

Neuroanesthesia and Intensive Care

Brief review: Practice variation in end of life care in the ICU: implications for patients with severe brain injury

[Revue sommaire de la variation des soins aux mourants dans les USI : implications pour les patients atteints de lésion cérébrale sévère]

Graeme M. Rocker DM MHSc,* Deborah J. Cook MD MSc,† Sam D Shemie MD‡

Purpose: To review end of life care issues in the intensive care unit (ICU) and how practice variation might affect the ultimate outcome of acute brain injury.

Sources: Bibliographic literature search and personal files.

Findings: In Canada, 10–20% of critically ill adults die in the ICU. Many of these deaths follow acute brain injury in the setting of clinical deterioration, life support limitation and brain death. This brief review addresses some key elements of end of life care for critically ill brain injured patients, including family interactions, making survival predictions, and factors influencing decision-making about cardiopulmonary resuscitation and withdrawal of mechanical ventilation.

Conclusions: Provision of compassionate high quality end of life care should be standard of practice for brain injured and all other critically ill patients who cannot survive. Inconsistencies in end of life care may affect where, when and how patients die, the quality of their death and whether or not they are considered for organ and tissue donation.

Objectif : Revoir la question des soins aux mourants dans les unités de soins intensifs (USI) et la façon dont les différentes pratiques peuvent modifier l'étape finale d'une lésion cérébrale aiguë.

Sources : Une recherche bibliographique des documents et des dossiers personnels.

Constatations : Au Canada, 10 – 20 % des adultes gravement malades meurent à l'USI. Beaucoup de ces décès suivent une lésion cérébrale aiguë dans le contexte d'une détérioration

clinique, une limitation du maintien des fonctions vitales et une mort encéphalique. Notre revue aborde certains éléments clés des soins aux mourants, qui ont de graves lésions cérébrales, dont les interactions avec la famille, les prédictions de survie et les facteurs qui influencent les décisions sur la réanimation cardiorespiratoire et le retrait de la ventilation mécanique.

Conclusion : Des soins de fin de vie de grande qualité, prodigués avec compassion, devraient être la norme de pratique pour les patients atteints de lésions cérébrales et de toute autre maladie grave. Le manque de cohérence des soins aux mourants peut modifier les circonstances et la qualité de leur mort et leur reconnaissance comme donneurs d'organes et de tissu.

IN Canada, 10–20% of critically ill patients die in adult intensive care units (ICUs).¹ Death is typically declared according to cardiac or neurological criteria. A cardiac declaration of death occurs in three ways: 1) despite full treatment, patients suffer a cardiac arrest and cardiopulmonary resuscitation (CPR) is unsuccessful; 2) despite full treatment, patients suffer cardiac arrest and no attempt at CPR is made; 3) decisions are made to limit life support, some treatment is withheld or withdrawn, the patient suffers a cardiac arrest (usually expected), and no attempt at CPR is made. For a fourth group of patients, a neurological declaration of death is made (brain death).

From the Department of Medicine,* Dalhousie University, Halifax, Nova Scotia; the Departments of Medicine & Clinical Epidemiology & Biostatistics,† McMaster University, Hamilton, Ontario; and the Division of Pediatric Critical Care,‡ Montreal Children's Hospital, McGill University Health Centre, Montreal, Quebec, Canada.

Address correspondence to: Dr. G.M. Rocker, Professor of Medicine, Dalhousie University, #4457, Halifax Infirmary, 1796 Summer St., Halifax, Nova Scotia B3H 3A7, Canada. Phone: 902-473-6611; Fax: 902-473-6202; E-mail gmrocker@dal.ca

Accepted for publication August 23, 2005.

Revision accepted February 17, 2006.

Competing interests: None declared.

