

17.10 Palliative and end-of-life care in the ICU

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ESSENTIALS What happens when organ support leads to prolongation of life, but with no hope of ultimate survival, or survival with unacceptable quality of life? For many—but not all—patients, families, and physicians, prolongation of life with little or no hope of a good quality of life is considered worse than death. The cultural milieu is central in determining the responses and needs of all parties in regard to end-of-life care. Excellent communication is required to prevent potential conflicts and provide both the medical team and the patient/family with peace of mind. The decision to institute palliative or end-of-life care should, if at all possible, always be reached via a negotiating process between the medical staff and the patient or their family. The best protection against conflict comes from a good bedside manner reflecting patience with the family, honesty, and some optimism. However, conflicts do arise, and rarely these require the intervention of third parties such as ethics committees or courts.

Introduction As is clear from other chapters in the critical care section of this book, incredible progress has been made in ICU-based organ support over the last decades. Patients are able to survive illnesses today that would have led to certain and rapid death only a few years ago. This progress, however, has been accompanied by dilemmas of quantity versus quality. What happens when organ support leads to prolongation of life, but with no hope of ultimate survival, or survival with unacceptable quality of life? For many—but not all—patients, families and physicians, prolongation of life with little or no hope of good quality of life is considered worse than death. So arises the need for palliative and end-of-life care in the ICU. In this chapter we will explore the history and terms associated with end-of-life care, variability in practice, factors influencing the decision-making process, differing practices around the world, sources of conflict, and how we can improve. Two central tenets will become

clear during the course of this chapter—first that the cultural milieu is central in determining physicians', patients' and families responses and needs in regard to end-of-life care, and second that excellent communication is required to prevent potential conflicts and provide both the medical team and the patient/family with peace of mind. History From the beginnings of intensive care in the 1950s until around 1970, there was only one objective of therapy: to prolong life. It was considered medically, morally, ethically, and legally imperative to pursue treatment including cardiopulmonary resuscitation (CPR) until the moment of death. During this time, however, it became clear that medical interventions did not always lead to a meaningful recovery or to recovery at all. The concept arose that some treatments were deferring death rather than prolonging life. For some families this was intolerable and from 1970 on they sought the support of the courts in demanding that hospitals stop life-prolonging treatment and allow their loved ones to die. In the first such case (the Quinlan case in the United States in 1976) the court determined that the hospital would not be legally liable if artificial ventilation was stopped. This was a landmark case as it was the first time that a hospital could officially perform an action that might result in death rather than prolong life without fear of legal challenge or sanction. Increased involvement of the patient and their family in decision-making led to the growth of patient autonomy and the decline of physician paternalism; the patient would decide which of the offered treatments to receive rather than the physicians. This change in balance between the patients and their physicians had the potential for problems; physicians were at risk of losing their independence in medical decision-making. The change in balance also placed physicians in a difficult position as they possessed the knowledge of the illness and prognosis, while the family (in the extreme) was expected or considered themselves responsible for decision-making. Possibly in an attempt to rationalize this situation, medical decision-making adopted a series of positions to justify or objectify limitation of life support. These included financial justifications based on the concept of distributive justice (limiting therapy was necessary to limit costs and prevent waste), available resource justification (the demand for ICU beds often exceeded supply justifying limitation of therapy for those who were thought to have a poor prognosis), and the growth of the futility movement.

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3915 Futility was given several definitions, all of which centred on defining treatments that were of no benefit for the patient. If a treatment was defined as futile, then physicians were not obliged to provide it, thus making limitation of life-sustaining treatment an objective decision reached by the physician. Repeated studies, however, showed that physicians' ability to provide an accurate qualitative prognosis or estimate of the risk of death is far from perfect. Further, it soon became clear that 'benefit' was a subjective value judgement. Prolonging life with no quality represented futility to one, while it was a religious imperative to another. Changing the term 'futile therapy' to 'inappropriate therapy', perhaps in an attempt to dampen the negative connotation and portray objectivity, made no real difference to the cultural dilemmas associated with limiting therapy. The situation today is that the decision to institute palliative or end-of-life care is almost always reached via a negotiating process between the medical staff and the patient or their family. Paternalism does still exist, with some physicians making and instituting end-of-life decisions without patient/family involvement, or even against their will. Very occasionally, physicians will also continue full care despite a patient/family's wish to stop. Conflicts do arise and these sometimes, although rarely, require the intervention of third parties such as ethics committees or the courts. Decision-making and outcome

