

Hospital policy on appropriate use of life-sustaining treatment

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Objective: To describe the issues faced, and how they were addressed, by the University of Toronto Critical Care Medicine Program/Joint Centre for Bioethics Task Force on Appropriate Use of Life-Sustaining Treatment. The clinical problem addressed by the Task Force was dealing with requests by patients or substitute decision makers for life-sustaining treatment that their healthcare providers believe is inappropriate.

Design: Case study.

Setting: The University of Toronto Joint Centre for Bioethics/Critical Care Medicine Program Task Force on Appropriate Use of Life-Sustaining Treatment.

Participants: The 24-member Task Force included physician and nursing leaders from five critical care units, bioethicists, a legal scholar, a health administration expert, a social worker, and a hospital public relations professional.

Interventions: None.

Measurements and Main Results: Our specific lessons learned include a) a policy focus on process; b) use of a negotiation and mediation model, rather than a hospital ethics committee model, for this process; and c) the policy development process is itself a negotiation, so we recommend equal involvement of interested groups including patients, families, and the public.

Conclusions: This article describes the key issues faced by the Task Force while developing its policy. It will provide a useful starting point for other groups developing policy on appropriate use of life-sustaining treatment. (Crit Care Med 2001; 29:187–191)

KEY WORDS: ethics; end of life; futility; conflict resolution

The problem of “appropriate use of life-sustaining treatment,” commonly known as “futility,” arises when patients or their substitute decision makers request treatment their healthcare providers believe is inappropriate. Such requests generate distress for patients,

families, and critical care staff. For healthcare workers, the problem can lead to frustration, tension, and caregiver burnout as well as conflict within the team. For families, it can lead to anxiety, anger, loss of trust, and complications in the bereavement process.

When patients or substitute decision makers refuse treatment, the ethical and legal obligations of healthcare providers are clear, with the exception of some circumstances involving young children. A competent refusal of treatment must be respected based on the ethical principle of respect for persons and the legal doctrine of self-determination and informed consent. However, there is no widely accepted ethical and legal framework underlying the opposite situation when patients or substitute decision makers request treatment that healthcare providers believe is inappropriate. Because of the lack of a widely accepted ethical or legal framework, policy development has an important role in guiding practice (1, 2).

In the early 1990s, the Society of Critical Care Medicine, American College of Chest Physicians, and American Thoracic Society developed general guidelines on

foregoing life-sustaining treatment (3–5). More recently, the Society of Critical Care Medicine, American Medical Association, networks of hospitals, and various commentators have specifically developed policies regarding futility (6–10). These statements emphasize the process of decision-making, including obtaining second opinions and transferring the patient, if possible. They are based on an “ethics committee model,” where the hospital’s ethics committee plays a key decision-making role. Moreover, although these statements describe policy principles, they do not describe the actual process of policy development.

This article describes the issues we faced and the lessons learned while developing a hospital policy on appropriate use of life-sustaining treatment in Toronto. It also highlights important aspects of our approach that differ from recent approaches to the same issue. Although we also focused on process, we did not adopt an “ethics committee model.” Instead, we developed a model based on negotiation and mediation. We also recommend equal involvement of interested groups including patients, families, and the pub-

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lic. By sharing our experience, we hope to provide a useful starting point for other groups developing hospital policy regarding appropriate use of life-sustaining treatment.

THE UNIVERSITY OF TORONTO TASK FORCE

In 1996, we formed a University of Toronto Joint Centre for Bioethics/Critical Care Program Task Force on Appropriate Use of Life-Sustaining Treatment, which encompasses five critical care units (one of which is a pediatric unit) in eight teaching hospitals fully affiliated with the University. Chaired by the Directors of the Joint Centre for Bioethics and Critical Care Medicine Program, the Task Force included physician and nursing leaders from all the critical care units, bioethicists, a legal scholar, a health administration expert, a social worker, and a hospital public relations professional. The Task Force was connected by an email listserv to allow discussions between meetings. We met six times in 2 yrs and produced three major revisions of the model policy that were widely circulated for feedback. These were based, in part, on feedback we received when we consulted with critical care teams, clinical ethics committees, and consumer/family advisory committees. The Task Force unanimously endorsed its model policy (Appendix) on June 17, 1998.

Once approved by the Task Force, our model policy was posted on the University of Toronto Joint Centre for Bioethics website, making it available for public review (www.utoronto.ca/jcb/Resources/ccm_policy.htm).

Our model policy becomes operative only once adopted or adapted through usual hospital policy-making process. This permits each hospital to tailor the policy to suit its local culture.

