medical futility. *J Clin Ethics* 1994;5:100-5.
34. Fisher R, Ury W. *Getting to yes: negotiating agreement without giving in*. New York: Penguin; 1991.
35. *Health Care Consent Act*, SO 1996, c 2, sch A.
36. Bedell SE, Delbanco TL, Cook EF, Epstein FH. Survival after cardiopulmonary resuscitation in the hospital. *N Engl J Med* 1983;309:569-76.
37. Warner SC, Sharma TK. Outcome of cardiopulmonary resuscitation and predictors of resuscitation status in an urban community teaching hospital. *Resuscitation* 1994;27:13-21.
38. Ballew KA, Philbrick JT, Caven DE, Schorling JB. Predictors of survival following in-hospital cardiopulmonary resuscitation. A moving target. *Arch Intern Med* 1994;154:2426-32.
39. Schultz SC, Cullinane DC, Pasquale MD, Magnant C, Evans SR. Predicting in-hospital mortality during cardiopulmonary resuscitation. *Resuscitation* 1996;33:13-7.

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