RCSIsmj ETHICS CHALLENGE WINNER 2010

Can doctors say 'enough'?

Alison DeMaio,[1]
Nathan Clendenen[1]
[1]RCSI medical students

Introduction

The *RCSIsmj* Ethics Challenge for 2010 presented a case of a woman with longstanding medical issues that ultimately resulted in her staying in the surgical ICU for four months, dependent on ventilator support, haemodialysis and total parenteral nutrition. Though her physicians felt that she had no hope of surviving outside of the hospital, the patient's daughter continued to push for aggressive treatment.[1]

The aim of this article is to discuss the ethical issues highlighted by the case and to provide a course of action for the patient that suitably addresses these issues. Where appropriate, counter-arguments are introduced to highlight the complexity of this case. Though the case occurs in New York, we have approached it largely from the perspective of healthcare in Ireland. However, the issues in the article are indeed universal and are worthy of discussion for medical professionals everywhere. When does life support begin to prolong death and suffering? How can a physician determine the limits of his duty of care? Should allocation of limited resources be considered by the physician when he is making his decision to withdraw life-sustaining treatment?

Definitions of core principles in medical ethics

- **Autonomy:** the ability to deliberate and act upon personal goals, free from coercion. In relation to medical care, autonomy governs that a person may choose or refuse treatment; however, in cases of diminished mental capacity, patients are usually treated according to their best interests.
- **Beneficence:** the duty of a physician to do that which promotes the well-being of the patient.
- **Non-maleficence:** the obligation that a physician render no harm to his or her patient (*primum non nocere*).
- **Justice:** equality in distribution of medical resources, including a physician's time.[2]

Current guidelines for the transition to end-of-life care

Although many attempts have been made, there are no formal guidelines regarding transition to palliative care that are accepted by the greater medical community. This is especially true in fields outside oncology, where patients are referred to palliative care once appropriate treatments are exhausted.[3-5] In clinical practice, the decision is reached after careful consultation between the medical team, the patient (or their proxy) and the patient's family.

The principles outlined by the American College of Surgeons for care at the end of life are as follows:

- respect the dignity of both patient and caregivers;
- be sensitive to and respectful of the patient and their family's wishes;
- use the most appropriate measures that are consistent with the choices of the patient or the patient's legal surrogate;
- ensure alleviation of pain and management of other physical symptoms;
- provide access to therapies that may realistically be expected to improve the patient's quality of life;
- provide access to appropriate palliative care and hospice care; and,
- recognise the physician's responsibility to forego treatments that are futile.[6]

Ethical issues

The key ethical issues illuminated by this case are as follows:

- the patient's autonomy and her right to refuse treatment;
- the patient's quality of life;
- the physician's dilemma of the balance of beneficence and non-maleficence;
- the issue of medical futility;
- the role of the daughter as surrogate medical decision maker;
- the issue of justice and the allocation of limited resources; and,
- physician duty of care and potential legal or ethical ramifications for refusing to continue treatment.

Patient autonomy

Self-determination is a cornerstone of good medical care, and physicians have a duty to uphold patient autonomy. Their ability to do so is severely limited in cases where the patient's ability to communicate is diminished. In this case, the patient is incapable of any sort of communication and left no directions for her care prior to falling ill, except for a vague statement to her daughter ("Don't let anything happen to me").[1]

This case underlines the importance of advanced directives and, more importantly, good communication between a physician and his patient.

Discussing end-of-life care before the patient is too ill to do so has been shown to have positive results, including improved quality of life, less aggressive care, and families that are happier with their loved one's care. Physicians may worry that discussing such topics may distress their patients, but this has not been shown to be the case.[7,8]

Preserving patient autonomy extends beyond explicit patient wishes, especially in cases where these cannot be known. This includes the duty of physicians to relieve pain and suffering, which is paramount to good care.

If judged to be in the best interests of the patient, it is not considered unethical to withdraw life-sustaining treatments.[9,10]

Usual practice is that if a patient becomes incompetent, their family becomes their surrogate decision maker, if there is no advance directive instructing otherwise.

