

Cultural issues in end-of-life care

Sara-Catrin Cook and Carol Peden

Correspondence Email: saracatrincook@hotmail.com

INTRODUCTION

The passage of life to death is a very individual experience for each patient and their family, and is influenced by many different factors. Race, ethnicity, age, religion, spiritual beliefs and socio-economic status influence a patient's wishes and expectations for their end-of-life care.¹ Within the culture of an Intensive Care Unit (ICU) the training, the desire for quality outcomes and the finances available are some of the factors that can influence the delivery of end-of-life care. The spectrum of values, beliefs, habits, customs and traditions that influence end-of-life management is extensive. All aspects are important and need to be addressed in order to deliver compassionate and personalised end-of-life care for each individual.

The ICU is becoming a common place to die, with 22.4% of deaths in the United States occurring after admission to ICU.² With an increasingly ageing population and the ability to provide more and more medical intervention, the number of patients dying on intensive care is likely to rise.^{2,3} While the ICU staff are experienced at caring for the dying, evidence suggests that the process of care surrounding death is not always done well.^{4,5,6} The last few years has seen a growing focus addressing end-of-life management on intensive care. This article looks at some of the issues raised.

THE PATIENT AND FAMILY

The influence of culture, religion and ethnicity

The principle of autonomy, which can be described as the individual's right to self determination about their body, their lifestyle and their health,⁷ how they are treated and their right to receive information about themselves, is widely adopted by most Western countries.^{8,9} There are many legal and advisory documents across different countries to guide end-of-life decision making which address the concept of autonomy. It is important to appreciate that 'autonomy' is not a value held universally 'and as such, may be very foreign or even opposite to the views of patients and families from other cultures'.¹⁰ Even where autonomy is recognised, culture, religion and ethnicity heavily influence who is informed of a patient's diagnosis,

whether the patient themselves is told they are at the end-of-life, and what decisions are made.

Ethnicity

A study looking at differences in care according to race identified that black patients were almost twice as likely to choose to have cardiopulmonary resuscitation, and half as likely to choose withdrawal of care, as some other races.¹¹ Shrank et al identified that African-Americans were more likely to involve extended family, friends and spiritual leaders when making decisions about end-of-life care and that they put a strong emphasis on spirituality, 'healing' and preserving life at all cost.¹² White-Hispanics were more likely to limit end-of-life discussions to immediate family and placed greater importance on quality of life.¹²

Hispanic, Chinese and Pakistani families will actively ensure that their loved one is unaware of their terminal prognosis.¹³ The Vietnamese and Russians believe it is wrong to inform a patient that they have cancer and that such discussions should be held with the family only.¹⁰ Families from these cultures traditionally believe that it is their duty to protect their loved one, keeping them from the burden and anxiety of their diagnosis¹³ and preventing them from losing hope.¹⁰

Religion

Beliefs regarding end-of-life care, including those of withholding and withdrawal of medical intervention, vary widely between different religions.⁸ All health care professionals need to have some insight and knowledge into the beliefs of the major faiths they are likely to encounter, in order to be culturally sensitive to what their patient's wishes may be, and so that discussions and management can be targeted appropriately. However, it is important to appreciate that decision-making within the same religion or culture can vary considerably.¹⁴ Although patients may come from the same cultural background, experiences with immigration, education, acculturation (the modification of the culture of a group or individual as a result of contact with a different culture), medical and other encounters will differ significantly from person to person, influencing and individualising their decision making process.^{10,15,16}

Summary

With an increasingly aged world population and rising expectations of the level of therapy offered for a wide range of illnesses, the ICU is a common place to die. The attitudes of patient, relatives and medical staff vary greatly between countries, cultures and religions. This article provides an overview of the factors we should consider when managing patients with a critical illness, particularly concerning end-of-life care.

Sara-Catrin Cook
Anaesthetic Registrar

Carol Peden
Consultant in Intensive care
Royal United Hospital
Bath
Somerset
UK

End-of-life customs and rituals

Many religions and cultures have different end-of-life customs and rituals. These play an important role in preparing and dealing with death, for both the patient and loved ones.^{1,15} Customs and rituals vary widely. Muslim families may wish for their dying member to have their head turned towards Mecca.¹⁵ Pacific Islanders request that a window is left open while their family member is dying in order for the soul to be able to leave.¹ The Hindu family may wish to wash the body of their deceased family member themselves.¹⁵ Some ICUs may not be used to dealing with a variety of rituals, however, with some thought and consideration, most rituals can be accommodated, meeting the patient and family's spiritual and religious needs.

