

Commentary

Beyond ethical dilemmas: improving the quality of end-of-life care in the intensive care unit

Gordon D Rubenfeld¹ and J Randall Curtis²

¹Assistant Professor of Medicine, Division of Pulmonary and Critical Care Medicine, Harborview Medical Center, University of Washington, Seattle, Washington, USA

²Associate Professor of Medicine, Division of Pulmonary and Critical Care Medicine, Harborview Medical Center, University of Washington, Seattle, Washington, USA

Correspondence: Gordon D Rubenfeld, nodrog@u.washington.edu

Published online: 18 December 2002

Critical Care 2003, **7**:11-12 (DOI 10.1186/cc1866)

This article is online at <http://ccforum.com/content/7/1/11>

© 2003 BioMed Central Ltd (Print ISSN 1364-8535; Online ISSN 1466-609X)

Abstract

Consensus guidelines on providing optimal end-of-life care in the intensive care unit (ICU) are important tools. However, despite 30 years of ethical discourse and consensus on many of the principles that guide end-of-life care in the ICU, care remains inadequate. Although consensus on the most challenging ethical aspects of some cases will remain elusive, this need not deter clinicians from engaging in practical quality improvement, best practice, and educational interventions to provide compassionate care to all critically ill patients, including those who ultimately die.

Keywords consensus guidelines, end-of-life care, palliative care, quality improvement

The consensus guidelines developed by Hawryluck and coworkers [1] provide a nice summary of the current principles that guide palliative care in the intensive care unit (ICU). Although recommendations in that article can be found in a variety of published guidelines on end-of-life care in the ICU [2–5], this Delphi-based consensus study provides useful additions. The Intent section in Table 4 of the report by Hawryluck and coworkers [1] is particularly helpful to clinicians trying to understand the practical implications of the 'principle of double effect'. Specific examples of charting tools or protocols based on these general concepts would be a useful addition to the general principles presented in the article. The distinction between the compassionate withdrawal of life-sustaining treatments and euthanasia is made forcefully and repeatedly by the authors. Suggestions to incorporate support for the ICU staff is an important, and often overlooked, addition.

Unfortunately, more is needed than consensus on general principles. Studies from the past 10 years indicate that important problems persist with end-of-life care in the ICU, despite agreement on the general principles in that report. Patients die in ICUs in pain, receiving care that they and their

families did not request. Objective prognostic data and advance directives have had little impact on patient care [6,7]. Clinicians' decisions regarding the use of life-sustaining treatments are driven by their personal biases, including training, age, religiosity, and specialization, rather than patient factors [8,9]. Nurses are profoundly frustrated by the care provided to dying patients in the ICU [10,11].

These clinical problems concern ethical issues, but they will not be solved by consensus on ethics based guidelines because they are not caused by ethical discord. In fact, there is every reason to expect that solutions for improving end-of-life care in the ICU will look a lot like solutions for improving outcomes in other areas of critical care: for example, ventilator management, pulmonary artery catheter use, and reducing medical error [12]. An ICU with a culture that leads to nurses expressing sentiments such as "I'm not asked for any input – my professional opinion is not considered valid" has problems that go well beyond delivering excellent end-of-life care [11]. However, several features distinguish end-of-life care from other areas of quality improvement in the ICU. Good communication and negotiation skills, including eliciting patient values, conveying uncertain prognoses, and

helping families weigh the burdens and benefits of ongoing intensive care, are essential to excellent end-of-life care. These communication and negotiation skills will probably require more sophisticated training and quality improvement techniques than learning to reduce tidal volumes in patients with acute lung injury [13]. Finally, although we can measure the quality of ICU care with risk-adjusted mortality or process of care measures, tools are just becoming available to measure the quality of end-of-life care in the ICU [14]. Until we can agree on what outcomes constitute a good or bad death in the ICU, we will experience difficulty in evaluating methods to improve this care.

Available data and common sense suggest a number of interventions that can be implemented today. Every patient admitted to the ICU for more than postoperative observation who is at significant risk for death or for prolonged ICU stay should generate at least a brief meeting between the patient's family and the clinical team, at which the patient's condition is discussed and the patient's values about intensive care are elicited [15,16]. Protocols for withdrawing life-sustaining treatment and for documenting this process should be implemented [17]. Multidisciplinary rounds that are part morbidity and mortality conference and part ICU team debriefment should occur routinely in order to review deaths after ICU admission. It is particularly important that nurses and other ICU clinicians are part of a collaborative interdisciplinary team, are involved in the decision-making process, and have a venue to air their concerns in a nonthreatening environment. Techniques to communicate decisions about the limits of life-sustaining treatment clearly and unequivocally to all hospital staff should be implemented. Stuttering withdrawal of life-sustaining treatments (e.g. the decision to withhold necessary dialysis in a patient with acute renal failure while continuing all other forms of life support) should be avoided and responsible clinicians asked to provide a rationale for this inconsistent level of care. Although providing some life-sustaining treatments while withholding others may reflect informed decisions on the part of surrogates based on an assessment of the burdens and benefits of specific therapies, studies suggest that these inconsistent treatment plans are likely to be based on individual physicians' biases rather than families' requests [18]. Hospitals should try to humanize their ICUs by liberalizing visiting hours, providing educational materials about the ICU and critical illness, and making lay or professional counselors available to families [19].