A patient's quality of life at the end of their life

In order to adequately maintain a patient's dignity and autonomy, their quality of life must be the primary concern of the physician. Quality of life is unique to each individual patient, and is defined by one's interests and values.[11] If these are not adequately known, the physician should make decisions on their medical care based on what they judge to be in the best interests of their patient.[9,12] This becomes especially important in decisions about life-sustaining treatment, in which a physician must consider quality of life associated with survival, and also probability of survival.[7]

Maintaining quality of life is the aim of end-of-life (palliative) care. There comes a time when intensive care becomes a burden on the patient, and may even be seen as inhumane. Rather than preserving life, the extensive medical intervention may only prolong death. Thus, the interplay between beneficence and non-maleficence is disrupted; a physician can no longer claim that the benefit they are doing outweighs the harm endured by the patient.[13]

The patient in this case had no feasible possibility of recovering to a point where she could maintain life outside of the hospital, yet she continued to be subjected to treatments with their own complications.

Not only was she continually septic, she had developed a deep sacral ulcer.[1] Transitioning to end-of-life care would ensure the patient's comfort and return her to a more acceptable quality of life, for however short a time. Furthermore, palliative care seeks to address issues the patient's family members may have and aid in the bereavement process.[14]

Medical futility

In the broadest meaning of the word, medical futility is the inappropriate use of medical intervention to treat patients who have no likelihood of benefit. In 1990, Schneiderman defined futility as treatment that has a less than 1% chance of benefiting the patient.[15,16] Other definitions have been proposed since then in order to clarify the issue for physicians. Tan proposed that a futile intervention is one that cannot bring about an acceptable improvement to a patient's quality of life.[17] McConnell's explanation of futility is more applicable to life-sustaining treatments, as one that maintains that a state of permanent unconsciousness or dependence on aggressive care may be declared futile.[14,18] Gedge defines a specific type of futility – physiological futility – as those treatments that will not preserve a physiological function necessary to preserve life.[19]

In this case, it is apparent that the patient's treatment in the ICU may be deemed futile by any of the above definitions. Not only is it not benefiting her in any physiological way, the aggressive care has diminished her quality of life beyond an acceptable limit. Her physicians assert that there is no reasonable chance that she will recover to a point where she may live independent of hospital care. It can be argued that futility is a concept that is too difficult to define to be of clinical use and may be biased by the values of the physician. However, the American Medical Association has developed a fair unbiased process to determine futility and the subsequent withdrawal of futile interventions.[20]

Role of surrogate decision makers in end-of-life care

While the decision to transition the patient to palliative care seems to be the obvious choice, this particular case is complicated by the demands of the patient's daughter to continue with aggressive treatment. Usual practice is that if a patient becomes incompetent, their family becomes their surrogate decision maker, if there is no advance directive instructing otherwise. Communication between the surrogate and the physician is crucially important, and decisions should always be made based on what they believe the patient would have decided. The surrogate's decisions are generally accepted as a rule, though there are exceptions that may require intervention:

- no available family member is willing to become the surrogate decision maker;
- there is disagreement among the family members; and,
- a healthcare provider believes that the decision could not reasonably be judged to be in the patient's best interests.[9]

Based on the principles of maintaining the patient's autonomy and quality of life, in this case it is evident that the daughter is not acting in her mother's best interests, despite honourable intentions.

End-of-life medical treatment poses especially difficult ethical questions for physicians. The burden of intervention is often high, benefits are insignificant, and patient quality of life often suffers.

Justice and the allocation of limited resources

A striking issue that presents itself in this case is the focus of enormous resources on one person, rather than many others who could benefit to an unknown extent. As of 2006, Ireland housed only 195 ICU beds and up to 30% of patients requiring admission to ICU are not granted access. Furthermore, the increased mortality on being denied ICU admission is astounding, such that for every five patients turned away, one patient died.[13] Institutions have to carefully weigh issues of medical need when deciding which patients receive scarce medical resources. Criteria for making such a decision include likelihood of benefit, urgency of need, change in quality of life, and duration of benefit.[21] In the case of this particular patient, continued aggressive treatment is highly unlikely to result in a positive outcome, and thus ICU resources would be better employed elsewhere.

