

## End-of-life care in the intensive care unit

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## End-of-life care in the ICU

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## **Summary**

The transition from active, invasive interventions to comfort care for critical care patients is often fraught with misunderstandings, conflict and moral distress. The most common issues that arise are ethical dilemmas around the equivalence of withholding and withdrawing life-sustaining treatment, the doctrine of double effect, and balance between paternalism and shared decision-making; legal challenges around best-interest decisions for patients that lack capacity and conflict resolution; practical issues around medication and practices during the limitation of treatment. The aim of this article is to address commonly posed questions on these three aspects of end-of-life care in ICU, using best available evidence, and provide practical guidance to critical care clinicians in the UK. With the help of case vignettes, we clarify the disassociation of withdrawing and/or withholding treatment from euthanasia, offer practical suggestions for the use of sedation/ analgesia around the end of life, dissipating concerns about hastening death and advocate the inclusion of family in decision-making, when the patient does not have capacity. We propose a step-escalation approach in cases of family conflict and ask for incorporation of communication skills during medical and nursing training.

## **1. Introduction**

Despite significant technological advances in the field of critical care, the mortality of patients admitted in intensive care units (ICUs) remains considerable [1,2]. More than 80% of those deaths are a result of conscious decisions to withdraw life sustaining therapy [1], either when the therapeutic goal is not possible to be reached or when the burden of provided treatment is thought to outweigh its benefits. The transition from active, invasive interventions to comfort care is often fraught with misunderstandings, conflict and moral distress [3], as end-of-life decisions are influenced by individuals' culture, religion and geographical location [4,5]. The result is substantial variability in end-of-life practices between world regions, countries, individual ICUs within a country, but also individual intensivists within one ICU [6]. Even in countries where withdrawal practices are common, such as North America and Northern Europe [1,6], the differing legal frameworks prohibit unifying recommendations.

The importance of providing good quality end-of-life care in ICU has been recognised by many professional bodies in the last two decades [7-9]. Several key ethical concepts were introduced to clinical practice, namely the moral equivalence of withdrawing and withholding life-sustaining treatment (LST), and the difference between intended and foreseen circumstances [9]. Patient- and family-centred care emerged as a comprehensive ideal for end-of-life care in ICU, with guidance suggesting active involvement of the family in decision-making but also in the delivery of end-of-life care in ICU. Palliative care was proposed as a multi-faceted approach, much broader than symptom management, to improve the experience of patients and their families when active treatment had failed [10]. However, care near the end of life still presents several moral, legal and practical challenges to ICU clinicians, which have the potential to increase anxiety and conflict with patients and families, and lead to moral distress in healthcare providers [11]. The aim of this article is to summarise the main issues around end-of-life care in ICU and provide practical guidance to critical care clinicians in the UK, using clinical scenarios that illustrate common challenges.

## **2. Ethics around end of life**

A man aged 55 is admitted to ICU, following an out of hospital cardiac arrest. Prior to admission he had 10 minutes of bystander cardiopulmonary resuscitation (CPR) and then 30 minutes of CPR by a paramedic crew before return of spontaneous activity (initial rhythm was pulseless electrical activity). He had 4 days of routine post cardiac arrest care, as per international guidance. Two weeks off sedation, he is still unconscious but responds to pain by flexing his arms. Although he does not properly localise, his neurology has improved since his admission. His neurospecific enolase is elevated (suggesting a poor prognosis) and his computed tomography (CT) head suggests some loss of grey, white matter differentiation. An electroencephalogram is compatible with hypoxic brain damage. In view of his slight improvement in neurology, the consultant in charge feels they should continue with full support for at least a few more weeks. However, his wife of 35 years is adamant that he would not want to survive in a significantly dependent state, and so the critical care team start planning the limitation of life-sustaining treatment.

Is withdrawal of treatment the same as withholding?