Great strides have been made in defining ethical principles to guide end-of-life care in the 35 years since a panel reached consensus on guidelines to define brain death [20]. Nevertheless, it is important to recognize that consensus on all aspects of end-of-life care in the ICU may not be possible, and that when such a consensus is achieved it may only reflect local moral principles. Nowhere is this more evident than attempts to build consensus while acknowledging

unique cultural, religious, and economic factors that influence end-of-life care in ICUs around the world [21]. Ongoing efforts directed at consensus on difficult ethical and legal problems, particularly where they address international variability, are extremely valuable [22]. However, consensus on many aspects of end-of-life care in the ICU do exist and have been written about at great length. We should not let the exciting challenge of resolving areas of disagreement dissuade us from working on interventions to ensure that we are consistently providing high quality care to all critically ill patients, including those who ultimately die.

Competing interests

None declared.

References

1. Hawryluck LA, Harvey WR, Lemieux-Charles L, Singer PA: **Consensus guidelines on analgesia and sedation in dying intensive care unit patients.** *BMC Med Ethics* 2002, **3**:3. [<http://www.biomedcentral.com/1472-6939/3/3>]
2. Campbell ML: *Forgoing life-sustaining therapy: how to care for the patient who is near death.* Aliso Viejo, CA: American Association of Critical-Care Nurses; 1998.
3. Curtis JR, Rubenfeld GD (Eds): *Managing Death in the ICU: the Transition from Cure to Comfort.* New York: Oxford University Press; 2000.
4. Brody H, Campbell ML, Faber-Langendoen K, Ogle KS: **Withdrawing intensive life-sustaining treatment: recommendations for compassionate clinical management.** *N Engl J Med* 1997, **336**:652-657.
5. Lo B: *Resolving Ethical Dilemmas: a Guide for Clinicians.* Baltimore: Williams & Wilkins; 1995.
6. The SUPPORT Principal Investigators: **A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT).** *JAMA* 1995, **274**:1591-1598.
7. Schneiderman LJ, Kronick R, Kaplan RM, Anderson JP, Langer RD: **Effects of offering advance directives on medical treatments and costs.** *Ann Intern Med* 1999, **117**:599-606.
8. Cook DJ, Guyatt GH, Jaeschke R, Reeve J, Spanier A, King D, Molloy DW, Willan A, Streiner DL: **Determinants in Canadian health care workers of the decision to withdraw life support from the critically ill.** *JAMA* 1995, **273**:703-708.
9. Christakis NA, Asch DA: **Biases in how physicians choose to withdraw life support.** *Lancet* 1993, **342**:642-646.
10. Asch DA: **The role of critical care nurses in euthanasia and assisted suicide.** *N Engl J Med* 1996, **334**:1374-1379.
11. Asch DA, Shea JA, Jedrziewski MK, Bosk CL: **The limits of suffering: critical care nurses' views of hospital care at the end of life.** *Soc Sci Med* 1997, **45**:1661-1668.
12. Lynn J, Arkes HR, Stevens M, Cohn F, Koenig B, Fox E, Dawson NV, Phillips RS, Hamel MB, Tsevat J: **Rethinking fundamental assumptions: SUPPORT's implications for future reform. Study to Understand Prognoses and Preferences and Risks of Treatment.** *J Am Geriatr Soc* 2000, **48**(suppl):S214-S221.
13. Curtis JR, Engelberg RA, Wenrich MD, Nielsen EL, Shannon SE, Trelease PD, Tonelli MR, Patrick DL, Robins LS, McGrath BB, Rubenfeld GD: **Studying communication about end-of-life care during the ICU family conference: development of a framework.** *J Crit Care* 2002, **17**:147-160.
14. Curtis JR, Patrick DL, Engelberg RA, Norris K, Asp A, Byock I: **A measure of the quality of dying and death. Initial validation using after-death interviews with family members.** *J Pain Symptom Manage* 2002, **24**:17-31.
15. Lilly CM, De Meo DL, Sonna LA, Haley KJ, Massaro AF, Wallace RF, Cody S: **An intensive communication intervention for the critically ill.** *Am J Med* 2000, **109**:469-475.
16. Dowdy MD, Robertson C, Bander JA: **A study of proactive ethics consultation for critically and terminally ill patients with extended lengths of stay.** *Crit Care Med* 1998, **26**:252-259.

17. Rubenfeld GD, Crawford SW: **Principles and practice of withdrawing life sustaining treatment in the intensive care unit.** In *Managing Death in the ICU: the Transition from Cure to Comfort*. Edited by Curtis JR, Rubenfeld GD. New York: Oxford University Press; 2000:127-147.
18. Christakis NA, Asch DA: **Medical specialists prefer to withdraw familiar technologies when discontinuing life support.** *J Gen Intern Med* 1995, **10**:491-494.
19. Abbott KH, Sago JG, Breen CM, Abernethy AP, Tulsky JA: **Families looking back: one year after discussion of withdrawal or withholding of life-sustaining support.** *Crit Care Med* 2001, **29**: 197-201.
20. Anonymous: **A definition of irreversible coma. Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death.** *JAMA* 1968, **205**:337-340.
21. Engelhardt HT Jr: **Critical care: why there is no global bioethics.** *J Med Philos* 1998, **23**:643-651.
22. European Society of Intensive Care Medicine: *International Consensus Conference in Intensive Care Medicine: Preliminary Programme – Challenges in End-of-Life Care in the ICU: 2003 24–25 April; Brussels, Belgium.* 2002 [http://www.esicm.org/ICCICM_preliminaryProgram_070802.pdf]