ETHICS AND END-OF-LIFE CARE FOR ADULTS IN THE INTENSIVE CARE UNIT

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Summary: The intensive care unit (ICU) is where patients are given some of the most technologically advanced life-sustaining treatments, and where difficult decisions are made about the usefulness of such treatments. The substantial regional variability in these ethical decisions is a result of many factors, including religious and cultural beliefs. Because most critically ill patients lack the capacity to make decisions, family and other individuals often act as the surrogate decision makers, and in many regions communication between the clinician and family is central to decision making in the ICU. Elsewhere, involvement of the family is reduced and that of the physicians is increased. End-of-life care is associated with increased burnout and distress among clinicians working in the ICU. Since many deaths in the ICU are preceded by a decision to withhold or withdraw life support, high-quality decision making and end-of-life care are essential in all regions, and can improve patient and family outcomes, and also retention of clinicians working in the ICU. To make such a decision requires adequate training, good communication between the clinician and family, and the collaboration of a well-functioning interdisciplinary team.

Keywords: End-of-life care, Palliative care, End-of-life decision making, Withdrawal of life support; Surrogate decision-making, ICU

Introduction

Critical care is an integral part of hospital care, and the intensive care unit (ICU) is the setting where patients are given the most technologically advanced life-sustaining treatments. These treatments are expensive and resource-intensive, but can sustain life despite severe and multiple organ dysfunction. The ICU is, however, also a setting where death is common and end-of-life care is frequently provided. Since the focus in ICUs is on sustaining life, the delivery of high-quality end-of-life care can be particularly challenging, and clinicians often find the dual responsibilities of saving lives and delivering end-of-life care difficult. Because of the nature of critical care, difficult decisions often need to be made about the usefulness of life-sustaining treatments, not only in terms of the probability of survival but also the quality of life associated with survival. Difficult decisions also need to be made about the fairness of expending substantial resources on one patient.[1] Furthermore, because most critically ill patients do not have the capacity to make decisions, the family frequently becomes involved in discussions about the goals of care and often represents the values and preferences of the patient.[2] The extent to which the family is directly involved in such decisions varies according to the countries and cultures;[3] however, good communication between the clinician and family is essential for quality end-of-life care in the ICU, irrespective of the location.[4]

Data from observational studies indicate that end-of-life care in the ICU varies greatly between countries.[5–9] The reasons for this variability have not been clearly defined, but are probably diverse, including differences in religion,[10] legislation and culture,[10,11] organisation of care in the ICU,[7,12,13] attitudes of physicians toward end-of-life care,[14] severity of illness and casemix,[7,15] and the physician’s predictions of prognosis and future quality of life.[15] Variability also exists within countries[16–19] and between intensivists within hospitals.[20]

Admissions and triage decisions

The availability of ICU resources vary substantially in different countries, and decisions about admission, triage, and end-of-life care vary accordingly. For example, ICU care is not available in many countries in the developing world and in rural regions of developed countries. Even where ICU care is available, the proportion of hospital beds that are ICU beds differs between centres.[21] The availability of beds in the ICU will, by necessity, affect decisions about indications for care in the ICU; this assertion is supported by an association between the mortality rate in the ICU and availability of beds in the ICU.[21,22] However, the availability of beds should not affect the ethical principles that guide the use of intensive care.

An integral part of the ethics of critical care is the process used for decisions about who needs treatment in the ICU, and when that treatment is no longer indicated. Treatment might be judged to be not indicated because patients are not sick enough for care in the ICU, or because they are too sick and such care is unlikely to provide benefit. The American Thoracic Society has outlined several important principles that should guide decision making about admission and triage.[1]

The main duty of the ICU team is to ensure patient welfare and that care in the ICU, when appropriate, constitutes basic medical care. The duty of the ICU team to provide benefit to a patient has limitations when provision of care for that patient unfairly compromises care for others.

The recommendation that every ICU should have explicit and written criteria for admission and discharge of the patient is supported by statements from critical care professional societies.[1,23,24] Most ICUs do have such criteria, but they generally require interpretation in the application to individual patients, and intensivists report that these criteria are not explicitly used to decide admission or triage status for most patients.[21]

Availability of ICU resources in a region will have important effects on decisions about admission and triage. Importantly, these decisions should be governed by ethical principles, irrespective of the availability of beds in the ICU.

