

CLINICAL DECISIONS

INTERACTIVE AT NEJM.ORG

Care of an Unresponsive Patient with a Poor Prognosis

Arthur S. Slutsky, M.D., and Leonard D. Hudson, M.D.

This interactive feature addresses the diagnosis or management of a clinical case as informed by research published in this issue of the Journal. A case vignette is followed by specific clinical options, none of which can be considered either correct or incorrect. In short essays, experts in the field then argue for each of the options. In the online version of this feature, available at NEJM.org, readers can participate in forming community opinion by choosing one of the options and, if they like, providing their reasons.

CASE VIGNETTE

A 56-year-old homeless man was found having a seizure and was transported to the hospital. He was found to have a subarachnoid hemorrhage and acute hydrocephalus. He underwent intubation, and mechanical ventilation was started. A shunt was placed to relieve the hydrocephalus; cerebral angiography revealed a ruptured aneurysm of the anterior communicating cerebral artery and an unruptured aneurysm of the posterior cerebral artery. The patient had a score of 5 on the Glasgow Coma Scale. The neurosurgeon stated that without clipping of the aneurysm there was a 50% chance of recurrence of bleeding in the next 6 months, should the patient survive. However, the aneurysm was in a location that would be difficult to reach surgically, and the risk associated with the procedure would be high. The patient's condition did not improve over the next 3 days, and both the neurologist and the neurosurgeon opined that he had a chance of approximately 80 to 90% of being in a long-term persistent vegetative state and a chance of 5 to 10% of any recovery. His prognosis, at best, was to have a severe disability that would leave him dependent on care by others.

The patient had not been in contact with his family for several years. He had a son who, under the law of the state, was the legal next of kin for making medical decisions if the patient was unable to do so himself. The patient also had a brother and a mother; all three relatives lived 1500 miles away. They were contacted and told of the patient's situation. They were all in agreement that the patient would not want to live in a state in which he would be largely dependent on others for daily care and would have severely impaired cognition. However, the son described the patient

as "a fighter" who would want aggressive care until the prognosis was much more certain.

Supportive care, including mechanical ventilation, was continued for the next 3 weeks, without any clinically significant change in the patient's neurologic state. During this time it was discovered that the patient had a very close relationship with a counselor at a homeless shelter with whom he had talked at least every couple of weeks. The counselor came to see the patient and related that the patient had told him that he wished to avoid hospitals and that "when his time came" he wanted no aggressive medical care.

Placement of a percutaneous endogastric tube for feeding was attempted but was unsuccessful. Upper endoscopy was performed and revealed a large duodenal ulcer with fungating edges, strongly suggestive of cancer and partially obstructing the gastric outlet. Biopsy results were inconclusive, but the endoscopist believed that the lesion was probably malignant and that the indeterminate biopsy results were due to sampling error.

Given the lack of improvement in the patient's neurologic state, the extremely poor prognosis for any meaningful recovery of cognitive function, and the high probability of cancer, the care team strongly believed that all aggressive and supportive measures should be discontinued and the goals of care changed to those of providing comfort. The brother and mother, who had been quick to respond to queries from the beginning, agreed with the shift to comfort care. However, the son, who had become increasingly difficult to contact and rarely returned telephone calls from the caregivers, disagreed. He had hardened his position, wanting full aggressive-care measures to be taken, including clipping of the aneurysm.



Choose an option and comment on your choice at NEJM.org

Which one of the following care options, any of which could be considered correct, would you find most appropriate for this patient? Base your choice on the published literature, your past experience, recent guidelines, and other sources of information, as appropriate.

1. Continue aggressive care and pursue an ethics consultation with the patient's surrogate.

As requested by the patient's son, continue all aggressive care, including mechanical ventilation, feeding, and attempted cardiopulmonary resuscitation should the patient have a cardiac arrest. Given the risks associated with clipping of the aneurysm and the uncertainty regarding the son's rationale for his requests, pursue attempts to involve the son through a personal visit or a formal ethics consultation (or both).

2. Write a do-not-resuscitate order and transfer the patient to a skilled nursing facility.

After appropriate consultations, write an order of "Do not attempt resuscitation in the case of cardiac arrest," on the rationale of attempted resuscitation being futile, and transfer the patient to a skilled nursing facility that accepts patients un-

dergoing mechanical ventilation. Inform the son and other relatives of this decision.