The equivalence between withdrawing and withholding of LST has been a matter of intense debate, with ethicists arguing strongly mainly in favour [12], but also against [13]. The moral equivalence is implied in the UK professional guidelines [14] and supported by international decision-support tools [15], as well as in the report of an international Ethics Round Table Conference [16]. Despite ethicists' arguments favouring the equivalence theory, critical care clinicians appear more uncomfortable withdrawing treatment than withholding it, making a distinction that seems to persist through time [17,18]. Several explanations have been offered for the rejection of the equivalence theory in practice, such as the perceived moral difference between an act (withdrawing) and omission (withholding) [19], the stronger association between an action and the result (death), as well as the short temporal link between them. Furthermore, physicians find some types of therapy more difficult to withdraw than others, with removal of the endotracheal tube being the least practiced act of withdrawal globally [20]. The disparity between the philosophical stance and the observed practice has led some ethicists to state that instead of repeating '*ad nauseam* that withholding and withdrawing treatment are equivalent [...], we must find ways of translating ethical analysis into practice' [12].

Is limiting life-sustaining treatment the same as euthanasia?

Whether withdrawing/withholding LST and euthanasia are distinct moral entities has been the focus of many heated debates and the full analysis of the ethical arguments is well beyond the scope of the present article. In summary, in one of the most cited papers in medical ethics published almost 40 years ago, the philosopher James Rachels asserted that 'the distinction between active and passive euthanasia is thought to be crucial for medical ethics. The idea is that it is permissible, at least in some cases, to withhold treatment and allow a patient to die, but it is never permissible to take direct action to kill a patient' [21]. Since then, the notion of 'passive euthanasia' has been strongly contested as a 'contradiction in terms' [22], as has the association between limitation of life-prolonging therapy and euthanasia [23,24]. The most common reason for the moral distinction is the absence of intent that characterises the former action: when withdrawing treatment, the physician's aim is to stop the interventions that are unlikely to benefit the patient or that are causing them distress, without a chance to restore them back to health. Their intention is not to cause the patient's death, as it would have been in a case of euthanasia. If the patient dies after the limitation of treatment, then this is a foreseeable but not intended outcome. The disassociation of withdrawing/withholding LST from euthanasia is essential to allow ICU clinicians to perform their clinical duties unhindered, not only morally but also legally (since euthanasia is illegal in most countries). An interesting dialogue on this contentious topic was recently published and demonstrates the alternative positions that still exist in key areas of ethical tension [25].

Does analgesia/ sedation hasten death?

Analgesia and sedation are important agents in the treatment of ICU patients, in order to manage pain, anxiety and agitation, avoid failure of LST equipment and involuntary extubation, and enhance synchrony with mechanical ventilation. Clinicians are concerned that symptom control (particularly by analgesia) at the end of life may hasten death, however there is no solid evidence to support this. A systematic review that synthesised evidence around terminal withdrawal of

mechanical ventilation in adult ICUs revealed inconclusive findings [26]. Robert et al. found that there was no association between doses of sedation and analgesia and the shortening or delay of death [27]. Mazer et al. reported that higher doses of opioids given the hour before death after terminal extubation correlated with statistically significant longer time to death [28], whereas Long et al. reported that higher doses of opioids and benzodiazepines were associated with shorter time to death [29].

In order to avoid moral conflict, it must be made clear that the patient is dying and that the goal is to avoid an uncomfortable death, even if the timing of death is potentially influenced by medication delivery. As discussed above, the distinction lies in the intention, which is to provide symptom control around the end of life and not hasten it. This principle, known as the Doctrine of Double Effect, is aligned with ethics and law across many jurisdictions and religions, serving as a conduit for effective treatment [30].

How much weight does the opinion of the family carry?

One of the cornerstones of contemporary healthcare is that every competent patient has the right to accept or reject any intervention. This shift towards the individual autonomy model has gained popularity since the 1980's especially in North American and Northern European countries. However, patients in ICU frequently lack the capacity to participate in discussions and make decisions about their health, so those close to them, mainly family, are asked to act as surrogate decision-makers. In this section, only the ethics behind decision-making will be presented; the legal framework will be presented in the following section.