Five terms are

commonly associated with levels of therapy in the ICU and describe a spectrum of limitation of life-sustaining therapies. The spectrum ranges from 'Full Therapy' through do not resuscitate (DNR) orders, withholding and/or withdrawing therapy, to active shortening of the dying process. Definitions and descriptions of these levels of care are provided in Table 17.10.1. Most of the large critical care or medical organizations (including the British Medical Association, the American Thoracic Society and the Society of Critical Care Medicine) concur that there is no ethical difference between decisions to withhold or withdraw therapy. There is, however, recognition that stopping an existing therapy may be associated with 'greater emotional difficulty' for the ICU physician and patient/family than not starting a life-prolonging therapy. Most societies and countries define active shortening of the dying process (euthanasia) by a physician as unacceptable or illegal, although the administration of drugs with the primary intent to relieve symptoms is accepted even if that has the secondary effect of shortening life (sometimes referred to as the 'principle of double effect'). The effects and outcomes of limiting the treatments to be offered vary across the spectrum. A DNR order can be instituted by a patient in good health to be applied only if and when required. People may live healthy, long, and fulfilling lives with existing DNR orders in the form of living wills. Withholding decisions implemented during ICU admission are associated with significant mortality (89% after a median of 14 hours), while withdrawing decisions are associated with a 99% mortality within a median of 4 hours. Active shortening of the dying process is associated with 100% mortality. One of the central ethical tenets of medicine in the western world is patient autonomy, meaning that the patient should determine which of offered medical interventions he/she receives. This is reflected in the process for acquiring informed consent before many medical interventions. When the patient is capable, consent for treatments or procedures should be sought in the ICU, but many patients in the ICU are unable to express their preferences. Pre-existing medical directives (advance directives or living wills) are maintained by only a small minority of patients, but their presence should be actively sought in discussion with the patient or their family. When the patient is not able to make decisions, and there is no advance directive, decision-making authority is usually passed to a proxy: a loved one, family member or close friend who is presumed to know the patient's wishes or to share the patient's outlook on life.

In most Table 17.10.1 Terminology used to describe levels of treatment offered to patients and end-of-life care

A) Full therapy	All interventions to sustain and prolong life are to be employed.
B) Withholding treatment	Certain intermittent interventions should not be started or reinstituted. For example, do not start dialysis, or do not start vasoactive drugs if and when needed. As dialysis is an intermittent intervention, not restarting dialysis after a previous session would also be considered withholding. A Do Not Resuscitate (DNR) (also referred to as DNAR—Do Not Attempt Resuscitation, NFR—Not For Resuscitation or No Cardiopulmonary Resuscitation—No CPR) order can also be considered as a type of withholding as when and if required, cardiopulmonary resuscitation will not be started. Some consider DNR orders a special case of general withholding orders and classify DNR orders separately.
C) Withdrawing treatment	Cessation of an existing continuous therapy even if indicated to prolong life. Such an intervention might be extubation in a mechanically ventilated patient not expected to survive without further mechanical ventilation. Withdrawing therapy differs from withholding in that it involves cessation of a continuous life-supporting intervention while withholding relates to not instituting or restarting an intermittent therapy.
D) Active shortening of the dying process (also termed active euthanasia by some)	These interventions are performed to actively hasten death and might include administration of high doses of potassium chloride, opiates, or sedatives. These measures must be distinguished from palliative (comfort) measures (such as the administration of morphine to prevent dyspnoea) which

have the primary purpose of preventing suffering, but might also be associated with inevitable side effects such as depression of ventilation. The purpose of administering morphine during the dying process is usually to relieve suffering. Morphine is not given specifically to cause apnoea, although this is an accepted side effect. Therefore morphine administration is considered a comfort measure and not an intervention to actively shorten the dying process. If morphine is given in very large doses (greater than needed to relieve pain or suffering) only to produce apnoea, it would be considered an intervention to shorten the dying process. Clearly there is potential overlap between palliative therapy and active shortening of the dying process. E) Brain death (brain stem death in the United Kingdom) Removal of ventilation or cessation of vasoactive drugs after formal declaration of brain death by the appropriate criteria is considered by some to be a form of withdrawal. As brain death is an accepted definition of death by most jurisdictions, life-supporting therapy becomes an oxymoron and therefore cessation of ventilation (e.g.) is not considered by most to be a form of withdrawal.

