

EDITORIALS

End-of-life in the ICU: moving from ‘withdrawal of care’ to a palliative care, patient-centred approach

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End of life decisions in the Intensive Care Unit [ICU] are difficult for patients, families and doctors alike, yet they are increasingly common; ICNARC data (UK) shows that 15–25% of those admitted will die in the ICU¹ and European data shows approximately 70% of these deaths occur after the withholding or withdrawal of life-sustaining treatments.² Between 10 and 20% of the population at large now die in ICU, underlining the importance of end-of-life care to everyday practice and training for anaesthetists and intensivists.

Despite how common end-of-life decisions are in ICU, they are very variable, with studies showing important differences reported between regions, countries, individual ICUs and even between individual clinicians practicing in the same ICU.^{2–3} This was demonstrated by a recent systematic review; its accompanying editorial introduced the concept that these practice variations may be good or bad.⁴ Good variations reflecting patient-centered care, and bad variation reflecting failures in professionalism.⁴ Currently the ETHICUS 2 (world-wide) study is underway, collecting prospective, data on ICU end-of-life practices, in a manner similar and comparable with the initial ETHICUS study, which occurred in 1999–2000. Consequently, the results of ETHICUS 2, will likely reflect the practice changes of the past 16 yr and the resultant changes in both good and bad variations. For example, high profile end-of-life cases in Europe have generated intense media debate leading to increased public awareness of withholding and withdrawal of life-sustaining treatments,⁵ and the Liverpool Care Pathway has

caused a re-examination of aspects of hospital end-of-life practices and emphasized the importance of appropriately integrated palliative care strategies.⁶

Terminology confusion however, has been slowing progress in quality end-of-life care. For example, three European studies examined end-of-life practices in ICU in the period 1995–2000 and each of them had differences in their definitions of the withholding and withdrawal of life-sustaining treatments.^{2–8} The WELPICUS study however, has achieved world-wide consensus on key end-of-life issues and terminology.⁹ Using a Delphi technique requiring 80% agreement, 35 definitions and 46 consensus statements regarding 22 end-of-life ICU issues were processed.⁹ Agreement was reached on the majority of these definitions and statements which included the ‘withholding and withdrawal of life-sustaining treatments’ (see Table 1). The WELPICUS consensus now provides health-care professionals with terminology for everyday purposes, thereby limiting previous confusing variations.

However, whether ‘withholding’ and ‘withdrawal’ are ethically equivalent is debated. Equivalence implies that if a treatment, (e.g. mechanical ventilation) is disproportionately burdensome for the patient, in that it will offer no clinical improvement and/or may prolong suffering, then regardless of whether ventilation that is already ongoing is stopped (withdrawal), or not started from the outset (withheld), the principle (preventing prolonged patient suffering via a non-beneficial therapy) is regarded as the same. This is supported in the guidelines of most critical care societies and medical regulatory bodies.¹⁰

Table 1 Shows 3 of the key end-of-life definitions that reached consensus in the WELPICUS study

Term	Definition
Active shortening of the dying process	A circumstance in which someone performed an act with the specific intent of hastening death or shortening the dying process. These acts do not include withdrawing or withholding life-sustaining treatment.
Withdrawing life-sustaining treatment	Decision to actively stop a life-sustaining intervention presently being given.
Withholding life-sustaining treatment	Decision not to start or increase a life-sustaining intervention.

Nonetheless, doctors' viewpoints vary with studies showing that less than 40% of questioned intensive care physicians considered withholding and withdrawal to be equivalent.^{11 12} In practice, however, withholding preceded or accompanied withdrawal in >90% of the studied patients showing that both are practiced alongside each other.² One study also highlighted that these differences may be primarily practical rather than conceptual as withholding is more likely to occur during on-call h, and withdrawal more likely during the working day.¹³ It argued that the withholding/withdrawal difference merely reflected the higher likelihood of consensus being achieved (among key stakeholders such as the anaesthetist/intensivist, admitting physician, senior nursing staff and family) during daytime h.