Brain death usually follows progressive and irreversible neurological decline in a setting of traumatic or vascular brain injury. In one large Canadian retrospective study, 8.4% of deaths were due to brain death.²

The true incidence of brain injury and of brain death across Canada is unknown, since research is limited and there is no mandatory reporting mechanism. Cerebrovascular accidents and traumatic brain injury are the most common conditions that ultimately lead to brain death in adults³ and children.⁴ In the Calgary Health Region, the incidence of severe traumatic brain injury is 11.4 per 100,000 and mortality is 5.1 per 100,000.⁵ Mortality from motor vehicle accidents has declined with the introduction of seat belt laws and increased helmet use (<http://www.urbanfutures.com/research.html>), associated with a presumptive corresponding decrease in the incidence of brain death. In the absence of national Canadian data that describe the natural history of severe brain injury, it is not possible to accurately predict who will die and who will survive with severely impaired neurological function. Moreover, many patients with severe brain injury also develop non-neurological organ dysfunction which itself is associated with increased mortality.⁶ For patients with severe neurological impairment who fail to respond to neuroprotective measures and resuscitation, the possibility of withdrawal of life support is often discussed with families.⁷ This review addresses some key elements of end of life care in the ICU, and outlines how practice variation might affect the process of care and ultimate outcome of patients with acute brain injury.

End of life care in the ICU: variations in processes of care

Two Canadian studies documented that 65%⁸ to 79%¹ of ICU deaths followed withdrawal or withholding of treatment. In a provincial registry in which approximately 20% of patients were admitted with primary traumatic or vascular brain injury, preferences to withhold rather than to withdraw treatment were influenced by whether the setting was an academic or community centre.⁹ In a USA study involving 131 centres, the rates of life support limitation preceding death ranged from 0% to 79%.¹⁰ This practice variation cannot be explained by patient demographics alone; recently, many factors that influence the administration and forgoing of life support have been examined. For example, a self-administered survey of 1,300 Canadian ICU nurses and physicians asked respondents, in the absence of patient or family directives, to indicate the level of care they would recommend for patients described in case scenarios.¹¹ There was striking vari-

ability in responses. In eight of 12 scenarios, more than 10% of respondents chose care at the opposite ends of the treatment spectrum, ranging from palliation to full life support. While some of the variation in end of life care in the ICU can be explained by patient factors such as illness acuity, advance directives, and patient preferences, variation in the level of care chosen may reflect simply the preferences and values of the involved physicians.^{9,12,13} Different specialists use different probabilities of survival to invoke mechanical ventilation or CPR, which has been documented both in hypothetical scenarios in surveys¹⁴ and in clinical settings.¹⁵ Additional physician factors that influence processes of care include age, experience, religion, subspecialty, and setting (academic *vs* community centre, and open *vs* closed ICU).^{9,12,13,16} Physicians also make different choices about comfort medications¹ and how mechanical ventilation is withdrawn.¹⁷ These biases potentially influence the framing of discussions with families, the decisions about CPR and whether to formally withhold or withdraw mechanical ventilation. For patients with brain injury, a decision to withdraw life support in advance of criteria for a neurological declaration of death determines whether or not organ donation is pursued.¹⁸

Predicting mortality

The ability to make an accurate prediction of mortality is an important aspect of any end of life discussion. Efforts to make accurate predictions for patients with brain injury to reduce overly optimistic or pessimistic predictions date back several decades.^{19,20} Recent publications have focused on the utility of somatosensory evoked potentials, both in adults²¹ and in children²² and in brain injury of traumatic or of ischemic anoxic origin.²³ When the prognosis is dismal, a planned withdrawal of life support will often reflect the fact that continuation of treatment is seen simply as an unwarranted and unfortunate delay of a natural death. This notwithstanding, physicians have a tendency to be overly pessimistic when they make predictions for ICU patients.^{24,25} In the international Level of Care study,²⁵ daily predictions of survival were made for 851 mechanically ventilated patients (including 130 with central nervous system disease) expected to remain in ICUs for > 72 hr. In addition to overestimating probability of death, physician predictions of a < 10% probability of survival was associated with the provision of less intensive care, and a significantly higher odds of withholding or withdrawal of life support modalities.²⁵

For neurosurgical patients, a recent Canadian study has also documented variable reliability in predicting

the outcomes in patients presenting to Ontario emergency departments with acute brain injury.²⁶ For such patients, a similar pessimistic attitude of physicians can prevail. Despite predictions of mortality among 87 patients presenting with subarachnoid hemorrhage and an intracerebral hemorrhage volume of > 60 mL and Glasgow coma score of < 8, several survived hospital and some achieved functional independence.²⁷ In this study, 17% of substitute decision makers thought that a decision to withdraw life support was made prematurely.²⁷ These investigators also found that neurologists and neurosurgeons differed in the intensity with which they approached the same type of clinical problem within one institution, again highlighting the variable care that patients may receive according to where and by whom they are cared for.²⁷ Others have found influences on outcome according to whether patients are admitted to a general or to a neurosurgical ICU²⁸ or whether surgical intervention is early or delayed,²⁹ in the use of induced hypothermia, seizure medications, paralytic agents,³⁰ use of intracranial monitoring,^{30,31} or according to physician prediction of severely impaired future cognitive function.³²