3. Withdraw life support on the basis of substituted judgment.

Withdraw all life support, including mechanical ventilation and feeding, accepting the brother's, mother's, and counselor's statements as evidence for a substituted judgment on the part of the patient that he would not wish for such care in his current condition.

To aid in your decision making, each of these approaches to care is defended by an expert in bioethics in the following short essays. Given your knowledge of the patient's condition and the points made by the experts, which treatment approach would you choose? Make your choice on our Web site (NEJM.org).

No potential conflict of interest relevant to this article was reported.

From the Keenan Research Center at the Li Ka Shing Knowledge Institute of St. Michael's Hospital, Interdepartmental Division of Critical Care Medicine, and Department of Medicine, University of Toronto, Toronto (A.S.S.); and the Division of Pulmonary and Critical Care Medicine, Department of Medicine, University of Washington, Seattle (L.D.H.).

TREATMENT OPTION 1

Continue Aggressive Care and Pursue an Ethics Consultation with the Patient's Surrogate

Nancy N. Dubler, LL.B.

Clinical ethics consultation entails expert discussion, facilitation, and mediation. Once a dispute has escalated, it is best managed through bioethics mediation, which levels the playing field, focuses the principal parties' attention on interests rather than positions, distinguishes medical facts from expert opinion, and highlights differences in values that impede consensus.¹

Confrontations frequently occur when a patient's legally empowered surrogate makes choices that oppose the recommendations of the care team. But often, care providers — despite strong

feelings — offer choices as if they were medically and ethically in equipoise, treating patients' surrogates, who are generally family members, as junior consultants who must weigh, judge, and choose among equal options.

Misguided legal teaching² that informed consent requires professional neutrality and uncertainty regarding outcome, even when a patient's prognosis is dismal, often causes the care team to withhold from the surrogate its own recommendations and justifications for a particular course of care. When the surrogate chooses the "wrong" course and thereby requires the team to act in a manner it considers unethical, care providers despair. The care providers describe the chosen approach as futile or unreasonable and attempt to convince the surrogate to choose differently in deference to their ethical beliefs.^{3,4}

However, in reality, most patients' family mem-

bers are not medical professionals; if the patient in the case vignette died, his surrogate would become just another grieving son. The team owes the surrogate and the rest of the family emotional support and informed, compassionate — not dispassionate — guidance⁵; its ethical obligations to the patient himself may be purely palliative. The surrogate in the case vignette, the son, is increasingly elusive, ignoring professionals who are attempting to set ethical limits on end-of-life care and to respond to societal and institutional imperatives to shorten lengths of stay and limit costs.

Clinical ethics mediation is most effectively accomplished face-to-face. In this case, the patient's mother and brother may have ethically relevant information and perspectives that could influence the outcome; their presence might change the dynamic of the discussion. An interactive video format might be the best way to hold a meeting involving family members and providers while keeping costs low.

The obligations of a clinical ethics mediator are to convene the entire medical team; to prevent consideration of false choices; to maintain transparency; to frame, reframe, summarize, and restate what is said until all participants have a common understanding; to maximize options, including the use of time-limited interventions, after which the patient's status would be reviewed for improvement; and to help the team shoulder responsibility for difficult decisions without disempowering the surrogate. The consultant must remember that many people have difficulty understanding statistics and probabilities and their application to a particular case, so the consultant should help them work through these abstract concepts. Finally, members of minority groups may be well aware of data on health care disparities among racial or ethnic groups and may be particularly sensitive to attempts to withhold care.

Defining what is in a patient's best interest is a value-laden proposition in the post-Terri Schiavo United States.⁶ If the son remains adamant, the conversation should continue. Ultimately, he is the legal decider and must be brought into a shared solution, have his decision implemented, or be challenged in court.

No potential conflict of interest relevant to this article was reported.

From the Montefiore–Einstein Center for Bioethics, Montefiore Medical Center, Bronx, NY.

TREATMENT OPTION 2

Write a Do-Not-Resuscitate Order and Transfer the Patient to a Skilled Nursing Facility

Charles Weijer, M.D., Ph.D.