FROM CLINICAL CRITERIA TO PROCESS

The initial inclination of the Task Force was to develop clinical criteria that could be used to determine whether treatment was appropriate. The Task Force accepted the principle that health-care providers are not obliged to provide treatments that lie outside the standard of care (11). In the initial draft of our policy, written by intensive care physicians, we attempted to define clinical cri-

teria that could be used to withhold intensive care. Examples of the criteria included imminent death, lethal condition, and severe, irreversible condition.

However, consumer and family groups who were consulted indicated that the first draft of the Task Force policy was "frightening, paternalistic, and biased in favor of health providers with little regard for the rights of patients and families."

Task Force members also made two arguments against the use of clinical criteria. First, by limiting discussion and communication, clinical criteria would not diminish—and could in fact increase—the conflict between patients/families and healthcare workers that is commonly at the heart of disputes about life-sustaining treatment.

Second, clinical criteria may be discriminatory in certain circumstances (12, 13). For example, patients with severe Alzheimer's disease or persistent vegetative state, although enormously impaired, have the same legal and political rights as any other patient. To deny these patients treatment because of their disability discriminates against them. Similarly, patients and families occasionally request treatment on the basis of cultural or religious beliefs; denial of such requests without appropriate consideration of these factors can also be discriminatory.

Because of these reactions and arguments, the clinical criteria do not serve as the basis of decision-making in our policy. Instead, they provide a consensus view of the goals of critical care (Appendix, Section E) and serve as a background to the policy process by elaborating on the principle of standard of care (Appendix, Section C, principle 2). The policy is based on a process involving the following steps that guide decision-making: interprofessional team consensus; communication; negotiation; consultation; second opinion; trial of therapy; patient transfer; mediation; arbitration/adjudication; notice of intention to withdraw/withhold life-sustaining treatment; and withdrawing/withholding treatment (Appendix, Section D and Table 1).

UNIQUE ELEMENTS OF OUR PROCESS

Our policy differs from other procedurally oriented policies (6–10) in one major way. Previous policies are based on an "ethics committee model," wherein the hospital ethics committee adjudicates

Any group that addresses appropriate use of life-sustaining treatment will encounter issues similar to those we addressed.

the disagreement about treatment. We recognized that hospital ethics committees rarely have the necessary authority or expertise, and our policy does not rely on them to adjudicate claims of appropriateness. Our policy is instead based on a negotiation and mediation model.

The reliance on mediation and negotiation manifests in six specific ways. First, our policy explicitly recognizes that conflict can arise within the healthcare team. It therefore requires team consensus as a necessary first step (Table 1, step 1). Second, it contains negotiation as an early step (Table 1, step 3). Third, if negotiation between the healthcare provider and patient or family breaks down, our policy calls for mediation (Table 1, step 8). Fourth, if mediation fails, our policy calls for arbitration (Table 1, step 9). Fifth, consistent with the recommendation of the Society of Critical Care Medicine Ethics Committee (9), our policy provides an explicit opportunity for patients or substitute decision makers to challenge the process in court (Table 1, step 10). Finally, our policy recognizes that the healthcare team and hospital need to ensure that the patient and family are treated fairly during steps in the process, such as obtaining a second opinion, choosing another provider, and legal advice (Table 1, steps 5, 7, and 10).

The final, albeit controversial, step in our process is the withdrawal of treatment despite the objection of the patient and family. This would only occur, however, after patients and families have had the opportunity to address the dispute in court. This step was added at the insistence of intensive care providers who felt that even if family members were opposed to withdrawal, there were times when treatment withdrawal should proceed. We do not know how well this step will work from a legal or institutional perspective. We recommended that individual hospitals adopting the model pol-