Relationships with patients and families

The importance of human relationships in ICU care was highlighted 20 years ago in this quote from a UK theologian: "The success of intensive care is not, therefore to be measured only by the statistics of survival, as though each death were a medical failure. It is to be measured by the quality of lives preserved or restored; and by the quality of the dying of those in whose interest it is to die; and by the quality of human relationships involved in each death."³³

Patients themselves remind us of our failings as professionals working in stressful environments where too easily we set aside the importance of human relationships.³⁴ For families facing the impending death of a loved one, clinicians underestimate the levels of anxiety and depression that family members experience.³⁵ When death approaches and consideration of organ and tissue donation becomes a reality, how we interact with families may be a key determinant of how events proceed. It is crucially important to understand whether and how families wish to participate in decision-making. In Canada, families report preferring shared decision-making.³⁶ Honesty, completeness of information and compassion shown to family members are important predictors of family satisfaction with intensive care.^{37,38} In France, where a more parental approach by physicians has prevailed, about half of families visiting patients in the ICU do not wish to participate in decision-making.³⁹ In both

these Canadian and French studies, families identified the need for improved physician communication.^{37,40} Others have since demonstrated that this involves listening more and speaking less,⁴¹ while ensuring management plans are shared with all members of the multidisciplinary team.⁴²

The multidisciplinary team approach has been shown to benefit patients with acute brain injury, both acutely⁴³ and during rehabilitation.⁴⁴ For example, hospital mortality and the duration of stay were lower after the introduction of a specialized neurocritical care team.⁴³ For patients dying in the ICU, how we approach their families and how we frame discussions about end of life care will influence outcomes and the mode of death for these patients. In the final analysis, the mode of death (with or without a withdrawal of life support) will determine who may be eligible for organ donation and who will not.

Establishing cardiopulmonary resuscitation directives

In the Level of Care Study, among 2,916 eligible ICU patients, the time of admission, type of ICU and centre were as important as traditional biomedical factors in determining whether or not CPR directives were established in the first 24 hr of ICU admission, and what those directives were.⁴⁵ Only 11% of patients had explicit CPR directives established within the first 24 hr. Residents in the ICU established the largest proportion of the directives and significantly more directives were established at night and at weekends. Ideally, the crucial decision to resuscitate a patient should not be dependent on the serendipity of the admitting team, or the hospital, or the centre to which patients are admitted.

Withdrawal of mechanical ventilation

Mechanical ventilation is the most common form of advanced life support used in the ICU. Mechanical ventilation is the most frequent life support withdrawn from critically ill patients, and often precedes death in the ICU. Many factors, including patient age, illness severity, chronic health, patient wishes, and past and future quality of life influence decisions to withhold and withdraw life support. In an international observational study to examine the determinants of withdrawal of mechanical ventilation, 851 mechanically ventilated adult patients predicted to stay in 15 ICUs for at least 72 hr were followed prospectively.³² Of the 851 patients, 63% were successfully weaned, 17% died while mechanically ventilated and 20% had mechanical ventilation withdrawn. Rather than age, illness severity and organ dysfunction, the three strongest predictors

of ventilator withdrawal were 1) central nervous system disease; 2) physician prediction of less than 10% probability of survival; and 3) physician perception of patient preferences to limit life support.

For patients with brain injury, in a study from the USA involving 2,109 patients, two factors made it 50% less likely that withdrawal of mechanical occurred among patients admitted to a neurology/neurosurgery unit. These factors were an African-American background (odds ratio 0.50, confidence interval 0.36–0.68) and whether a neurosurgical operation had occurred (odds ratio 0.44, confidence interval 0.2–0.67).⁴⁶ Together, the results from these two major studies question the traditional biomedical model of withdrawal of life support that focuses on patient age and physiologic determinants such as worsening organ function. While findings in the Canadian study²⁹ suggest a life support withdrawal process today that is attentive to patient values, these values are not necessarily concordant with family members⁴⁷ and physicians⁴⁸ perceptions of those wishes. This in itself should encourage subsequent research in end of life care for critically ill patients to focus on interactions with families and precisely how we elicit and honour patient preferences.