The case described in the vignette is best handled by reducing uncertainty where possible, defining appropriate treatment alternatives, and promoting family consensus. First, the diagnostic uncertainty regarding the duodenal mass must be addressed. Endoscopy and biopsy should be repeated, and abdominal computed tomography should be performed. If the diagnosis of adenocarcinoma is confirmed, the extent of the cancer's spread should be documented. I will assume here that the findings of these tests worsen the patient's already poor prognosis.

Next, medically appropriate treatment options for the patient must be identified and justified. In light of the patient's very poor prognosis, the son's demands for "full aggressive-care measures to be taken, including clipping of the aneurysm" are inappropriate. The concept of medical futility has been proposed as a means for overriding patients' or families' demands for inappropriate care. Unfortunately, no consensus has emerged on the definition of medical futility, and the courts have not recognized physicians' right to act on it.⁷ Firmer ground may be provided by the ethical and legal notion of the medical standard of care — that is, the range of treatments endorsed by at least a respectable minority of expert practitioners.⁸ This approach presumes that the "health care professional has an obligation to allow a patient [or surrogate] to choose from among medically acceptable treatment options . . . or to reject all options."⁹ Medically acceptable treatment options are those that, given available medical evidence and expert clinical opinion, are consistent with the physician's duty to provide competent care to the patient.

How should the team proceed in this case? Patients who have a cardiac arrest after initial or recurrent aneurysmal subarachnoid hemorrhage may be resuscitated successfully, but they have a significantly increased risk of death.¹⁰ Survival rates among patients in the intensive care unit (ICU) who have cancer and who undergo cardio-

pulmonary resuscitation are very low (2.2%).¹¹ Accordingly, resuscitation in the event of a cardiac arrest is very unlikely to be successful in this patient, and a do-not-resuscitate order should be written. In addition, the neurosurgeon should reassess the patient's candidacy for surgery. Since the initial assessment that surgery posed a high risk was made, the patient's prognosis has worsened substantially. It is unlikely, therefore, that performance of surgery would be consistent with the standard of care. If the patient is no longer a candidate for resuscitation or neurosurgery, the ICU is not the best setting for his care, and he ought to be transferred to a skilled nursing facility that accepts ventilator-dependent patients. Appropriate care includes ensuring the patient's comfort and preventing complications, which can be accomplished better — and less expensively — in a long-term care facility.

Discussions between the health care team and family members should focus on options consistent with competent medical care, all of which can be implemented outside the ICU. In this case, the options include the importance of comfort measures, the prevention and treatment of complications, and the identification of attainable treatment goals. Although “full aggressive-care measures” are not an option, many difficult questions remain: What is the best way to deal with the probable cancer? How long should the team wait for signs of neurologic improvement? Should ventilation or administration of food and fluids be withdrawn, and if so, when? In addressing these questions with the family, the team should foster, and try to maintain, family consensus.

No potential conflict of interest relevant to this article was reported.

From the Departments of Philosophy and Medicine, University of Western Ontario, London, ON, Canada.

TREATMENT OPTION 3

Withdraw Life Support on the Basis of Substituted Judgment

Mark R. Tonelli, M.D.

The patient in the vignette not only has debilitating and life-threatening medical conditions but also has lost his ability to participate directly in decisions regarding his care. He is no longer —

and will never again be — an autonomous being. Physicians must therefore find some other way to decide what should be done for him. In the United States today, patients' autonomy is valued to such an extent that we seek a method for exercising autonomous choice even after a clear and lasting loss of decision-making capacity. We ask friends, family members, and other surrogates, “What would he want if he could talk to us now, understanding his circumstances and prognosis?” We ask for a substituted judgment.

Courts and bioethicists prefer the substituted-judgment standard over other approaches to making such decisions, primarily because it respects autonomy in a way that the consideration of best interests, or what a reasonable person would think, does not.¹² Although this standard does not in itself always allow for the inclusion of other important considerations in end-of-life discussions,¹³ it remains central to these discussions for several reasons. It permits the consideration of patients' specific goals and values, and it avoids the need to make judgments regarding the value of another person's life. If a patient never wanted to live in a severely debilitated state, and surrogates can give a convincing voice to that preference, then respecting the patient's autonomy requires the discontinuation of supportive medical therapies — without any need to invoke the concept of medical futility, the issue of quality of life for those in a persistent vegetative state, or social justice.

