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The legal framework for end of life care: a United Kingdom perspective

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It should be noted that, although within the United Kingdom, Scotland has an independent parliament and system of law, and there are many aspects in which English and Scottish law differ.

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Introduction

Contemporary intensive care in the United Kingdom differs little from that in other developed countries both in the capacity to support indefinitely most physiological systems of most patients and in uncertainty as to the benefit of this process for many admissions, namely; which patients are likely to survive to leave the unit, for how long, and with what quality-of-life? The UK, in common with other countries, also faces factors other than uncertainty which potentially skew decisions on withholding, limiting or withdrawing aspects of intensive care: the combination of a fixed resource and increasing demand from a population of rising age, co-morbidity and increasingly heroic surgical intervention, generates overlap between defensible decision making, triage and covert rationing. It can reasonably be asked therefore: who decides, with what authority, by what criteria and by how explicit a process?

As medical practice moves from paternalism to patient autonomy, society will take a view on these questions, particularly in the UK where a series of public scandals have heightened suspicion of medical opinion. The outcome of paediatric cardiac surgery at Bristol demonstrated shortfalls in performance, consent and accountability [1]. The retained organ scandal at Alder Hey Children's Hospital demonstrated behaviour that was completely outwith societal expectation [2]. The medical serial killer Harold Shipman revealed not only malevolence amongst healthcare workers but significant shortcomings in the regulatory body, the General Medical Council

(GMC) (<http://www.the-shipman-inquiry.org.uk>). Given this context, it is inevitable that medical opinion as to the futility of life-sustaining medical treatment (LSMT) will be challenged, with subsequent conflict being played out in the courts and media (*The Times*, 22 October 2005, p 13; *The Guardian*, 27 August 2005, p 1).

Away from such high-profile cases, routine medical decision making is directed by ethical principles and guidelines from the professional bodies [3], which should be comprehensive, unambiguous and compatible with the law. There is, however, no formal legislation in the UK governing end-of-life care, and this perspective is therefore an amalgamation of common law, judgments from individual legal cases, and elements of statute such as the Human Rights Act 1998 and the recently introduced Mental Capacity Act (<http://www.opsi.gov.uk/acts/acts2005/20050009.htm>). It will be seen that there are many obstacles to a unifying set of principles which can be applied consistently to every possible scenario.

Who decides?

The competent patient

Respect for autonomy is a fundamental principle of contemporary healthcare, and the competent patient has a right to choose, after provision of full information, whether to undergo any aspect of treatment that is offered.

This includes the right to have LSMT such as ventilation withdrawn (see the case of Ms. B., discussed below), and allows by an advance directive for any such wish to remain active if the patient were to lose capacity in the future, as seen in the 'release forms' on the part of members of the Jehovah's Witnesses when refusing blood products. Respect for autonomy therefore is invariably translated into a right to refuse treatment with little parallel rights to demand such. This position is, however, in a state of flux, with recent court rulings supporting patients' access to expensive therapy (e.g., trastuzumab for early breast cancer), whilst at the same time endorsing the lawfulness of considering financial restraints when funding treatment [4]. The resource implications of allowing patients prospectively to demand LSMT under Article 2 of the Human Rights Act 1998 (<http://www.opsi.gov.uk/acts/acts1998/80042-d.htm>), the right to life, was also a consideration in the successful appeal of the GMC against an earlier judgment which rejected absolute medical authority in this arena (*R., on the application of Burke, v The General Medical Council*, 2004 EWHC 1879), a case previously discussed in this journal [5, 6]. Although the proceedings revolved around a patient's right to receive artificial nutrition and hydration (ANH), considered by many to be basic care, the Intensive Care Society made representations at the appeal on the resource implications of the primary judgment. The best interests of the patient should, however, be defined by their condition and prognosis, harms and benefits of treatment, along with consideration of their wishes, and not dictated by resources.

The incompetent patient

Authority in decision making for the incompetent patient is a contentious and changing subject. The first obstacle lies in determining incompetence as defined by the courts (re *M.B.*, 1997; 2 FLR 541), when either: (a) the patient is unable to comprehend and retain the information which is material to the decision, especially as to the likely consequences of having or not having the treatment in question, or (b) the patient is unable to use the information and weigh it in the balance as part of the process of arriving at the decision. Whilst this is not an issue for the usual ICU patient who is sedated to the point of unresponsiveness, there is clearly a spectrum of capacity prior to initiation of sedation or on emergence, during which time the patient may be exposed to a variety of interventions to which they express opposition by verbal and physical responses. Although these patients may at times fulfil the criteria for capacity as defined above, most intensivists will overcome any opposition to planned treatments by chemical and physical restraint, or simply allow discomfort and agitation, in the hope of longer term health benefit, a consideration not easily accommodated under legislation.