Summary: providing quality end of life care for all ICU patients

Regardless of site, city, centre or physician, providing consistent, compassionate high quality end of life care should be a standard of practice in ICUs. The trend towards more family-centered care for critically ill patients is encouraging but not in itself sufficient.⁴⁹ Outside of Canada there is a body of evidence to suggest that end of life care in the ICU falls short of these standards, leading to calls for better palliation.^{50,51} The situation in Canada appears more encouraging with families reporting that most patients die in comfort in the ICU¹⁷ and that the families themselves feel supported during the dying process.³⁷ However, inconsistencies in end of life care practices may affect where patients die, how they die, the quality of that death^{52,53} and whether or not patients are considered for organ and tissue donation in the ICU.¹⁸ These practice variations lead to concerns about decision-making that determines access to ICUs for the purposes of prognostication and treatment²⁶ which may in turn influence outcome for brain injured patients, and the quality of their end of life care. Care does not stop with a neurological declaration death after brain injury. It must continue in how we honour the wishes of deceased patients undergoing organ donation, and in the care we provide to families of the deceased as bereavement begins.

References

- 1 Hall RI, Rocker GM. End-of-life care in the ICU. Treatments provided when life support was or was not withdrawn. *Chest* 2000; 118: 1424–30.
- 2 Keenan SP, Busche KD, Chen LM, McCarthy L, Inman KJ, Sibbald WJ. A retrospective review of a large cohort of patients undergoing the process of withholding or withdrawal of life support. *Crit Care Med* 1997; 25: 1324–31.
- 3 Badovinac K, Greig PD, Ross H, Doig CJ, Shemie SD. Organ utilization among deceased donors in Canada, 1993–2002. *Can J Anesth* 2006; 53: 838–44.
- 4 Tsai E, Shemie SD, Cox PN, Furst S, McCarthy L, Hebert D. Organ donation in children: role of the pediatric intensive care unit. *Pediatr Crit Care Med* 2000; 1: 156–60.
- 5 Zygun DA, Laupland KB, Hader WJ, *et al.* Severe traumatic brain injury in a large Canadian health region. *Can J Neurol Sci* 2005; 32: 87–92.
- 6 Zygun DA, Kortbeek JB, Fick GH, Laupland KB, Doig CJ. Non-neurologic organ dysfunction in severe traumatic brain injury. *Crit Care Med* 2005; 33: 654–60.
- 7 O'Callahan JG, Fink C, Pitts LH, Luce JM. Withholding and withdrawing of life support from patients with severe head injury. *Crit Care Med* 1995; 23: 1567–75.
- 8 Wood GG, Martin E. Withholding and withdrawing life-sustaining therapy in a Canadian intensive care unit. *Can J Anaesth* 1995; 42: 186–91.
- 9 Keenan SP, Busche KD, Chen LM, Esmail R, Inman KJ, Sibbald WJ. Withdrawal and withholding of life support in the intensive care unit: a comparison of teaching and community hospitals. The Southwestern Ontario Critical Care Research Network. *Crit Care Med* 1998; 26: 245–51.
- 10 Prendergast TJ, Claessens MT, Luce JM. A national survey of end-of-life care for critically ill patients. *Am J Respir Crit Care Med* 1998; 158: 1163–7.
- 11 Cook DJ, Guyatt GH, Jaeschke R, *et al.* Determinants in Canadian health care workers of the decision to withdraw life support from the critically ill. Canadian Critical Care Trials Group. *JAMA* 1995; 273: 703–8.
- 12 Asch DA, Faber-Langendoen K, Shea JA, Christakis NA. The sequence of withdrawing life-sustaining treatment from patients. *Am J Med* 1999; 107: 153–6.
- 13 Cook DJ, Giacomini M, Johnson N, Willms D. Life support in the intensive care unit: a qualitative investigation of technological purposes. Canadian Critical Care Trials Group. *CMAJ* 1999; 161: 1109–13.
- 14 Hanson LC, Danis M, Garrett JM, Mutran E. Who decides? Physicians' willingness to use life-sustaining treatment. *Arch Intern Med* 1996; 156: 785–9.
- 15 Tanvetyanon T, Leighton JC. Life-sustaining treatments