However, the unfair distribution of resources to one person in a seemingly futile case should not be a concern of the patient's physician when making decisions about withdrawing life-sustaining treatments.[7] The physician's duty is the care of his patient, and thus decisions of allocation of resources should be out of his hands.[21] Rather, the focus should be on the patient's quality of life and what is in their best interest.[11]

Potential ethical and legal ramifications for withdrawing life-sustaining treatment

Patient autonomy does have limits, and ends where the physician's autonomy begins. Patients cannot compel their physician to act against their conscience, and they have a duty not to demand unrealistic treatment.[22,23] Additionally, there is no ethical obligation that a physician deliver care that he believes has no possibility of benefiting his patient.[24] Above all, the physician must concern himself with his patient's best interests, even if that means discontinuing life-sustaining treatment and moving to end-of-life care. It can be difficult to know how far a physician's duty of care extends, and it is important to assess each case on an individual basis. There is some precedence for these sorts of cases in the legal system in Ireland, which sheds light on the issue. For patients who are not wards of court, standard practice is that the physician consults with the patient's family and from there makes decisions regarding their medical care. Though this practice has been questioned, the courts traditionally support physicians in their decision-making for incompetent patients.[22,25]

Conclusion

End-of-life medical treatment poses especially difficult ethical questions for physicians. The burden of intervention is often high, benefits are insignificant, and patient quality of life often suffers.[26,27] This case makes it evident that there is a need for clear guidelines to assist physicians when faced with dilemmas of life-sustaining treatment. In 2009, Bradley and Brasel proposed specific criteria that would refer patients in the surgical ICU on to a palliative care consult:

- family request;
- declaration of futility by the medical team;
- family dispute with the medical team or the patient's advanced directive, for more than seven days;
- death expected during the same ICU stay;
- ICU stay lasting more than one month;
- a diagnosis with median survival for less than six months;

- more than three ICU admissions during the same hospitalisation;
- Glasgow Coma Score of less than 8, for more than one week, in a patient over 75 years of age; and,
- multiorgan failure in more than three systems.[28]

The patient in this case fits nearly all of these criteria, and it is abundantly clear that her medical care should be re-focused to end-of-life comfort measures. Any medical intervention that the patient is receiving that does not directly alleviate pain and suffering should be discontinued. Before any transition takes place, there must be extensive communication with the patient's daughter.[29] Included in the palliative care umbrella is bereavement services for patients' loved ones, and the daughter should be encouraged to avail of these services.