Under current UK law ultimate authority for medical care of the incompetent adult rests with the treating physicians rather than the next-of-kin, or indeed the courts, the power of which lies in a declaration of the lawfulness or otherwise of what is proposed. Medical authority is, however, limited to acting in the 'best interests' (re *A.*, 2000; 1 FLR 549) of the patient and on the basis of 'necessity', whereby any delay in treatment, in anticipation of a return of competence, would compromise the outcome. Best interests are not limited, however, to 'best medical interests', directives from the government and regulatory bodies dictating that these incorporate 'the patient's wishes and beliefs when competent, their general well-being and their spiritual and religious welfare' [7, 8]. Despite the equivocal position at law, where even a formal power of attorney is limited to non-medical matters, there is a requirement for the next-of-kin to be involved in the process of consent if only to seek their perspective as to the patient's 'wishes and beliefs'. The implications of this involvement for the multi-disciplinary and multi-intervention process that is intensive care have been debated previously [9].

The Mental Capacity Act 2005, a new statutory framework for the management of mentally incapacitated adults, is intended to address the previous shortcomings and comes into force in 2007. The binding nature of an advance directive refusing LSMT is endorsed, but this must be written, specific, signed and witnessed to be valid. Authority for medical decision making may now be invested in others through a 'lasting power of attorney', but this does not include refusal of LSMT unless the patient had specifically intended this, using the same criteria as the advance directive. In the absence of an advance directive or a nominee with lasting power of attorney, the reforms allow for the selection of a court-appointed deputy for proxy decision making. The criteria for these appointments are not specified, but such a deputy, again, does not have the authority to refuse LSMT. It can be seen therefore that even after the new Act comes into force, the same ethical, legal and logistical difficulties will still arise when medical practitioners consider it appropriate to withhold/withdraw LSMT, or indeed initiate/maintain, against the wishes of the next-of-kin.

The withholding/withdrawing of LSMT

By what criteria: clinical, legal or religious/cultural?

In the absence of a specific advance directive decisions on withholding/withdrawing LSMT may legitimately be based on a range of clinical criteria, including unresponsive physiological deterioration, overwhelming and irreversible pathology such as brainstem death, and progression of co-morbidity against a background of significant impairment of quality-of-life prior to the critical illness. The majority of patients do not, how-

ever, fall conveniently into these categories, generating uncertainty as to survival of the critical illness, survival to leave hospital, longer term survival and associated quality-of-life. Scoring systems are not robust enough to prognosticate in these circumstances [10], creating a need to exercise professional judgment with inherent fallibility and the potential for either continuing futile harmful support or prematurely withdrawing that support and denying the patient the chance of a meaningful recovery. When uncertainty as to outcome is influenced by discrimination on age, quality-of-life, or diseases such as HIV infection [11], by resource limitations, by individual practitioner variation [12] including religious beliefs [13], or some combination of factors [14], it is inevitable that there will be differences of opinion between intensivists and ICU colleagues, referring medical specialties and next-of-kin.

Professional guidelines emphasise the importance of multi-disciplinary consensus when reaching decisions of this significance but disputes will inevitably arise, and if not resolvable by ongoing dialogue between parties, or simply continuing support indefinitely, there are a limited number of pathways available. Once a breakdown in communication or trust has occurred, it can be questioned how independent a medical second opinion actually is, given that the request is usually initiated by the attendant practitioner. Although clinical ethics committees are becoming increasingly established within the UK, there is little evidence that intensivists are turning to these for guidance, leaving the option of the courts for resolution. Although a court ruling, by simply supporting the position of either party, does nothing to resolve the primary breakdown of trust, it should be noted that ethical principles are applied in reaching a judgment. ‘Welfare appraisal’ is carried out, with the benefits of ongoing therapy balanced against the harms (re A., 2000; 1 FLR 549), a more robust criterion than survivability or a simplistic medical declaration of futility.

This suggests that in the absence of certainty decision making should be based on contemporary ethical principles of respect for autonomy, beneficence and non-maleficence [15]. Respect for autonomy does involve soliciting the views of the next-of-kin as to the patient’s personal, cultural or religious beliefs, and the position of certain religions, notably Islam and Judaism, in opposing withdrawal of LSMT is understood. This does not impose a duty on any individual to suffer, however, and the UK courts would not allow this religious perspective to be determinative if from a purely medical perspective the harm of ongoing support and intervention outweighed the likely benefit from this (*The Guardian*, 27 August 2005, p 1). This position on the sanctity of life has been clarified as; ‘a view that life must be preserved at all costs does not sanctify life’ (in the matter of a Ward of Court, 1995; 2 IRLM 401, Ir Supreme Court) and ‘sanctity of life was not a principle on which legal structures should

be based, since it depended on a religious outlook that not everyone shared’ (House of Lords’ Select Committee on Medical Ethics, 1993–1994, HL paper 21). Unlike in other countries and religions, neither the medical profession nor the courts in the UK consider there to be any ethical or legal distinction between withholding and withdrawing LSMT. The criteria for either decision are equal and as described above, namely futility, whereby there is no chance of a return of an acceptable quality-of-life, or a negative welfare appraisal, whereby the harm of ongoing support outweighs any potential benefit.