- in patients who died of chronic congestive heart failure compared with metastatic cancer. *Crit Care Med* 2003; 31: 60–4.
- 16 *Christakis NA, Asch DA*. Medical specialists prefer to withdraw familiar technologies when discontinuing life support. *J Gen Intern Med* 1995; 10: 491–4.
 - 17 *Rocker GM, Heyland DK, Cook DJ, Dodek PM, Kutsogiannis DJ, O'Callaghan CJ*. Most critically ill patients are perceived to die in comfort during withdrawal of life support: a Canadian multicentre study. *Can J Anesth* 2004; 51: 623–30.
 - 18 *Rocker GM*. Organ and tissue donation in the intensive care unit. *CMAJ* 2002; 167: 1248–9.
 - 19 *Jennett B, Teasdale G, Braakman R, Minderhoud J, Knill-Jones R*. Predicting outcome in individual patients after severe head injury. *Lancet* 1976; 1: 1031–4.
 - 20 *Narayan RK, Greenberg RP, Miller JD, et al*. Improved confidence of outcome prediction in severe head injury. a comparative analysis of the clinical examination, multimodality evoked potentials, CT scanning, and intracranial pressure. *J Neurosurg* 1981; 54: 751–62.
 - 21 *Fischer C, Luaute J*. Evoked potentials for the prediction of vegetative state in the acute stage of coma. *Neuropsychol Rehabil* 2005; 15: 372–80.
 - 22 *Carter BG, Butt W*. A prospective study of outcome predictors after severe brain injury in children. *Intensive Care Med* 2005; 31: 840–5.
 - 23 *Zandbergen EG, de Haan RJ, Stoutenbeek CP, Koelman JH, Hijdra A*. Systematic review of early prediction of poor outcome in anoxic-ischaemic coma. *Lancet* 1998; 352: 1808–12.
 - 24 *Christensen C, Cottrell JJ, Murakami J, Mackesy ME, Fetzer AS, Elstein AS*. Forecasting survival in the medical intensive care unit: a comparison of clinical prognoses with formal estimates. *Methods Inf Med* 1993; 32: 302–8.
 - 25 *Rocker G, Cook D, Sjøkvist P, et al*; Level of Care Study Investigators, Canadian Critical Care Trials Group. Clinician predictions of intensive care unit mortality. *Crit Care Med* 2004; 32: 1149–54.
 - 26 *Tenn-Lyn NA, Doig CJ, Shemie SD, Teitelbaum J, Cass DE*. Potential organ donors referred to Ontario neurosurgical centres. *Can J Anesth* 2006; 53: 732–6.
 - 27 *Becker KJ, Baxter AB, Cohen WA, et al*. Withdrawal of support in intracerebral hemorrhage may lead to self-fulfilling prophecies. *Neurology* 2001; 56: 766–72.
 - 28 *Diringer MN, Edwards DF*. Admission to a neurologic/neurosurgical intensive care unit is associated with reduced mortality rate after intracerebral hemorrhage. *Crit Care Med* 2001; 29: 635–40.
 - 29 *Servadei F*. Prognostic factors in severely head injured adult patients with acute subdural haematoma's. *Acta Neurochir (Wien)* 1997; 139: 279–85.
 - 30 *Tilford JM, Simpson PM, Yeh TS, et al*. Variation in the therapy and outcome for pediatric head trauma patients. *Crit Care Med* 2001; 29: 1056–61.
 - 31 *Bulger EM, Nathens AB, Rivara FP, Moore M, MacKenzie EJ, Jurkovich GJ*; *Brain Trauma Foundation*. Management of severe head injury: institutional variations in care and effect on outcome. *Crit Care Med* 2002; 30: 1870–6.
 - 32 *Cook D, Rocker G, Marshall J, et al*. *Level of Care Study Investigators*, Canadian Critical Care Trials Group. Withdrawal of mechanical ventilation in anticipation of death in the intensive care unit. *N Engl J Med* 2003; 349: 1123–32.
 - 33 *Dunstan GR*. Hard questions in intensive care. A moralist answers questions put to him at a meeting of the Intensive Care Society, Autumn, 1984. *Anaesthesia* 1985; 40: 479–82.
 - 34 *Misak CJ*. The critical care experience: a patient's view. *Am J Respir Crit Care Med* 2004; 170: 357–9.
 - 35 *Pochard F, Azoulay E, Chevret S, et al*. Symptoms of anxiety and depression in family members of intensive care unit patients: ethical hypothesis regarding decision-making capacity. *Crit Care Med* 2001; 29: 1893–7.
 - 36 *Heyland DK, Cook DJ, Rocker GM, et al*. Decision-making in the ICU: perspectives of the substitute decision-maker. *Intensive Care Med* 2003; 29: 75–82.
 - 37 *Heyland DK, Rocker GM, Dodek PM, et al*. Family satisfaction with care in the intensive care unit: results of a multiple center study. *Crit Care Med* 2002; 30: 1413–8.
 - 38 *Heyland DK, Rocker GM, O'Callaghan CJ, Dodek PM, Cook DJ*. Dying in the ICU: perspectives of family members. *Chest* 2003; 124: 392–7.
 - 39 *Azoulay E, Pochard F, Chevret S, et al*. Half the family members of intensive care unit patients do not want to share in the decision-making process: a study in 78 French intensive care units. *Crit Care Med* 2004; 32: 1832–8.
 - 40 *Azoulay E, Chevret S, Leleu G, et al*. Half the families of intensive care unit patients experience inadequate communication with physicians. *Crit Care Med* 2000; 28: 3044–9.
 - 41 *McDonagh JR, Elliott TB, Engelberg RA, et al*. Family satisfaction with family conferences about end-of-life care in the intensive care unit: increased proportion of family speech is associated with increased satisfaction. *Crit Care Med* 2004; 32: 1484–8.
 - 42 *Rocker GM, Cook DJ, O'Callaghan CJ, et al*. Canadian nurses' and respiratory therapists' perspectives on withdrawal of life support in the intensive care unit. *J Crit Care* 2005; 20: 59–65.