Section 17 Critical care medicine 3916 jurisdictions the natural proxy is assumed to be the patient's parent (even if the patient is above the age of 18), partner or child, and these family members are able to make end-of-life decisions without a formal appointment. In other jurisdictions, or when there is conflict between family members, an official court order of guardianship is sometimes required. Variability in end-of-life practices From the beginning of research into end-of-life practices it became clear that there is huge variability in the decision-making process and in end-of-life practices. Across hospitals in the United States the use of withhold and withdraw orders in patients who subsequently died ranged from zero to 67% and zero to 79%, respectively. Similarly, in Europe there is great variability with a marked north/south divide. Northern European countries are significantly more liberal in their use of limitation orders than Southern European countries. In case scenarios, DNR orders were issued by 91% of Dutch physicians as compared to 8% of Italian physicians, while 71% of French physicians would be willing to prescribe drugs that would speed death, compared to 8% of Portuguese physicians. Many non-patient-related physician variables beyond nationality have been associated with the end-of-life decision-making process. These include physician age (younger physicians being more likely to withdraw therapies than older physicians), religiosity, religious affiliation, specialty, level of training, and others. In other words, it appears that physicians' cultural background and cognitive processes may affect end-of-life decisions as much as the patient's physiological condition. From the patient's perspective, the cultural (rather than ethnic) background also affects decision-making. This has been explored by examining population migration. For example, in a scenario based end-of-life questionnaire, English-speaking Japanese Americans (assumed to be highly acculturated to American life) have been compared to Japanese speaking Japanese Americans (less acculturated to America) and to Japanese in Japan (not acculturated to America). English-speaking Japanese Americans agreed in a high proportion that the patient should be told his diagnosis, and they were more willing to withdraw care, which are values commonly found in the general American population. A progressively lower proportion of the other two groups agreed to these sentiments, with Japanese in Japan making decisions furthest away from English-speaking Japanese Americans. This study suggests a process of acculturation, meaning that cultural elements may be imposed on one's ethnic background. In the face of this great national, ethnic, and culture variation in end-of-life care, an attempt to identify areas of common ground and differences in attitudes to end-of-life care was recently described in the WELPICUS study. This study examined concurrence between 1366 physicians, nurses, social workers, and others from a

variety of national and cultural backgrounds concerning 81 statements about end-of-life care. On repeated questionnaire with adaptation of the end-of-life statements, consensus was reached for 77 of 81 statements (95%). Agreement could not be reached between more than 80% of the respondents for four statements. All these statements involved interaction with the patient's family: withholding or withdrawing therapies without the consent of the patient or family; hastening the dying process at a family member's request; and a family's refusal to accept brain death. So, in spite of variations in practice, there seems to be considerable common ground regarding the concepts of end-of-life care. This difference between theory and practice in end-of-life care has also been identified empirically. Family members often agree that the therapies being given to a patient are inappropriate or unnecessary, and even that they would not want them for themselves. However, families will not agree to stop these therapies for their loved one. This even occurs when the patient has previously clearly defined their requirements in the event of life-sustaining therapy being required. In conclusion, non-medical-related variables among both physicians and patients are highly influential on the end-of-life decision-making process. Given the ever increasing multicultural nature of medical practice in many countries, cultural or ethnic differences between physicians and their patients are inevitable.

Communication One of the earliest investigations into communication around the end-of-life was the SUPPORT study published in 1995. This study demonstrated that on approximately 50% of occasions, ICU physicians were unaware of their patients' wishes regarding resuscitation. While family involvement in decision-making is almost universal in the United States, conflicts have been described by families in up to 63% of cases, many of which were not identified by physicians. In Europe physicians have been described as making end-of-life decisions without involving the family at all in 28% of cases, or have informed the families of the decision (rather than involved them in decision-making) on 59% of occasions. In Hong Kong and Japan family involvement is high, with decisions sometimes being made with the exclusion of the patient, even when the patient is mentally competent. The reasons for lack of good communication have not been widely explored. They may relate to difficulty in discussing end-of-life issues, physician preconceptions, cultural norms, or lack of teaching of end-of-life care in medical school and during clinical training programmes. Several tools have been published to improve communication, developed mainly from the oncology field where breaking bad news is a frequent occurrence. These include SPIKES and VALUE, which share several similarities (see Box 17.10.1 and Box 17.10.2). A common element of family discussions, which we consider an error, is exaggerated attention to the risks and possibility of negative outcomes. Many physicians prefer to paint a bleak picture, as then Box 17.10.1