An appreciation of each patient's culture, religion, race and ethnicity is important in order to understand how these will influence a patient's response to dying.¹⁵ It is important that the care provided is individualised and that patients are not stereotyped by ethnic or cultural group;^{16,17} this can only be facilitated by asking the patient, or their advocate, about their individual wishes. Examples of relevant questions are:^{10,15,17}

- When a diagnosis is established does the patient wish to be told, or would they prefer that this is discussed with the family instead?
- Does the patient themselves want to make decisions, or do they want this referred to their family?
- How 'aggressive' does the patient want their care to be? Should everything possible be done?
- What are their religious and spiritual views, how important are they and do they have any customs or rituals that must be observed?

It is important to ask these questions in order to be able to provide end-of-life care that is in keeping with the patient's wishes.^{10,15}

Caring for the family

Dame Cicely Saunders, credited as a founder of the hospice movement and a leader in the development of palliative care, stated 'How one dies remains in the memories of those that live on.'

Providing care that focuses on the family, as well as the patient, brings with it many benefits. Increasing family participation,¹⁸ focusing on communication with them^{18,19} and supporting their spiritual and emotional needs,^{19,20} increases satisfaction amongst family members and surrogate decisions regarding end-of-life decision making¹⁹ and the overall ICU encounter.²⁰ In addition, fewer suffer psychological consequences from the experience.¹⁸ Introduction of quality initiative improvements for end-of life care, with family involvement, such as conferences to improve communication about end-of-life care issues, lead to significant reduction in ICU days before death.²¹

Family-centred care, with responsibility for the welfare of the family as well as the patient, is seen as the ideal model for end-of-life management and that 'caring for family members is an important part of caring for the critically ill patient'.²² Reinforcing this as part of the ICU culture is fundamental to improving the quality of end-of-life care and is advocated by many Intensive Care Societies.¹⁴

THE INTENSIVE CARE UNIT

Training in end-of-life care

A general consensus exists that there is insufficient training in end-of-life care for health care professionals¹⁴ and that end-of-life care 'demands the same high level of knowledge and competence as all other areas of ICU practice'.²² A change in culture, to one where end-of-life training is seen to be as important as learning how to manage respiratory failure, is required. Doctors in particular, need improved teaching in palliative care that commences in medical school, but continues throughout their career, with particular attention to improving communication skills. However, specific end-of-life care is important for all health care professionals, so that all care-givers involved in the care of a dying patient are able to deal with the medical, social and psychological issues of end-of-life care.²³

Variation in decision-making between different ICUs: withdrawing and withholding care

The decision to move from curative-led to palliative-led care is always difficult. It requires careful consideration, balancing the risk of unnecessary distress, discomfort and prolongation of suffering against the possibility of withholding or withdrawing intervention in a patient that may survive.¹⁴ Most decisions regarding end-of-life care can be guided by ethical and legal principles, however, what decisions are made, how and when they are reached and the extent to which family and other clinical staff are involved in the decision making process, varies considerably from physician to physician, ICU to ICU and country to country.

A study from Canada, looking at health care worker characteristics, identified the number of years since graduation, the city and province they worked in, the number of beds on their ICU and the consideration of what their colleagues would do, as characteristics that influenced decisions to withdraw treatment.²⁴

The ETHICUS study, a study of end-of life practices in 37 ICUs in 17 European countries, identified that the majority of ICU deaths that occur across Europe do so after a decision has been made to limit treatment being provided.²⁵ Yet within this European sample the decision to limit life-sustaining treatment differed markedly according to country, religion, duration of time on the ICU, diagnosis and patient age.²⁵ Northern European units were more likely to implement limitations to care and take a shorter period of time to reach the decision than Central or Southern European units.²⁵ Atheist, Protestant or Catholic physicians were more likely to withdraw treatment than Greek Orthodox, Jewish or Muslim colleagues.²⁵ Miccinesi et al identified that religion was a determinant of physician attitude towards end-of-life decisions, alongside age, gender and previous experience with dying patients.²⁶ However the strongest determinant of physician attitude was country.²⁶

A number of differences have been identified between countries and their approach to end-of-life care. The United States is most likely to involve ethicists and courts of law in assisting with decision-making. Japan, Turkey, the United States, Southern Europe and Brazil are more likely to continue treatment in a deteriorating vegetative patient with no family or advanced directive. This is in contrast to Northern and Central Europe, Australia and Canada.⁷ Northern and Central

Europe are most likely to involve nurses in end-of-life care decisions, whereas Southern Europe, Japan, Brazil, Turkey and the United States are least likely.²⁷ In the ETHICUS study nurses were involved in around 78% of cases, but only initiated discussion in 2% of cases; however disagreement between carers occurred in only 0.6% of cases.²⁷ The involvement of nurses in end-of-life decisions is an important consideration.¹⁴ Nurses can be excluded from the decision making process,^{27,28} yet it is they who potentially form the closest relationships with patients and their families, and are most likely to be familiar with the values, beliefs and wishes of those concerned.