- 43 *Suarez JI, Zaidat OO, Suri MF, et al.* Length of stay and mortality in neurocritically ill patients: impact of a specialized neurocritical care team. *Crit Care Med* 2004; 32: 2311–7.
- 44 *Semlyen JK, Summers SJ, Barnes MP.* Traumatic brain injury: efficacy of multidisciplinary rehabilitation. *Arch Phys Med Rehabil* 1998; 79: 678–83.
- 45 *Cook DJ, Guyatt G, Rocker G, et al.* Cardiopulmonary resuscitation directives on admission to intensive-care unit: an international observational study. *Lancet* 2001; 358: 1941–5.
- 46 *Diringer MN, Edwards DF, Aiyagari V, Hollingsworth H.* Factors associated with withdrawal of mechanical ventilation in a neurology/neurosurgery intensive care unit. *Crit Care Med* 2001; 29: 1792–7.
- 47 *Smucker WD, Houts RM, Danks JH, Ditto PH, Fagerlin A, Coppola KM.* Modal preferences predict elderly patients' life-sustaining treatment choices as well as patients' chosen surrogates do. *Med Decis Making* 2000; 20: 271–80.
- 48 *Teno JM, Hakim RB, Knaus WA, et al.* Preferences for cardiopulmonary resuscitation: physician-patient agreement and hospital resource use. The SUPPORT Investigators. *J Gen Intern Med* 1995; 10: 179–86.
- 49 *Clarke EB, Curtis JR, Luce JM, et al.* Quality indicators for end-of-life care in the intensive care unit. *Crit Care Med* 2003; 31: 2255–62.
- 50 *Danis M, Federman D, Fins JJ, et al.* Incorporating palliative care into critical care education: principles, challenges, and opportunities. *Crit Care Med* 1999; 27: 2005–13.
- 51 *Carlet J, Thijs LG, Antonelli M, et al.* Challenges in end-of-life care in the ICU. Statement of the 5th International Consensus Conference in Critical Care: Brussels, Belgium, April 2003. *Intensive Care Med* 2004; 30: 770–84.
- 52 *Emanuel EJ, Emanuel LL.* The promise of a good death. *Lancet* 1998; 351(Suppl 2): SII21–9.
- 53 *Smith R.* A good death. An important aim for health services and for us all. *BMJ* 2000; 320: 129–30.