The choices of legal surrogates do not necessarily represent substituted judgments, nor should substituted judgments be taken at face value. Due diligence is required to ascertain whether a substituted judgment seems to be a valid expression of a patient's previously held goals and values. Other assessments regarding the best interests and the values of the patient and the integrity of the family should be considered. Clearly, this is a difficult task. In cases from *Quinlan* through *Schiavo*, courts have struggled to define the types and standards of evidence that apply to such decisions. Practically and ethically, physicians will need less evidentiary support for a substituted judgment that seems concordant with the patient's best interests and reasonable medical practice — and should demand more support for one that does not.¹⁴

In the case described in the vignette, there is clear and ample evidence of the patient's prefer-

ences regarding supportive therapy in the event of persistent loss of cognitive function and ability to function independently — evidence from statements of family members and close contacts, including the initial assessment of the son who then, for reasons that have not been fully explored, began to demand ongoing care. The substituted judgment that supportive care should be withdrawn seems medically reasonable and in the patient's best interest, which alleviates any ethical uncertainty in its application. The right course of action is clear, complicated only by an estranged son's unsupported obstruction.

The care team should inform the son that support will be withdrawn in concordance with his father's previously stated goals and values, allowing the son an opportunity to challenge the decision legally. But absent such a challenge, all supportive measures should be discontinued, with care focusing solely on the patient's comfort. That is the only action that respects the man this patient once was.

No potential conflict of interest relevant to this article was reported.

From the Department of Medicine, Division of Pulmonary and Critical Care Medicine, and the Department of Bioethics and Humanities, University of Washington Medical Center, Seattle.

1. Dubler NN, Liebman CB. Bioethics mediation: a guide to shaping shared solutions. New York: United Hospital Fund, 2004.
2. Kapp MB. Treating medical charts near the end of life: how legal anxieties inhibit good patient deaths. *Univ Toledo Law Rev* 1997;28:521-46.
3. Luce JM. Physicians do not have a responsibility to provide futile or unreasonable care if a patient or family insists. *Crit Care Med* 1995;23:760-6.
4. Truog RD, Cist AF, Brackett SE, et al. Recommendations for end-of-life care in the intensive care unit: The Ethics Committee of the Society of Critical Care Medicine. *Crit Care Med* 2001;29:2332-48.
5. Dubler NN. The doctor-proxy relationship: the neglected connection. *Kennedy Inst Ethics J* 1995;5:289-306.
6. Annas GJ. "Culture of life" politics at the bedside — the case of Terri Schiavo. *N Engl J Med* 2005;352:1710-5.
7. Helft PR, Siegler M, Lantos J. The rise and fall of the futility movement. *N Engl J Med* 2000;343:293-6.
8. Weijer C, Singer PA, Dickens BM, Workman S. Bioethics for clinicians: 16. Dealing with demands for inappropriate treatment. *CMAJ* 1998;159:817-21.
9. President's Commission for the Study of Ethical Problems in Medicine and Biomedical Research. Deciding to forego life-sustaining treatment: a report on the ethical, medical and legal issues in treatment decisions. Washington, DC: Government Printing Office, 1983.
10. Toussaint LG III, Friedman JA, Wijdicks EF, et al. Survival of cardiac arrest after aneurysmal subarachnoid hemorrhage. *Neurosurgery* 2005;57:25-31.
11. Reisfield GM, Wallace SK, Munsell MF, Webb FJ, Alvarez ER, Wilson GR. Survival in cancer patients undergoing in-hospital cardiopulmonary resuscitation: a meta-analysis. *Resuscitation* 2006;71:152-60.
12. Buchanan AE, Brock DW. Deciding for others: the ethics of surrogate decision making. Cambridge, England: Cambridge University Press, 1990.
13. Berger JT, DeRenzo EG, Schwartz J. Surrogate decision making: reconciling ethical theory and clinical practice. *Ann Intern Med* 2008;149:48-53.
14. Tonelli MR. Substituted judgment in medical practice: evidentiary standards on a sliding scale. *J Law Med Ethics* 1997;25:22-9.

Copyright © 2009 Massachusetts Medical Society.

RECEIVE IMMEDIATE NOTIFICATION WHEN
A JOURNAL ARTICLE IS RELEASED EARLY

To be notified when an article is released early on the Web and to receive the table of contents of the *Journal* by e-mail every Wednesday evening, sign up through our Web site at **NEJM.org**