References

1. RCSI. Ethics Challenge. Royal College of Surgeons in Ireland Student Medical Journal. 2010;3(1):5.
2. The Belmont Report: Ethical principles and guidelines for the protection of human subjects of research. Cited October 13, 2010. Available from: ohsr.od.nih.gov/guidelines/belmont.html.
3. Marsella A. Exploring the literature surrounding the transition into palliative care: a scoping review. Int J Palliat Nurs. 2009;15(4):186-9.
4. Hauser JM. Lost in transition: the ethics of the palliative care handoff. J Pain Symptom Manage. 2009;37(5):930-3.
5. Pattison N. Integration of critical care and palliative care at end of life. Br J Nurs. 2004;13(3):132-6,8-9.
6. ST-28 Principles Guiding Care at the End of Life, 1998. Cited October 14, 2010. Available from: www.facs.org/fellows_info/statements/st-28.html.
7. Curtis JR, Vincent JL. Ethics and end-of-life care for adults in the intensive care unit. Lancet. 2010; October 7 [epublished].
8. Gries CJ, Curtis JR, Wall RJ, Engelberg RA. Family member satisfaction with end-of-life decision making in the ICU. Chest. 2008;133(3):704-12.
9. American Medical Association. E-2.20 Withholding or Withdrawing Life-Sustaining Medical Treatment, 1996. Cited October 19, 2010. Available from: https://ssl3.ama-assn.org/apps/ecomm/PolicyFinderForm.pl?site=www.ama-assn.org&uri=/ama1/pub/upload/mm/PolicyFinder/policyfiles/HnE/E-2.20.HTM.
10. Cassell EJ. The principles of the Belmont report revisited. How have respect for persons, beneficence, and justice been applied to clinical medicine? Hastings Cent Rep. 2000;30(4):12-21.
11. American Medical Association. E-2.17 Quality of Life, 1994. Available from: https://ssl3.ama-assn.org/apps/ecomm/PolicyFinderForm.pl?site=www.ama-assn.org&uri=/ama1/pub/upload/mm/PolicyFinder/policyfiles/HnE/E-2.17.HTM.
12. Sims JM. A brief review of the Belmont report. Dimens Crit Care Nurs. 2010;29(4):173-4.
13. Intensive Care Society of Ireland. Adult intensive care capacity planning and development in Ireland. Dublin: Intensive Care Society of Ireland, October 2006.
14. Coustasse A, Quiroz T, Lurie SG. To the bitter end: disparities in end-of-life care. J Hosp Mark Public Relations. 2008;18(2):167-85.
15. Schneiderman LJ, Jecker NS, Jonsen AR. Medical futility: its meaning and ethical implications. Ann Intern Med. 1990;112(12):949-54.
16. Schneiderman LJ, Jecker NS, Jonsen AR. Medical futility: response to critiques. Ann Intern Med. 1996;125(8):669-74.
17. Tan SY. Medical decisions at the end of life: lessons from America. Hawaii Med J. 1995;54(4):514-20.
18. Layson RT, McConnell T. Must consent always be obtained for a do-not-resuscitate order? Arch Intern Med. 1996;156(22):2617-20.
19. Gedge E, Giacomini M, Cook D. Withholding and withdrawing life support in critical care settings: ethical issues concerning consent. J Med Ethics. 2007;33(4):215-8.
20. Council on Ethical and Judicial Affairs. Medical futility in end-of-life care: report of the Council on Ethical and Judicial Affairs. JAMA. 1999;281(10):937-41.
21. American Medical Association. E-2.03 Allocation of Limited Medical Resources, 1993. Cited October 19, 2010. Available from: https://ssl3.ama-assn.org/apps/ecomm/PolicyFinderForm.pl?site=www.ama-assn.org&uri=/ama1/pub/upload/mm/PolicyFinder/policyfiles/HnE/E-2.03.HTM.
22. Gleeson D. Is it time for advance healthcare directives? Irish Council on Bioethics, 2007.
23. Torke AM, Alexander GC, Lantos J. Substituted judgment: the limitations of autonomy in surrogate decision making. J Gen Intern Med. 2008;23(9):1514-7.
24. American Medical Association. E-2.035 Futile Care. American Medical Association, 1994. Cited October 19, 2010. Available from: https://ssl3.ama-assn.org/apps/ecomm/PolicyFinderForm.pl?site=www.ama-assn.org&uri=/ama1/pub/upload/mm/PolicyFinder/policyfiles/HnE/E-2.035.HTM.
25. Meisel A, Snyder L, Quill T. Seven legal barriers to end-of-life care: myths, realities, and grains of truth. JAMA. 2000;284(19):2495-501.
26. Walker RM. Ethical issues in end-of-life care. Cancer Control Journal. 1999;6:2.
27. Rousseau P. Ethical and legal issues in palliative care. Prim Care. 2001;28(2):391-400.
28. Bradley CT, Brasel KJ. Developing guidelines that identify patients who would benefit from palliative care services in the surgical intensive care unit. Crit Care Med. 2009;37(3):946-50.
29. Burt RA. The medical futility debate: patient choice, physician obligation, and end-of-life care. J Palliat Med. 2002;5(2):249-54.