Table 1. Process of decision making

1. Interprofessional team consensus—The healthcare team should reach consensus regarding the range of appropriate treatment.
2. Communication—In collaboration with other members of the healthcare team, the most responsible physician should:
 - a) as early as possible, discuss with patients, while capable, their prognosis and wishes for treatment
 - b) explore why the patient or substitute decision maker wishes treatment to be continued, and address these issues directly
 - c) discuss with the patient and/or substitute decision maker the rationale for withholding or withdrawing life-support treatment
 - d) describe palliative care measures that emphasize patient comfort and dignity
 - e) offer hospital resources such as social work, chaplaincy, or bioethics to assist the patient/family with their psychosocial, cultural, spiritual, and informational needs
 - f) document pertinent details of this communication in the patient's health record
3. Negotiation—The most responsible physician or other designated members of the healthcare team should attempt to negotiate a plan of treatment that is acceptable to both the patient/substitute decision-maker and the healthcare providers who are actively involved in the care of the patient.
4. Intensive care consultation—If intensive care admission may be required, a consultation from an intensive care physician should be obtained as early as possible.
5. Second opinion—The patient or substitute decision-maker should be given an opportunity to request a second opinion and should be assisted by the healthcare team to obtain one.
6. Trial of therapy—A time-limited trial of therapy may result from the negotiation described in step 3.
7. Patient transfer—The patient or substitute decision-maker should be given an opportunity to identify another provider willing to assume care of the patient and should be assisted by healthcare team to do so.
8. Mediation—A person designated by the hospital for this purpose should meet with the patient/substitute decision maker and healthcare team to attempt to mediate the disagreement.
9. Arbitration/adjudication—If mediation fails, the hospital lawyer should be consulted regarding the appropriateness of an appeal to the Consent and Capacity Board (under section 37 of the *Health Care Consent Act*), arbitration, or court proceedings.
10. Notice of intention to withhold or withdraw life-sustaining treatment—If the healthcare team intends to withhold or withdraw the disputed life-sustaining treatment, the patient or substitute decision maker should be informed, given an opportunity to challenge this decision in court, and assisted by the hospital to do so.
11. Withholding/withdrawal of life-sustaining treatment—If all the procedures in this policy have been followed, the healthcare provider may withhold or withdraw the disputed life-sustaining treatment including intensive care.

icy should explicitly consider whether this step should be included, and we recognize that the policy can be adopted with or without it.

PARTICIPATION IN POLICY DEVELOPMENT

Our Task Force consisted of three main sectors: critical care, clinical ethics, and the community. Critical care workers are obvious stakeholders in the policy process. We involved medical and nursing leaders from each of the participating hospitals' critical care units. This involvement was essential for their acceptance and for the adoption of the final policy. Critical care workers not on the Task Force were consulted about drafts of the policy.

We also included clinical ethics committee members in the process. The bioethicists or ethics committee chairs of four hospitals were represented on the Task Force. Clinical ethics committees of the participating hospitals were consulted about drafts of the policy. To be implemented, the policy must be adopted at each hospital through the clinical ethics committee and the normal policy process of the hospital.

Finally, the importance of community involvement in policy development has been well recognized (14). Our Task Force included a hospital public relations

professional, several of the clinical ethics committees we consulted had community members, and we presented drafts of the model policy to the consumer/family advisory committee of one of the hospitals. The community input we received was extremely valuable, but unfortunately our approach limited this kind of input. In future policy development, we recommend earlier involvement of the community or inclusion of community members in policy-making bodies such as our Task Force. This, of course, raises the problem of how these members would be selected and who they would represent. Involvement of patients and families who have been involved in conflict over life-sustaining treatment would be particularly useful to ensure that their concerns and experiences are addressed in policy documents. Despite the practical difficulties of legitimate representation, the policy development process itself represented a negotiation between these different groups, and they should all be represented equally during the policy development process.

CONCLUSIONS

Any group that addresses appropriate use of life-sustaining treatment will encounter issues similar to those we addressed. Our specific lessons learned in-

clude the following: a) a policy focus on process; b) use of a negotiation and mediation model, rather than a hospital ethics committee model, for this process; and c) the policy development process is itself a negotiation, so we recommend equal involvement of interested groups including patients, families, and the public. We hope these lessons will assist other groups in building on our experiences and in developing policies that yield a favorable result for all parties involved in the decision-making process.

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APPENDIX: MODEL POLICY ON APPROPRIATE USE OF LIFE-SUSTAINING TREATMENT¹

A. Preamble

Health care providers have an ethical obligation to provide quality end of life care. This includes appropriate palliative care, and helping patients and families make decisions regarding life-sustaining treatment. The health care team values the provision of compassionate care for dying patients. These important issues are addressed in the companion policy on Quality of End of Life Care.

Infrequently, a patient or the substitute decision maker of an incapable patient requests treatment be initiated or continued that health care providers actively involved in the care of the patient believe is inappropriate. This situation causes distress for patients, families and health providers. There is no available framework to mediate this conflict. Such a framework could help in these situations by providing a fair process for decision-making.

B. Purpose

The purpose of this policy is to provide a framework for resolving conflicts in situations of disagreement about appropriate use of life-sustaining treatment, including intensive care admission.

The focus on this policy is on situations where a patient or the substitute decision maker of an incapable patient requests treatment be initiated or continued that health care providers actively involved in the care of the patient believe is inappropriate. There is no clearly established ethical and legal framework for this situation. By contrast, there are clearly established ethical and legal principles in Ontario for situations where patients/substitute decision-makers decline treatment proposed by health care providers. In this latter situation, the legal principles in the *Health Care Consent Act* will supersede this policy. This policy may also be useful in resolving conflicts among family members or among different members of the health care team.

