

Cultural issues in end-of-life care

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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.

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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.

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