Furthermore, the words 'withholding' and 'withdrawal' (even when referring to 'life-sustaining treatments' rather than to 'withholding/withdrawal of care') may be negatively perceived and there has been a move away from their use. This may solve some of the terminology and ethical confusion that the two words generate. In the UK, for example, the General Medical Council (GMC UK) guidelines, and the Royal College of Paediatrics and Child Health (RCPCH) have changed the titles for their end-of-life guidelines, now omitting the words 'withholding' and 'withdrawing'. The GMC 2002 guidelines titled 'Withholding and withdrawing: guidance for doctors' were replaced in 2010 by guidelines titled 'Treatment and care towards the end of life: good practice in decision making.'^{14 15} The RCPCH 2004 guidelines titled 'Withholding, withdrawal of life-sustaining treatment in children: a framework for practice' have been replaced in 2015 by 'Making decisions to limit treatment in life-limiting or life-threatening conditions in children: a framework for practice.'^{16 17} Perhaps, given the confusing and somewhat negative nature of this terminology, 'withholding' and 'withdrawal' would be better replaced by the more encompassing and neutral term 'limitation', providing that it remains clear that it relates to limitation of 'disproportionately burdensome, life-sustaining treatments' and not to a limitation of medical 'care.'

There is a geographical pattern to the disparity in ICU end-of-life practices the Northern Region (Denmark, Finland, Sweden, the Netherlands, Ireland, UK), when compared with Southern Europe (Greece, Israel, Turkey, Italy, Spain, Portugal), having a significantly higher rate of withholding and withdrawal of life-sustaining therapies, and a lower rate of death after unsuccessful CPR.^{2 18} Case-mix, religion, culture, individual physician and institutional characteristics are contributing factors and jurisdictional law also plays a role, with some countries legislating for terminal sedation and even for the prohibition of ventilation withdrawal.^{2 19 20} Many of these variations may be reflective of the patient-physician-family-cultural-religious backdrop⁴ but the ETHICUS study noted a 6.2% incidence of Active Shortening of the Dying Process (ASDP), (i.e. active euthanasia in -the central European region) (Austria, Belgium, Czechia, Germany, Switzerland), a

practice generally not considered to be ethical.^{2 9} ETHICUS 2 will examine the evolution of end-of-life practices across Europe including whether ASDP remains an issue.

One aspect of ICU practice that has progressed over the past decade is the increasing and ready acceptance of the value of palliative care in end-of-life patient management. The World Health Organization defines palliative care as 'an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'- a concept readily applicable to ICU.²¹ In this approach, while clinicians may forgo life-sustaining treatments, care is enhanced as death approaches through thoughtful, patient-centred palliative care measures. Different models are described such as palliative care medicine participation on ICU ward rounds and family meetings, didactic teaching sessions, or use of palliative care evaluation scores and questionnaires.^{22 23} None have been shown to be superior and the choice may be guided by resources and accommodation to local patterns of service.^{22 23} One approach readily applicable to everyday practice, in terms of ease of utility, is adoption of the 'ABCDs' of end-of-life critical care: attitudes, Behaviours, Compassion and Dialogue.²⁴ This approach is likely to vary as determined by specific patient-centered palliative measures.

We hope the evolution in medical terminology and the increasing incorporation of palliation into Critical Care will improve the quality of end-of-life care in ICU. Further studies will be expected to reflect this change. Anaesthetists and intensivists will have an increasing role as clinicians, educators and researchers in this important evolution of intensive care and medical practice.

Declaration of interest

O.M. is the Irish coordinator of the ETHICUS II study. D.J.B. is a member of the editorial board of the BJA.

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Measurement for improvement in anaesthesia and intensive care

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'In God we trust; all others, bring data.'
Dr W. Edwards Deming

Measurement to understand our current performance and where we can improve is an essential component of ensuring that care is safe and effective for our patients. Most clinicians are familiar with audit,¹ and indeed, anaesthetists in the UK have used this

technique very effectively, especially with the Royal College of Anaesthetists' National Audit Projects (NAPs)^{2–3} and National Emergency Laparotomy Audit.⁴ However, many of us have been taught very little about other ways to measure for improvement, such as the use of sampling, the use of run charts and statistical process control charts, the understanding of unwanted variation, and the requirements to interrogate and analyse large databases.