The focus on this policy is on intensive care, defined as advanced and highly spe-

cialized care provided to medical or surgical patients whose conditions are life-threatening and require comprehensive care and constant monitoring usually administered in specially equipped units of a health care facility (National Library of Medicine, 1992). However, it is impossible to separate intensive care from other life-sustaining treatments provided in the hospital. For instance, the provision of cardiopulmonary resuscitation anywhere in the hospital, if successful, will likely lead to consideration of admission to the intensive care unit. Therefore, this policy will apply throughout the hospital.

C. Principles

1. Patients have a right to receive quality end of life care including appropriate palliative care and help making decisions regarding life-sustaining treatment. This principle is contained in the companion policy on quality end of life care.
2. Patients have a right to receive life-sustaining treatments that meet the standard of care, defined as the care provided by a reasonable health care provider who possesses and exercises the skill, knowledge and judgment of the normal prudent practitioner of his or her special group (Picard and Robertson, *Legal Liability of Doctors and Hospitals in Canada*, 1996; Weijer, Singer, Dickens, Workman, *CMAJ* 1998; 159: 817–21.). However, health care providers are not obliged to provide treatments that lie outside the standard of care. The consensus of health care providers regarding the standard of care with respect to appropriate use of life-sustaining treatment is described in section E of this policy.
3. Patients and substitute decision-makers have a right to a fair process when there is disagreement between them and health care providers about the appropriateness of life-sustaining treatment. The process to be followed is described in section D of this policy.

D. Process for Decision-Making

This section describes the steps that should be followed when there is disagreement between patients/substitute decision makers and health care providers about the appropriateness of initiating or continuing life-sustaining treatment including intensive care. This

process should commence as soon as the health care provider becomes aware of potential for future conflict. Although the steps are presented in the order they will most likely occur, the order of steps 1–8 may be varied and several steps may occur simultaneously. The patient's condition may not permit completion of this process.

1. Interprofessional team consensus—The health care team should reach consensus regarding the range of appropriate treatment.
2. Communication—In collaboration with other members of the health care team, the most responsible physician should:
 - a) as early as possible, discuss with patients while capable, their prognosis and wishes for treatment
 - b) explore why the patient or substitute decision maker wishes treatment to be continued and address these issues directly
 - c) discuss with the patient and/or substitute decision maker the rationale for withholding or withdrawing life-support treatment
 - d) describe palliative care measures which emphasize patient comfort and dignity
 - e) offer hospital resources such as social work, chaplaincy, or bioethics to assist the patient/family with their psychosocial, cultural, spiritual, and informational needs
 - f) document pertinent details of this communication in the patient's health record
3. Negotiation—The most responsible physician or other designated member of the health care team should attempt to negotiate a plan of treatment that is acceptable to both the patient/substitute decision-maker and the health care providers actively involved in the care of the patient.
4. Intensive care consultation—If intensive care admission may be required, a consultation from an intensive care physician should be obtained as early as possible.
5. Second opinion—The patient or substitute decision-maker should be given an opportunity to request a second opinion, and assisted by the health care team to obtain one.
6. Trial of Therapy—A time-limited trial of therapy may result from the negotiation described in step 3 above.
7. Patient Transfer—The patient or substitute decision-maker should be

¹ Posted on the web at www.utoronto.ca/jcb/Resources/ccm_policy.htm

- given an opportunity to identify another provider willing to assume care of the patient, and assisted by health care team to do so.
8. Mediation—A person designated by the hospital for this purpose should meet with the patient/substitute decision maker and health care team to attempt to mediate the disagreement.
 9. Arbitration/adjudication—If mediation fails, the hospital's lawyer should be consulted regarding the appropriateness of an appeal to the Consent and Capacity Board (under section 37 of the *Health Care Consent Act*), arbitration, or court proceedings.
 10. Notice of intention to withhold or withdraw life-sustaining treatment—If the health care team intends to withhold or withdraw the disputed life sustaining treatment, the patient or substitute decision-maker should be informed, given an opportunity to challenge this decision in court, and assisted by the hospital to do so.
 11. Withholding/withdrawal of life-sustaining treatment—If all the procedures in this policy have been followed, the health care provider may withhold or withdraw the disputed life-sustaining treatment including intensive care.

E. Provider Consensus Regarding Standard of Care

In developing this policy, the following consensus emerged among intensive care providers representing all intensive care units in the University of Toronto Critical Care Medicine Program regarding the standard of care with respect to appropriate use of life sustaining treatment.

