

End-of-life care on the intensive care unit: an overview for hospital medical practitioners

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Abstract

Modern intensive care fulfils advanced supportive roles for patients with actual or threatened multiple organ dysfunction. Whilst such roles prolong patients' lives and in the last two decades have reduced intensive care mortality rates, death following intensive care admission remains relatively common. Dealing with death and caring for dying patients is therefore a day-to-day reality of intensive care medicine and an urgent treatment. Clinicians have a duty to recognize the progression towards death and understand the ethical and legal concepts guiding best practice. This includes understanding the concept of medical futility, the ethical and medico-legal framework of decision making in such circumstances and what factors constitute a good death on a case by case basis. This approach can enable the provision of effective end-of-life care for the patient (physical and holistic) and effective guidance for the family.

Keywords End-of-life; ethics; futility; intensive care; palliation

Introduction

Intensive care has evolved from a variety of clinical settings including grouping post-operative neurosurgical patients together (1920s USA) and the first mass-application of positive pressure ventilation (1950s Scandinavian polio pandemic).¹ Consequently modern intensive care fulfils advanced supportive roles in the management of multiple organ dysfunction. Subsequently mortality rates following intensive care admission have reduced in the last two decades, although death remains relatively common often quoted as 15–20% of admissions.^{2,3} Within our NHS Trust deaths on intensive care (2006–13) accounted for 24% of all adult in-hospital deaths (ICNARC Case Mix Programme and Newcastle upon Tyne Hospitals NHS Trust.) Dealing with death and caring for dying patients is therefore a day-to-day reality of intensive care medicine and something that is regarded as an urgent treatment (Box 1).

The majority of intensive care deaths occur following the withdrawal or withholding of life-sustaining treatments, regarded

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'How we care for the dying is an indicator of how we care for all sick and vulnerable patients. Care of the dying is urgent care: with only one opportunity to get it right to create a potential lasting memory for relatives and carers.'

- Professor M. Richards, End-of-Life Care Strategy Advisory Board

Box 1

by the General Medical Council as the 'most challenging decision' in the domain of end-of-life care.^{4,5} Such treatments may be multiple ranging from withholding cardiopulmonary resuscitation (CPR) to withholding assisted nutrition, hydration and antimicrobial therapies with the evidence for benefits, burdens and risks of continuing or ceasing such treatments in dying patients not always being immediately clear, that is, in some circumstances they may only prolong the dying process and cause unnecessary distress and suffering; in others they may provide a window of physiological stability before death, allowing individuals' 'affairs to be put in order' eventually enabling a good death.

Decision making is therefore inevitably complex and emotionally distressing with the potential for conflict. Nevertheless this should not be avoided and clinicians have a duty to recognize progression towards death and understand ethical and legal concepts guiding best practice. This includes understanding the concept of futility and providing effective care for patients and effective guidance for families and other loved ones. If such understanding is linked to clear communications, clinicians can hold their practice up to scrutiny, minimizing conflict. This article therefore deals with the concept of futility and the ethical and medico-legal debates surrounding end-of-life care.

Futility

In its basic context futile treatment is 'care that does not accomplish its intended purpose'. Further sub-divisions reflect both physiological and normative/holistic aspects of care⁶:

1. Treatment that does not offer reasonable chances of survival.
2. Useless/ineffective treatment.
3. Treatment failing to offer a minimum quality of life or modicum of medical benefit.
4. Treatment that cannot achieve patients' goals.

Definitions 1 and 2 (*physiological futility*) relate to the physical effects of treatment. Defining futility involves collating all information relating to patients' conditions and assessing against the evidence base of mortality prediction models that utilize patients' acute pathophysiological status and chronic health scores. The predictive value of such scores is useful in demonstrating the odds of survival; however, they apply to patient populations not individuals and should therefore only be applied in conjunction with knowledge of the individual. If doubt exists after such considerations, a trial of active treatment may have to be instituted or continued to determine whether active interventions are actually 'useless' or 'ineffective' and all treatment options have been exhausted. Such an approach is not without the potential for controversy but a so-called SMART approach (Specific, Measureable, Agreed, Realistic and within a specified Time scale) can confirm to all involved that active treatment is

indeed futile and reassure the concerned that ‘everything has been done’.