The ageing population in many countries will increase the importance of these issues in the future. In the USA, for example, the proportion of all deaths that occur in the ICU is nearly 20%, and this proportion does not decrease with increasing age until after 85 years.[25] The proportion of all deaths in elderly people that are preceded by cardiopulmonary resuscitation is increasing.[26] Society and countries need to develop approaches to address the appropriate delivery of critical care to the increasing population of elderly people, especially those with chronic life-limiting disease. These approaches will probably vary according to the country and health-care system, but the ethical principles should be similar and many regions will have similar disparities that need to be addressed.

Communication about end-of-life care in the outpatient setting between physicians and patients with life-limiting disease is not associated with patient distress, and is associated with a reduction in use of unsuccessful life-sustaining treatments, improved quality of life, and reduction in health-care costs at the end of life.[27,28] Advance directives and advance care planning have recently been shown to be associated with patients receiving care matching their preferences, and have also been shown to be associated with less aggressive care at the end of life and with better family ratings of end-of-life care.[29–32] Although these discussions are generally not the purview of intensivists, efforts to increase the quality and quantity of these discussions when patients are stable are likely to improve our ability to maximize the effectiveness of intensive care, and reduce the burden of end-of-life care in the ICU on patients, families, and the health-care system.

End-of-life decisions

Interdisciplinary communication

End-of-life care in most settings is delivered by an interdisciplinary team that includes nurses and physicians. Ideally, end-of-life decisions should be made after discussions between all members of the interdisciplinary team. However, interdisciplinary collaboration about end- of-life care is often poor and varies across countries.[33,34] For example, in a prospective survey in 113 French ICUs, end-of-life decisions were made by one physician in 12% of cases, by medical staff alone in 34% of cases, and by medical and nursing staff in 54% of patients.[18] In a study of an ICU in Lebanon, nurses were not involved in 26% of end-of-life decisions.[35] In a questionnaire study of 1961 intensivists from 21 countries, for a hypothetical patient without any family, 62% of physicians from northern and central Europe would involve nurses in end- of-life discussions compared with only 32% of physicians in southern Europe, 39% in Japan, 38% in Brazil, and 29% in the USA.[9] Patients and families report that interdisciplinary collaboration is an essential part of good end-of-life care.[36] Poor interdisciplinary collaboration about end-of-life care is associated with increased symptoms of burnout, depression, and post-traumatic stress among clinicians working in the ICU.[37–39] Additionally, conflict between clinicians in the ICU is common, is increased with delivery of end-of-life care, and is associated with increased job stress.[40,41] Therefore, improved interdisciplinary collaboration for end-of-life care in the ICU is important for improvement of the quality of care and the work environment for clinicians.

Communication between clinician and family

Physicians caring for critically ill individuals have an obligation to disclose information about a patient's condition and prognosis to the patient and the patient's family. The families of critically ill individuals are an important source of information about the patient's values and treatment preferences. In 2005, five international critical-care societies issued a consensus statement advocating shared decision making about life- sustaining treatment in ICUs.[42] In this statement, a shared decision is defined as one in which "responsibility for decisions is shared jointly by the treating physician and the patient's family".[42] Guidelines for end-of-life care also emphasise the importance of involving the patient (when possible) and the family.[43] Nevertheless, substantial international differences exist in the amount of involvement of the patient and family in the end-of-life process. Moreover, although most families want the physician and ICU team to provide a recommendation about whether to restrict life support and then want to share in the final decision,[44,45] some families do not wish to be involved in such decisions or want to make decisions without a recommendation from the physician.[46–48]

Traditionally, families have been much more involved in end-of-life decision making in the USA than in Europe.[49] In the Ethicus study,[6] done in 37 ICUs in 17 European countries, end-of-life decisions were discussed with the family more commonly in northern (84%) and central (66%) than in southern (47%) Europe. Huge variations have been reported in family involvement – from 100% in India,[50] 98% in Hong Kong,[51] 79% in Lebanon,[35] 72% in Spain,[19] to just 44% in France.[18] In a questionnaire study of intensivists in Italy, 19% of physicians said the close family were never involved in such decisions and 56% would never involve patients even if competent.[52]