The most powerful argument for empowering those close to the patient to make decisions is that surrogate decision-making is thought to be an extension of the incapacitated person's autonomy [31]. It allows clinicians to learn of and incorporate values and previously expressed treatment preferences, thereby manifesting respect for the patient as a person. A related ethical justification is that it promotes patient self-determination by respecting who they chose as their representative, which goes beyond the actual choice the surrogate is making [31]. This model of shared decision-making has been endorsed by many critical care societies but is not without limitations [32]. Not all patients have discussed their end-of-life preferences with family and friends, and some do not have anyone close to them. Even though many surrogates appreciate being involved in value-ridden decision-making [33], a significant number are unable to understand the intricacies of critical illness or find the process psychologically distressing [34]. Equally, not many people can distinguish between the choice they would make for themselves from the one they are being asked to make on behalf of someone else.

Similar arguments can be made for advance directives as a way to promote self-determination, when decision-making capacity is lost. Despite the theoretical advantage of having a person's end-of-life preferences documented prior to an acute event, their uptake in critical care has been slow and fraught with caveats [35, 36]. Some of the issues raised are that individuals often cannot foresee the situations they may find themselves in and are quite inaccurate in predicting the intensity and duration of their emotions, expressing different treatment preferences in times of health and illness [36]. Furthermore, what one finds an 'acceptable quality of life' varies depending on age, culture, religion, the presence of comorbidities and whether the change in one's condition is acute or insidious.

*Tip:* Medical ethics should be viewed as science, not art. Practice applying the ethical reasoning at the bedside, using a decision-making tool such as the 'MORAL balance' [37].

### 3. Legal framework

A 21-year-old man is admitted to ICU with severe respiratory failure due to pneumonia, being treated with high flow nasal cannula oxygen. He has significant developmental delay, with non-verbal communication at best, he resides in a nursing home and is tube fed. He frequently gets chest infections and has been ventilated in ICU on several occasions. His mother and carers feel he has a significant quality of life, as he has awareness of his surroundings and is interactive in a non-verbal way; they would like 'everything done'. The ICU team feel invasive ventilation is not appropriate, but a decision needs to be made urgently as he is lying in bed struggling to keep the oxygen on, with a high secretion load, and appears very distressed.

Who decides when a patient can't make decisions in ICU?

When deciding on non-escalating or limiting treatment, the most important consideration is whether the patient has capacity to participate in such decisions. If patients have capacity, they legally have the right to make their own decisions and physicians have the responsibility to try and elicit this. The Mental Capacity Act (MCA) sets out a 2-stage test of capacity:

- 1) Does the person have an impairment of their mind or brain, whether as a result of illness or external factors, such as alcohol or drug use?
  
- 2) The person is unable to make a decision, if they cannot: a) understand the information relevant to the decision; b) retain that information; c) use or weigh up that information as part of the process of making the decision [38].

Establishing capacity in ICU is complex, as most times patients' conscious level will fluctuate. Patients may require medication that influences judgement or be unable to answer questions because of the tracheal tube. However, ICU physicians should always attempt to make an assessment, remembering that patients can lack capacity to make some decisions, but have capacity to make others. Mental capacity can also fluctuate with time – someone may not be capacitous at one point in time, but may be able to make a decision at a later point. All necessary steps must be taken to maximise the patient's decision-making ability, for example the use of a translator, audio-visual aids and most of all, patience and time.

If the patient does not have capacity, a best interests decision needs to be made. The MCA has a 'best-interests checklist', which includes the following suggestions [38]:

- 1) encourage participation – do whatever is possible to permit or encourage the person to take part; this, as discussed above, may be difficult in the ICU setting but not impossible
- 2) identify all issues and circumstances relating to the particular decision – try to establish what the patient would take into account if they were making the decision themselves; the involvement of family/ friends is paramount to achieve this

- 3) avoid discrimination – do not make assumptions on the basis of age, appearance, condition or behaviour; involve the whole ICU in the decision-making (doctors, nurses, allied health professionals)
- 4) clarify the person's views – including their past and present wishes and feelings, and any beliefs or values; ask family members, friends, faith leaders and/ or their general practitioner. If the patient's wishes about a particular course of action can be identified, doing something different must be justified
- 5) assess whether the person might regain capacity – consider whether the decision could be postponed until then; in ICU, decisions are usually time-critical so postponing them may not be an option [37]. If the patient has no one to advocate for them and lacks decision-making capacity, then the 2005 MCA states that an Independent Mental Capacity Advocate (IMCA) is required. In this case, the IMCA acts like family and friends on behalf of the patient, and the clinical team works with them to reach the best clinical decision.