Definitions 3 and 4 refer to *normative futility* that reflects holistic aspects of care. It requires information about patients’ personal views of achievable and meaningful recovery (i.e. what they regard as being a good quality of life). Ideally these issues should be discussed with competent patients; however, this is rarely possible in intensive care and so communication with the admitting teams, the family and the critical care staff is vital for decisions to be made. ‘Quality of life’ decisions must be legal, ethical and acceptable.⁷ It therefore follows that such decision making is associated with significant uncertainty, however a consistent approach with effective communication can minimize conflict, confusion and complaints.^{8,9} A working knowledge of ethics and the law therefore has a major role to play.⁸

Legal and ethical considerations in England and Wales

Legal provision for end-of-life issues is linked to the Mental Capacity Act 2005. If adult patients are conscious and orientated they are deemed to have the capacity to consent to or refuse treatments once all management options have been discussed with them. This is true even in circumstances where the clinical team may believe that the decision is ‘unwise’ (i.e. refusal of life-saving interventions by the patient). Patients lack capacity if they have *a disturbance or impairment (temporary or permanent) of the mind or brain that prevents them from making independent decisions*. In intensive care, patients invariably lack capacity due to a combination of severity of illness and drugs; however, this should not be immediately assumed unless the patient is comatose. Clinicians should assess capacity by ascertaining whether or not patients can understand and retain relevant information, weigh pros and cons and communicate decisions. They must consider:

- If loss of capacity is temporary, when is full capacity likely to return?
- Does the potential for capacity exist with respect to understanding particular treatment options?
- Can patients’ abilities to participate in decisions be improved e.g. altering sedation regimes?

Nevertheless given the clinical situation lack of capacity invariably remains and waiting for a return to appropriate capacity is often impractical in the context of serious medical treatments (Box 2) and clinical time frames. Thus clinicians must ensure care in patients’ *best interests* ensuring:

- Decisions concerning withdrawal of life-sustaining treatments are not motivated by a desire to bring about death.
- Consideration is given to patients’ past and present wishes, beliefs and values that may influence such decision making. The presence of an Advanced Decision to Refuse Treatment can assist in this context.
- Consideration of views from individuals named by the patient as someone to be consulted in this respect, that is, anyone with an interest in the patients welfare, anyone with a lasting Power of Attorney for the patient and any deputy appointed by the court.

Strict conditions apply to these and if conflict arises legal recourse can be sought.

Serious medical treatments

- A fine balance exists between benefits, burdens and risks to the patient
- There is a decision between choices of treatment that is finely balanced
- What is proposed is likely to have serious consequences for the patient regardless of the choice

Box 2

Advanced decision to refuse treatment (ADRT)

ADRTs are witnessed legal documents made during a period of full capacity. They can stipulate refusal of treatments or interventions at a future date if capacity is lost, although such refusals have to be specific; for example, ‘do not resuscitate me’ is too non-specific, whereas ‘do not continue resuscitation if I suffer an unwitnessed, in-hospital cardiorespiratory arrest associated with asystole or pulseless electrical activity’ has more clarity and specificity. If conflict or confusion arise it can be appropriate to continue treatments pending legal rulings.

Further legal provision occurs via the European Convention for Human Rights, specifically Articles 2, 3, 8, 10 and 14 (Box 3) and the four fundamentals of medical ethics; *beneficence* (doing good), *non-maleficence* (doing no harm), *autonomy* (an individual’s right) and *distributive justice* (an equitable distribution of healthcare resources).

Clinicians are guided by these principles and debate considers potential conflict and how they can be applied case by case. For example, Article 2 (‘The Right to Life’) can present an argument for continuation of life-sustaining treatments despite recognition of dying and futility. However Article 3 states that ‘no-one should be subjected to torture or inhuman treatment’. If a patient has been recognized as dying, the instigation and prolongation of futile treatments is potentially ‘inhuman and degrading’. Furthermore, by applying philosophical rather than physiological principles a ‘good death’ can be deemed part of the process of ‘life’, and in many cultural and religious contexts death is viewed

Relevant articles of the European Convention for Human Rights

- Article 2: with the exception of the prevention of criminal acts or lawful use of the death penalty, everyone’s right to life shall be protected
- Article 3: no one shall be subjected to torture or inhuman or degrading treatment or punishment
- Article 8: with respect to an individual within the norms of a democratic society an organization cannot interfere with their rights unless it is to uphold the law or protect the rights and freedoms of others
- Article 10: freedom to hold opinions/receive info./rights and responsibilities re others
- Article 14: to be free from discriminatory practises with respect to the convention

Box 3

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