Physicians need to be aware of the variety and complexity of attitudes present in our increasingly multicultural society, and adapt their approach to the situation. There is a range for physician's role in decision making from parentalism in which the physician makes the decision to autonomy where the patient or family makes the decision with shared decision-making in the middle.[53] The figure shows a potential approach to match the clinician's role with the needs of the patient and the patient's family. Shared decision making is the default position that is modified in three steps.[4] First, as the prognosis worsens and the certainty of the prognosis increases, so should the physician's willingness to take on the burden of making a decision. Second, the preferred decision-making role of the family is assessed. Last, the approach is adapted to the patient and family factors identified in the first and second steps. For this approach to work, communication between physicians and the family needs to be optimum. However, communication between the clinician and the family in the ICU is often inadequate; in one study, only half of families of patients in the ICU understood basic information about patients' diagnoses, prognoses, or treatments after discussion with clinicians.[54]

A focus on communication with the families of all critically ill patients is important, not just those expected to die. Whether critically ill patients will survive is often not clear at the time when communication between the clinician and family should be happening. Additionally, although the patient's death is a risk factor for psychological symptoms among the family, the families of patients who survive are also at increased risk of these symptoms.[55] Families of patients who survive are less satisfied with communication from ICU clinicians than are those of patients who die.[56]

Discussions between clinicians in the ICU and family about goals of care and medical decision making often take place during conferences between the inter- disciplinary team and family. Features of these conferences that are associated with improved family experience or assessment of communication have been identified in several studies. For example, improved outcomes are associated with a private place for family communication and with consistent communication by all members of the team.[57] Family are more satisfied when clinicians spend more time listening and less time talking.[58] Other features of clinician communication associated with improved family experiences include assurances that the patient will not be abandoned before death; assurances that the patient will not suffer; and explicit support for family decisions.[62] Empathic statements by clinicians are also associated with increased family satisfaction.[59] When there is conflict between staff and families, ethics consultations have been beneficial.[63]

When communication occurs across cultures or languages, the likelihood of miscommunication is increased;[64] involvement of family-specific religious or community leaders and professional interpreters could be helpful.[64] Errors in communication are common even with professional medical interpreters and might affect understanding, decision making, and emotional support.[65,66] Some simple steps can improve this communication: clinicians can meet briefly with interpreters before the conference, speak slowly allowing time for interpretation, restrict the number of simultaneous conversations, and use pictures or drawings when possible.[67] Another important part of care in the ICU is to assess the spiritual needs of the families and then offer them spiritual care if desired. Family satisfaction with care is increased if spiritual care needs are assessed, and spiritual care is provided by a spiritual-care provider.[68,69]

Withholding or withdrawing life support

Most patients who die in ICUs do so after a decision has been made to restrict life-sustaining treatments,[6–8,70] but there are substantial differences in the proportion of deaths preceded by withholding or withdrawing life support internationally. In the Ethicus study,[6] withdrawal of life-sustaining treatments was reported as more common (47% vs 18%, p<0,001) in northern European countries (Denmark, Finland, Ireland, Netherlands, Sweden, and UK) than in those in southern Europe (Greece, Israel, Italy, Portugal, Spain, and Turkey). In an analysis of 14 488 patients from 282 ICUs in seven different geographical regions, deaths occurring after a decision to restrict life-sustaining treatments vary from 26% in Central and South America to 48% in central and western Europe.[7] Life support was withdrawn or withheld in 59% of patients who did not survive in Hong Kong,[51] 53% in France,18 45% in Lebanon,[35] 41% in Sweden,[71] 35% in Spain,[19] and 49% in India.[47] Differences in religious and cultural backgrounds are likely to be one of the major reasons for these international differences.