The process of decision making can vary between two extremes, from paternalism where the doctor makes all decisions, to full patient autonomy, where the patient or their designated surrogate has responsibility for decision making while the doctor remains in an informative role only.²⁹ The 'paternalistic' approach runs the risk of failing to appreciate the patient's wishes, conversely decisions made by patients and family alone can be extremely stressful for those involved.^{18,31}

The 'Study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT)' identified that the majority of physicians did not know their patients' preferences for end-of-life care and that many patients did not receive the end-of-life care that they wished.⁴ Less than 5% of ICU patients retain the capacity to make decisions.³⁰ This highlights the importance of involving those closest to the patient with decisions, to ensure that, where the patient cannot express their preferences, family and friends can help guide to the care that the patient would want.¹⁹ Yet, as mentioned above, this comes at a price. A number of studies have shown that those involved in decisions about a loved one's end-of-life care, can be traumatised by the experience. Many suffer symptoms of anxiety, depression and post-traumatic stress following the episode.^{18,31}

Many studies have shown that patients favour their family as decision makers,^{32,33} others that families do not want to be involved,³⁴ and further papers that having both family and physicians contributing to the decision making process is preferable.^{35,36} It is the shared decision making approach that a consensus of international critical care societies advocate.¹⁴ This approach means that the family need not assume the full burden of the end-of-life care decisions, while allowing the health care team an opportunity to provide information and understanding to the family about the medical issues. In addition, the shared decision making approach allows the family to express what they feel are the patient's wishes and values, so that the health care team can acknowledge and incorporate these into end-of-life care recommendations and decisions.²⁹

Impact on the care providers

Both nursing and medical staff working in critical care are at high risk of burnout (an emotional condition marked by tiredness, loss of interest, or frustration that interferes with job performance).^{37,38} This is especially so when clinicians believe that the care that they are providing is inappropriate.³⁹ Caring for and making decisions pertaining to the end-of-life care of a patient are significant factors that contribute to the risk of burnout,^{37,39} as are the care giver's personal and professional values and beliefs, which may influence the extent of burnout that they experience.⁴⁰

A recent study looking at perceptions of appropriateness of care amongst intensive care nurses and physicians identified that good collaboration between nurses and doctors, involvement of nurses in end-of-life care decisions, and shared decision making between nurses and physicians with regard to symptom control, were variables that were associated with decreased perception of inappropriate care.³⁹ This study went on to suggest that managers should look to promote a culture and environment within the ICU where there is 'self-reflection, mutual trust, open communication, and shared decision making.... in order to improve the well-being of the individual clinicians and, thereby, the quality of patient care.'

CONCLUSION

Providing care for a patient at the end of their life is a key component of good quality care on the Intensive Care Unit, and as a result has been receiving increased attention over the last few years. Ensuring that a patient is free from pain and distress, that family members are supported and that the principle of shared decision making is promoted, are all key aspects of end-of-life care. All intensivists should strive to provide end-of-life care of the highest standard through research, education and quality improvement initiatives, with sensitivity to, and understanding of, the unique cultural needs of individual patients and their families.

FURTHER READING

Sprung CL, Cohen SL, Sjkovist P et al: ETHICUS study group. End of life practices in European intensive care units: the ETHICUS study. *JAMA* 2003; **290**: 790-7.

Sprung CL, Maia P, Bulow HH et al: ETHICUS study group. The importance of religious affiliation and culture on end-of-life decisions in European intensive care units. *Intensive Care Medicine* 2007; **33**: 1732-9.

Curtis JR, Vincent JL. Ethics and end-of-life care for adults in the intensive care unit. *Lancet* 2010; **376**: 1347-53.

Carey SM, Cosgrove JF. Cultural issues surrounding end-of-life care. *Current Anaesthesia and Critical Care* 2006; **17**: 263-70.

Schaefer KG, Block SD. Physician communication with families in the ICU: evidence-based strategies for improvement. *Current Opinion in Critical Care* 2009; **15**: 569-77.