SPIKES Setting—patient and/or family meetings should be planned in a suitable quiet uninterrupted setting
Perception—explore the patient/family's perception of the medical situation before starting to impart information
Invitation—establish how much the patient/family want to know
Knowledge—impart information after (when appropriate) giving warning that bad news is coming; avoid excessive bluntness
Empathy—show empathy for the emotional reaction
Strategy—explain the future plans, for the next hours or days as appropriate

17.10 Palliative and end-of-life care in the ICU 3917 they believe they have been honest, and that the family is prepared. If the outcome is good, then the families 'get a nice surprise'. Almost all families who have a loved one in the ICU understand that they are gravely ill and at risk of dying—why else would they be in the ICU? These families do not need to have the risks emphasized over and over: they need the truth, but they also need hope. In explaining the situation the physician clearly has to be honest, but if at all possible some positive aspect should be sought, even if this is only that the patient is no longer suffering and that the team is providing

them with the best possible care and treatment. If there is a realistic chance of recovery, this should not be kept from the family. Conflict Possibly owing to cultural variation and differences in expectations, conflicts between the ICU staff (physicians and nurses) and families are not uncommon. Conflicts also occur between members of the ICU team. At least half of these conflicts relate to end-of-life care, with most arising from the family's wish for more aggressive care than the physicians are recommending. Risk factors for conflict include previous discrimination in the hospital, possibly indicating a lack of trust. The best protection against conflict comes from a good bedside manner reflecting patience with the family, honesty, and some optimism. Involving the nurses, a social worker or a psychologist in family discussions is sometimes beneficial. These team members might be able to devote additional time to the family and explore their understanding of the information that the physicians are trying to impart. They can also raise particular areas of family concern that might require additional explanation at the next family meeting. Devoting time to communication usually leads to consensus and shared decision-making. Another source of conflict is mixed messages, with different prognoses being suggested by different doctors or others within the multidisciplinary team. Every effort should be made to agree a common understanding and message that should be presented by all those involved in the patient's care. Lack of good communication or conflict is associated with low family satisfaction in the ICU and once conflict occurs and trust is lost it is difficult, although not impossible, to regain that trust. In the event that an impasse is reached, third party help from outside the ICU can be sought. This might include an ethics consultation. Ethics committees vary from institution to institution but usually include nonmedical members in addition to physicians who hear both sides of the situation and attempt to mediate a decision. Unfortunately ethics committees are often seen as another arm of the hospital administration and thus as nonobjective. They are rarely convened. The judicial system remains a rare if final resort, although the time frame of court decision-making sometimes makes it irrelevant to end-of-life care. The authors' perspective Having described in depth the influence of cultural background to end-of-life decision-making, we should disclose our own environment as despite our best efforts to be objective we are undoubtedly influenced by this environment. Both authors have worked in healthcare systems in different countries with a variety of end-of-life practices. Currently we both work in an environment where withdrawal of continuous therapy is illegal, and the expectation of patients and families is almost invariably to fight on until the end with quantity of life exceeding the need for quality. We are unfortunately often faced with families and colleagues who 'want everything done', even when it is very clear that 'everything' will not be enough. We are thus frequently involved in family meetings that are emotionally charged. Patience, sensitivity, tolerance, and training can lead to better outcomes for patients and their families. FURTHER READING Azoulay E, et al. (2009). Prevalence and factors of intensive care unit conflicts: the conflicus study. *Am J Respir Crit Care Med*, 180, 853-60. Cook D, Rocker G (2014). Dying with dignity in the intensive care unit. *N Engl J Med*, 370, 2506-14. Kaplan M (2010). SPIKES: a framework for breaking bad news to patients with cancer. *Clin J Oncol Nurs*, 14, 514-6. Mark NM, Rayner SG, Lee NJ, Curtis JR. (2015). Global variability in withholding and withdrawal of life-sustaining treatment in the intensive care unit: a systematic review. *Intensive Care Med*, 41, 1572-85. Sprung CL, et al. (2003). End-of-life practices in European intensive care units: the Ethicus Study. *JAMA*, 290, 790-7. Sprung CL, et al. (2014). Seeking worldwide professional consensus on the principles of end-of-life care for the critically ill: the Consensus for Worldwide End-of-Life Practice for Patients in Intensive Care Units (WELPICUS) study. *Am J Respir Crit Care Med*, 190, 855-66. Truog RD, et al. (2008). Recommendations for end-of-life care in the intensive care unit: a consensus statement by the American College of Critical Care Medicine. *Crit Care Med*, 36, 953-63. Box 17.10.2 VALUE Value family statements Acknowledge family emotions

Listen to the patient and/or family Understand the patient as a person Elicit family questions

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