Although many ethicists and critical-care societies state that there is no ethical distinction between withholding or withdrawing life-sustaining treatments,[43,72,73] this perspective is not universally accepted, and some ethicists and intensivists believe that an important distinction exists between withholding and withdrawing life-sustaining treatments.[74,75] In Israel, for example, orthodox Jewish law allows life-sustaining treatments to be withheld, but withdrawal of continuous interventions is forbidden because it is regarded as an act to shorten life.[76] However, withdrawal of intermittent life-sustaining treatments is permitted because it is seen as the next treatment being withheld rather than the withdrawal of the present one.[76,77]

Religion is an important determinant of attitudes toward dying, death, and end-of-life care, and includes the religion of patients, their families, and their clinicians. For example, in the Ethicus study,[11] treatment was withheld more often than it was withdrawn if the physician was Jewish (81%), Greek orthodox (78%), or Muslim (63%), whereas withdrawal occurred more often when physicians were Catholic (53%), Protestant (49%), or had no religious affiliation (47%). Religion is also an important determinant of acceptance of brain death, a state that is widely, but not universally, accepted.[6,10]

With the large numbers of deaths now associated with a decision to withhold or withdraw life-sustaining treatments, improvement of the process by which life-sustaining treatments are withheld or withdrawn is an important aspect of improving quality of ICU care.[43] There are few data to guide clinicians in the practical aspects of withdrawing life-sustaining treatments.[78] Withdrawal of these treatments is a clinical procedure that deserves the same preparation and expectation of quality as do other procedures.[43] These decisions can become routine for clinicians working in the ICU, and, as such, clinicians must be careful to guard against the subtle institutional pressures to withdraw life-sustaining treatments.[79] Rationale for the decision to withdraw life support should be noted in the medical record.

An explicit plan for the procedure should be developed: the patient should be in the appropriate setting with irrelevant monitoring removed; the process should be carefully documented in the medical record, including the reasons why sedation or analgesia was increased; and outcomes should be assessed. The plan should also be discussed thoroughly with the patient (if possible) and family to ensure they understand the planned process, potential symptoms, and the plan for treatment of symptoms.[80]

Once a decision is made to withdraw life-sustaining treatments, the time during which a treatment is withdrawn should be determined by the potential for discomfort as treatment is stopped. The only legitimate rationale why life-sustaining treatment is tapered in this setting is to allow time to treat patient's symptoms. Mechanical ventilation is one of the few life-support treatments in which abrupt termination causes discomfort. Typically, the transition from full ventilatory support to T piece or extubation should take less than 10–20 min. Drugs, including opioids and benzodiazepines, are often used to treat the patient's distress or discomfort and there is some observational evidence to suggest that appropriate use of these drugs does not hasten death.[81,82] Few data exist to support whether patients should be extubated after terminal discontinuation of mechanical ventilation. No significant difference was noted in patient comfort in small studies, which lacked power to detect clinically important differences.[83] Families rate quality of dying higher when patients are extubated, but firm conclusions cannot be drawn because of the observational nature of such studies.[84] The decision to extubate should, therefore, be made on an individual basis, depending on the anticipated time to death and family preferences about the presence of an endotracheal tube and the potential for distressing respiratory sounds.

Like many aspects of critical care, a protocol to withhold or withdraw life-sustaining treatments, if carefully developed to accommodate local standards, could provide an opportunity to improve care and reduce inappropriate variability in care. An ICU order form for withdrawal of life-support that was assessed in a before and after study included preparations before withdrawal of life support (such as discontinuation of routine laboratory tests), and protocols for analgesia and sedation in this context, and ventilator withdrawal.[85] Physicians and nurses thought that the order form was helpful, and implementation was associated with increased use of benzodiazepine and opiate drugs in the hour before and the hour after ventilator withdrawal, but without an associated reduction in time from ventilator withdrawal to death, suggesting this approach can increase drug use for patient comfort without hastening death.

Conclusions

There is substantial regional and international variability in the approaches to end-of life care. Some of this variability will diminish as we develop a global consensus about the ethics of critical care, but some variability will inevitably remain because of regional variation in religious and cultural perspectives about end-of-life care, and also variation in the availability of ICU resources. Development of global consensus about end-of-life care, to the extent possible, will require open and continued discussion of these issues in international forums. In all regions, the delivery of ethical and high-quality critical care requires training and emphasis on ethical decision making, communication and collaboration throughout the interdisciplinary team, effective communication with patients and families, and identification and resolution of conflict within the team and with patients and families.

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