Curtis JR, Treece PD, Nielsen et al. Integrating palliative and critical care: evolution of a quality-improvement intervention. *Am J Respir Crit Care Med* 2008; **178**: 269-75.

Lautrette A, Darmon M, Megarbane B et al. A communication strategy and brochure for relatives of patients dying in the ICU. *NEJM* 2007; **356**: 469-78.

REFERENCES

1. Mazanec P and Tyler MK Cultural considerations in end-of-life care. *The American Journal of Nursing* 2003; **103**: 50-9.
2. Angus DC, Barnato AE, Linde-Zwirble WT et al; on behalf of the Robert Wood Johnson Foundation. ICU End-of-Life Peer Group Use of Intensive Care at the end of life in the United States: An epidemiologic study. *Critical Care Medicine* 2004; **32**: 638-43.
3. Nelson JE, Angus DC, Weissfeld LA et al. End-of-life care for the critically ill: A national intensive care unit survey. *Critical Care Medicine* 2006; **34**: 2547-53.
4. 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**: 1591-8.
5. Desbiens NA, Wu AW, Broste SK et al. Pain and satisfaction with pain control in seriously ill hospitalized adults: Findings from the SUPPORT research investigations. *Critical Care Medicine* 1996; **24**: 1953-61.
 6. Somogyi-Zaloud E, Zhong Z, Lynn J et al. Dying with acute respiratory failure or multiple organ system failure with sepsis. *Journal of the American Geriatrics Society* 2000; **48**: S140-S5.
 7. O'Brien J and Chantler C. Confidentiality and the duties of care. *Journal of Medical Ethics* 2003; **29**: 36-40.
 8. Bulow H-H, Sprung CL, Reinhart K et al. The world's major religions' points of view on end-of-life decisions in the intensive care unit. *Intensive Care Medicine* 2008; **34**: 423-30.
 9. Pauls M and Hutchinson RC Bioethics for clinicians: Protestant Bioethics. *Canadian Medical Association Journal* 2002; **166**: 339-43.
 10. Candib LM. Truth telling and advance planning at the end of life: Problems with autonomy in a multicultural world. *Families, Systems & Health* 2002; **20**: 213-28.
 11. Johnson RW, Newby LK, Granger CB et al. Differences in level of care at the end of life according to race. *American Journal of Critical Care* 2010; **19**: 335-43.
 12. Shrank WH, Kutner JS, Richardson T et al. Focus group findings about the influence of culture on communication preferences in end-of-life care. *Journal of General Internal Medicine* 2005; **20**: 703-9.
 13. Searight HR and Gafford J Cultural diversity at the end of life: issues and guidelines for family physicians. *American Family Physician* 2005; **71**: 515-22.
 14. 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 Medicine* 2004; **30**: 770-84.
 15. Carey SM and Cosgrove JF. Cultural issues surrounding end-of-life care. *Current Anaesthesia and Critical Care* 2006; **17**: 263-70.
 16. Crawley LM. Racial, cultural and ethnic factors influencing end-of-life care. *Journal of Palliative Medicine* 2005; **8**: S58-69.
 17. Koenig BA and Gates-Williams J. Understanding cultural difference in caring for dying patients. *The Western Journal of Medicine* 1995; **163**: 244-9.
 18. Lautrette A, Darmon M, Megarbane B et al. A communication strategy and brochure for relatives of patients dying in the ICU. *The New England Journal of Medicine* 2007; **356**: 469-78.
 19. Gries CJ, Curtis JR, Wall RJ et al. Family member satisfaction with end-of-life decision making in the ICU. *Chest* 2008; **133**: 704-12.
 20. Wall RJ, Engelberg RA, Gries CJ et al. Spiritual care of families in the intensive care unit. *Critical Care Medicine* 2007; **35**: 1084-90.
 21. Curtis JR, Patrick DL, Shannon SE et al. The family conference as a focus to improve communication about end-of-life care in the intensive care unit: Opportunities for improvement. *Critical Care Medicine* 2001; **29**: N23-N26.
 22. Truog RD, Campbell ML, Curtis JR et al. Recommendations for end-of-life care in the intensive care unit: A consensus statement by the American College of Critical Care Medicine. *Critical Care Medicine* 2008; **36**: 953-63.
 23. Leadbetter C and Garber J. Dying for change. Available at: http://www.demos.co.uk/files/Dying_for_change_-_web_-_final_1_.pdf?1289561872. Accessed: 22/12/11.
 24. 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. *JAMA* 1995; **273**: 703-8.
 25. Sprung CL, Cohen SL, Sjokvist et al. End-of-life practices in European intensive care units: The ETHICUS Study. *JAMA* 2003; **290**: 790-7.
 26. Miccinesi G, Fischer S, Paci E et al. Physicians' attitudes towards end-of-life decisions: a comparison between seven countries. *Social Science and Medicine* 2005; **60**: 1961-74.
 27. Benbenishty J, Ganz FD, Lippert A et al. Nurse involvement in end-of-life decision making: the ETHICUS study. *Intensive Care Med* 2006; **32**: 15-7.
 28. Yaguchi A, Truog RD, Randall Curtis J et al. International difference in the end-of-life attitudes in the intensive care unit. *Archives Internal Medicine* 2005; **165**: 1970-5.
 29. White DB, Malvar G, Karr J et al. Expanding the paradigm of the physician's role in surrogate decision-making: an empirically derived framework. *Critical Care Medicine* 2010; **38**: 743-50.
 30. Prendergast TJ and Luce JM. Increasing incidence of withholding and withdrawal of life support from the critically ill. *American Journal of Respiratory and Critical Care Medicine* 1997; **155**: 15-20.
 31. Azoulay E, Pochard F, Kentish-Barnes N et al. Risk of post-traumatic stress symptoms in family members of Intensive Care Unit patients. *American Journal of Respiratory and Critical Care Medicine* 2005; **171**: 987-90.
 32. Singer PA, Choudhry S and Armstrong J. Public opinion regarding consent to treatment. *Journal of the American Geriatrics Society* 1993; **41**: 112-6.
 33. Roupie E, Santin A, Boulme R et al. Patients' preferences concerning medical information and surrogacy: results of a prospective study in a French emergency department. *Intensive Care Medicine* 2000; **26**: 52-6.
 34. Azoulay E, Pochard F, Chevret 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. *Critical Care Medicine* 2003; **32**: 1832-8.
 35. Heyland DK, Rocker GM, O'Callaghan CJ et al. Dying in the ICU: perspectives of family members. *Chest* 2003; **124**: 392-7.
 36. Heyland DK, Cook DJ, Rocker GM et al. Decision-making in the ICU: perspectives of the substitute decision maker. *Intensive Care Medicine* 2003; **29**: 75-82.
 37. Poncet MC, Toullic P, Papazian L et al. Burnout syndrome in critical care nursing staff. *Am J Respir Crit Care Med* 2007; **175**: 698-704.
 38. Embriaco N, Azoulay E, Barrau K et al. High level of burnout in Intensivists - Prevalence and associated factors. *Am J Respir Crit Care Med* 2007; **175**: 686-92.
 39. Piers RD, Azoulay E, Ricou B et al. Perceptions of appropriateness of care among European and Israeli Intensive Care Unit nurses and physicians. *JAMA* 2011; **306**: 2694-703.
 40. Altun I. Burnout and nurses' personal and professional values. *Nursing Ethics* 2002; **9**: 269-78.