What happens if clinicians and family disagree?

In case of disagreement between clinicians and family regarding goals of care, treatment escalation plans or limitation of LST, intractable conflict may arise. Conflict in ICU is common, resource intensive and can be emotionally draining for all parties involved [11]. Internal factors, such as prior experiences, stigma and bias, affective reasoning, and power imbalances but also external factors, including disparate values and preferences, prognostic uncertainty, and ineffective communication create an environment where conflict can emerge [39]. A full analysis of the causes of conflict is beyond the scope of this article, which will focus on developing strategies to improve conflict resolution in ICU.

The first step is to recognise when discordance in opinion exists and that conflict is imminent, with potentially detrimental effects not only for the patient/ family but also for the entire ICU team. Being able to explore individual values, pre-existing experiences and external influences, and reach compromise and common ground requires time and patience but may lead to de-escalation of the conflict. If a consensus is not possible, the next step is an external intervention, in the form of a palliative care or clinical ethics consultation or formal mediation. Despite evidence that suggest these third-party interventions are successful in ICU conflict resolution [40], scarcity of resources and ICU-specific barriers prevent their wide employment [39].

The final step is the Court of protection (CoP), which oversees the operation of the MCA and tries to resolve all disputes when the patient's next of kin and healthcare team disagree about the former's best interests. Cases can be brought to the court by family members, as well as advocates and professionals involved in decisions. A CoP judge is available 24/7 and a court can be convened at very short notice if required. Although proceedings in the CoP are not particularly adversarial, they have important implications for those concerned: until a verdict is reached, the patient is still in ICU, the family / friends are still visiting, and the ICU team are still actively treating the patient, whilst in the middle of a court battle. Since this is a highly stressful situation, turning to the CoP is seen as last resort in the conflict resolution algorithm and demands increased emotional support for all parties involved. The General Medical Council has published extensive guidance on managing patients nearing the end of life and is a useful reference point [14].

*Tip: a statute is law set by parliament, as opposed to case law, which is the practical application of the law based on set precedents. Verdicts on cases decided by the CoP are individual, which means that are not generalisable. Some will set precedent (generally those made by the supreme court), which will then guide or inform future judgements, thus forming case law. For the first case to come before the Supreme Court under the MCA, see *Aintree University Hospitals NHS Foundation Trust v David James* [41].*

*Tip: capacity is not something to try and assess in the middle of a busy ward round. The same is true about holding conversations with a patient/ family when there is conflict. Assign a period of uninterrupted time, bring a member of the multidisciplinary team who may have built rapport with the patient/family. Be prepared for multiple conversations and ensure that a consistent message is conveyed.*

#### **4. Practical aspects**

What is the role of palliative care in ICU?

Palliative care is a multi-disciplinary approach, whose goal is to maintain and improve the quality of life of patients and families during any stage of life-threatening illness. It aims to prevent and relieve suffering by early identification, assessment, and treatment of physical and psychological symptoms, as well as emotional and spiritual distress [42]. It is not a mutually exclusive alternative to life-prolonging care but rather an integral component of comprehensive care for critically ill patients. Since many ICU patients are admitted with life-threatening conditions and a significant number will die, integration of palliative care in ICU appears intuitive and beneficial [43]. However, multiple barriers to the integration have been identified, including unrealistic expectations regarding post-ICU outcomes on the part of patients, families, and clinicians, insufficient training of clinicians in relevant communication skills and competing demands for clinicians' time [10].

Two models of ICU-based palliative care have been described: an integrative one in which ICU personnel implement the delivery of compassionate care within their day-to-day practice and a consultative intervention, where a specialised clinician is invited to interact with the patient and/or family [10]. The effectiveness of each model but also the general impact of palliative care in ICU have been difficult to quantify, as there has been a wide range of heterogeneous interventions and outcomes used in the literature [44]. Enhancing essential palliative care skills for all ICU clinicians, promoting the integration and acceptance of the specialty in everyday practice and setting clear research priorities to assess its impact, should be part of the future agenda of ICU-based palliative care.