1. The goal of intensive care is to prevent unnecessary suffering and premature death by treating *reversible* illnesses for an appropriate period of time.
2. Imminent death: A patient facing imminent death has an acute illness whose reversal or cure would be unprecedented and will certainly lead to death during the present hospitalization within hours or days, without a period of intervening improvement. "Life-sustaining treatments" or intensive care

cannot achieve their intended effect, and lie outside the standard of care.

3. Lethal condition: A patient with a lethal condition has a progressive, unrelenting terminal disease incompatible with survival longer than 3–6 months. Intensive care should not be provided for the underlying condition, since this is inconsistent with the goal of intensive care (see above). Life-sustaining treatment including intensive care should be provided to treat superimposed, reversible illness only with clearly defined and achievable goals in mind. For instance, life-sustaining treatments may be used to permit provision of an experimental treatment which may cure or alleviate the underlying condition, or to help the patient achieve a personal goal (e.g., seeing a loved one for the last time who is flying in from afar). These goals should be mutually agreeable to the patient/substitute decision-maker and health care providers. Section D of this policy provides a process for resolution of disagreement.
4. Severe, irreversible condition: A patient has a severe and irreversible condition impairing cognition or consciousness but death may not occur for many months. Examples of such conditions include persistent vegetative state and severe dementia. Intensive care should not be provided for the underlying condition, since this is inconsistent with the goal of intensive care (see above). Life-sustaining treatment including intensive care should be provided to treat superimposed, reversible illness only with clearly defined and achievable goals in mind. For instance, life-sustaining treatments may be used to help the patient achieve a personal goal (e.g., seeing a loved one for the last time who is flying in from afar). These goals should be mutually agreeable to the patient/substitute decision-maker and health care providers. Section D of this policy provides a process for resolution of disagreement.

REFERENCES

1. Tomlinson T, Czlonka D: Futility and hospital policy. *Hastings Center Report* 1995; 25: 28–35
2. Johnson SH, Gibbons V, Goldner JA, et al: Legal and institutional policy responses to medical futility. *J Health Hosp Law* 1997; 30:21–36

3. Task Force on Ethics of the Society of Critical Care Medicine. Consensus report on the ethics of foregoing life-sustaining treatments in the critically ill. *Crit Care Med* 1990; 18: 1435–1439
4. American College of Chest Physicians/Society of Critical Care Medicine Consensus Panel: Ethical and moral guidelines for the initiation, continuation, and withdrawal of intensive care. *Chest* 1990; 97:949–958
5. Withholding and withdrawing life-sustaining therapy. This Official Statement of the American Thoracic Society was adopted by the ATS Board of Directors, March 1991. *Am Rev Respir Dis* 1991; 144:726–731
6. Halevy A, Brody BA: A multi-institution collaborative policy on medical futility. *JAMA* 1996; 276:571–574
7. Council on Ethical and Judicial Affairs, American Medical Association: Medical Futility in End-of-Life Care: Report of the Council on Ethical and Judicial Affairs. *JAMA* 1999; 281:937–941
8. Bay Area Network of Ethics Committees (BANEC) Nonbeneficial Treatment Working Group: Nonbeneficial or futile medical treatment: conflict resolution guidelines for the San Francisco Bay Area. *West J Med* 1999; 170:287–290
9. The Ethics Committee of the Society of Critical Care Medicine: Consensus statement of the Society of Critical Care Medicine's Ethics Committee regarding futile and other possibly inadvisable treatments. *Crit Care Med* 1997; 25:887–891
10. Canadian Healthcare Association, Canadian Medical Association, Canadian Nurses Association, and Catholic Health Association of Canada: Joint Statement on Preventing and Resolving Ethical Conflicts Involving Health Care Providers and Persons Receiving Care. <http://www.cma.ca/inside/policybase/1998/12-04.htm>
11. Weijer CE, Singer PA, Workman SR, et al: Bioethics for clinicians 16: Dealing with demands for "inappropriate" treatment: Medical futility and other approaches. *Can Med Assoc J* 1998; 159:817–821
12. Wachter RM, Luce JM, Hearst N, et al: Decisions about resuscitation: inequities among patients with different diseases but similar prognoses. *Ann Intern Med* 1989; 111: 525–532
13. Weijer C: Cardiopulmonary resuscitation for patients in persistent vegetative state: Futile or acceptable? *Can Med Assoc J* 1998; 158: 491–493
14. Spielman B: Community futility policies: the illusion of consensus? *In: Medical Futility and the Evaluation of Life-Sustaining Interventions*. Zucker MB, Zucker HD (Eds). Cambridge, Cambridge University Press, 1997, pp 168–178