St George's Hospital. Anaesthesia. Update. ACSA Review date: 8 June 2015. 1 June 2015 Issue 19. Anesthesia & Analgesia - system to predict Mortality In Severe Sepsis Spinal Cord Pressure Evaluation Study. *Anaesthesia*; 120(1):76-84. in the Emergency Department: a derivation *Critical Care Medicine*; 42(3):646-655. The scientific journal *Update in Anaesthesia* is included in the Scopus database. Based on 2020, SJR is 0.138. Publisher country is USA. Paper quality checking service is in demand among researchers who wish to make final improvements to their work before submitting it to the target journal. The experienced editors of ORES, who have published papers in cited journals, with the participation of foreign partners go through finished articles. *Update in Anaesthesia*. The local anaesthetic to be injected intrathecally that the needle is inserted and stays in the midline. should be in a single use ampoule. by a tiny particle of tissue or clot. It is imperative. 10 *Update in Anaesthesia*. 11. When CSF appears, take care not to alter the position of the spinal needle as the syringe of local anaesthetic is being attached. 2 *Update in Anaesthesia*. TRANSPORTATION OF THE CRITICALLY ILL AND INJURED PATIENT Dr Peter J. Shirley, Intensive Care Fellow, Frimley Park Hospital, Surrey, UK. pjshirl@hotmail.com. Terminology. *Update in Anaesthesia*. 9. Paracervical block serves to relieve the pain of uterine contractions, but because the pudendal nerves are not blocked, additional analgesia is required for delivery.