What drugs should be use around end of life?

Two systematic reviews have identified that a combination of morphine and midazolam is most commonly used during withholding and withdrawing of LST in critically ill ICU patients [25,45]. A continuous intravenous (IV) infusion is commonly used, as this mode can maintain a consistent blood concentration that can be adjusted according to the infusion rate [46]. For end-of-life patients, morphine, midazolam and haloperidol are also the most prescribed drugs in non-ICU palliative care

settings, where the subcutaneous route is preferred [47]. As intravenous access is already established in ICU patients and continuous monitoring is possible, IV administration of opioids and sedation may be the most efficient route to provide effective symptom management. However, most standardised guidance on medication dosing is via the subcutaneous route, with little guidance on intravenous dosing. Future research may focus on the development of equivalence tables for analgesic and sedative medications via different routes, review of maximum dosing adjusted for the complexity of ICU patients and assessment of potential drug interactions, due to the known polypharmacy in these patients. Overall, evidence shows that doses increase during the end-of-life process, reflecting adjustments needed to alleviate discomfort during the final stages of life [25,45].

What is the right family approach?

Since many ICU patients are unable to participate in treatment escalation planning around the end of life, these complex decisions are frequently deferred to their surrogates/ family. Stressful discussions around patient values and goals, discordance about prognosis and the impact of the acute critical illness increase psychological distress in family members, a complication identified as ‘post-intensive care syndrome – family’ [48]. Family-centred support interventions have focused on open or flexible family presence by the bedside, even during resuscitation efforts; using structured interventions to support family (ICU diaries, decision support tools, use of the VALUE mnemonic: Value family statements, Acknowledge emotions, Listen, Understand the patient as a person, Elicit Questions); conducting routine interdisciplinary meetings at regular timepoints; inviting external consultations if necessary (palliative care, psychology, social worker, spiritual support); attending to environmental and organisational factors, such as nurse empowerment to support family members, noise reduction and sleeping provisions [49,50]. Offering families the opportunity to be present during cardiopulmonary resuscitation has been debated for over two decades, with potential benefits being weighed against the possibility of stress induced in health care providers and an increase in the emotional burden on family members [51,52].

Communication skills during end of life should be part of the medical and nursing academic curriculum, as teaching on cardiovascular or advance respiratory support is. The words we use when we talk to patients and families matter. Substituting phrases such as ‘continuing care is futile’ with ‘further treatment won’t be beneficial’ and avoiding expression such as ‘withdrawal of care’ (since care is never withdrawn, treatment is) may enhance communication, reduce conflict and improve family satisfaction at a very difficult time [53]. Another important aspect is communication of prognosis, especially around end of life, since many misunderstandings and subsequent conflict results during that time. Physicians’ difficulty to discuss prognosis directly and the variability of these discussions, in combination with inaccurate interpretations of prognostications from surrogates impair the information transfer. Discordance between physicians and surrogates about prognosis in patients with advanced illness seems to arise partly from optimistic biases (‘unrealistic optimism’), rather than simple misunderstandings [50]. Based on this review, we make a number of recommendations to inform clinical practice:

## **Recommendations**

- End-of-life care demands the same high level of knowledge and competence as all other areas of ICU practice
- Basic ethical reasoning skills and basic palliative care should become part of routine training for intensive care clinicians
- Offer families the opportunity to participate in decision-making and in delivering patient care around end of life
- Be aware of the cultural, socio-economic and geographic variation in end-of-life practices, which could create conflict with patients and their families
- Try to recognise potential conflict with family early and seek input from a multi-disciplinary team (external opinion, clinical ethics forum, pastoral input)
- Dedicate time to assess patient capacity, bearing in mind their views may be opposite to yours
- Titrate medications around end of life with the aim to alleviate distressing symptoms – there are no maximum doses
- Future research should focus on improving communication with families around end-of-life care, identifying palliative care interventions in ICU and exploring symptom medication dosing in this complex setting.

## **Competing Interests**

All authors declare no conflict of interest.

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