Process of withdrawal of care

Despite the ethical and legal equivalence of withholding and withdrawing LSMT, UK law is at pains to avoid endorsing any act which would bring about a patient’s death and thereby fulfil the criteria for murder. This has resulted in some questionable legal judgments, particularly in the field of permanent vegetative state (PVS). Medical, ethical and legal precedents were set in 1993 by the case of Tony Bland, in PVS following an hypoxic-ischaemic brain injury, when it was judged lawful to bring about his death by withdrawal of artificial nutrition and hydration ANH (*Airedale NHS Trust v Bland*, 1993, AC 789). This declaration of lawfulness required defining ANH as medical treatment rather than basic medical care, and the process of withdrawal as an omission rather than an act. The judgment in this case also established a requirement to bring the withdrawal of ANH in PVS patients before the courts, creating an unsatisfactory paradox whereby this process would appear unlawful without court authorisation, raising questions as to how the courts could rule lawful that which was inherently unlawful.

The Courts do not, however, take such an interest in the withdrawal of other aspects of medical treatment, endorsing the responsibility of physicians to undertake this as soon as such treatments are considered futile; ‘where the responsible doctor comes to the reasonable conclusion . . . that further continuance of an intrusive life-support system is not in the best interests of the patient, he can no longer lawfully continue that life-support system: to do so would constitute the crime of battery and tort or trespass to the person’ (*Airedale NHS Trust v Bland*, 1993; AC 789 per Lord Browne Wilkinson).

The law is minded, however, that withdrawal of other treatments should not be viewed as an act predicted to bring about the patient’s death, as illustrated by the case of Ms. B., who was rendered tetraplegic and ventilator dependent after a vascular accident in the upper spinal cord. Ms. B. had produced an advance directive refusing such support after a previous episode, was considered competent and persisted with her request. In the face of medical opposition Ms. B. was forced to seek court authorisation to remove the ventilatory support (*Ms. B. v an NHS Hospital*

Trust, 2002; EWHC 429, Fam), which was granted on the basis of an individual's legal right to self-determination, including the right to refuse LSMT. The hospital was found guilty of assault but fined only a nominal sum at the request of the patient.

Whilst the appropriate result for the patient was undoubtedly achieved, the case exposed weaknesses in the law, similar to those in the Bland case above. Once again, the termination of ventilatory support had to be defined as an omission rather than an act, despite the fact that an active intervention was required. Secondly, despite the clear knowledge and indeed intention that this would rapidly cause death, at that patient's request, this had to be defined as something other than actively assisting a suicide, which carries a custodial sentence under the Suicide Act 1961; 'a person who aids, abets, counsels or procures the suicide of another, or an attempt by another to commit suicide, shall be liable on conviction on indictment to imprisonment for a term not exceeding fourteen years'.

Thirdly, the associated authorisation by the courts of the administration of agents prior to withdrawal of ventilation to prevent any suffering, whilst ethically defensible, does sit somewhat uneasily with the absolute opposition to euthanasia in other applications placed before the courts (see the case of Dianne Pretty, discussed below) and indeed the position of the British Medical Association (BMA); 'consideration must be given to the continuing residual effect of suppressing the patient's ability to breathe unaided. Failure to do so could be interpreted, in law, as action taken with the purpose or objective of ending the patient's life' [16].

This case demonstrates therefore not only the problems at law but the spectrum of opinion within the medical profession as to the ethically and legally correct course of action. Whilst certain practitioners consider it defensible to administer muscle relaxants prior to extubation [17], others feel vulnerable when administering analgesics and sedatives pre-emptively, despite endorsement by legal authorities of the duty to relieve pain and suffering; 'if the purpose of medicine, the restoration of health, can no longer be achieved there is still much for a doctor to do, and he is entitled to do all that is proper and necessary to relieve pain and suffering, even if the measures he takes may incidentally shorten life' (*R. v Bodkin Adams*, 1957; CLR 365). Given the above position of the BMA, and further legal judgments which denounce the principle of 'double-effect'; 'a defendant does in law intend a consequence of his actions if he knows it to be a virtually certain outcome of his actions' (*R. v Woollin*, 1998; 4 All ER 103, HL), it is not unexpected that such uncertainty persists.

The opinion of the presiding judge, Dame Butler Schloss, in the case of Ms. B., is highly relevant on this subject and of particular interest to intensivists. Regarding the medical suggestion of a 'one-way wean', whereby

ventilatory support would be gradually withdrawn and not escalated in the face of a deterioration in respiratory parameters, the judge took the view that this; 'appears to have been designed to help the treating clinicians and the other carers and not in any way designed to help Ms B. . . she would die in discomfort and possibly in pain'.

The UK position on euthanasia

The interplay between the above scenario and Lord Joffe's Assisted Dying for the Terminally Ill Bill (HL; <http://www.publications.parliament.uk/pa/ld200304/ldbills/017/2004017.htm>) is all too apparent. The current rejection of this Bill by the House of Lords [18] reflects persistent medical rather than societal opposition (<http://www.bma.org.uk/ap.nsf/Content/Endoflife~euthanasia?OpenDocument&Highlight=2,euthanasia>), with many reasons expounded for this opposition: (a) euthanasia would create a fundamental shift in the physician-patient relationship already compromised in the aftermath of the Shipman case, (b) the potential exists for vulnerable individuals to feel pressured into taking this option so as not to be a burden on family, carers or society, and (c) the possibility of treatable components of illness such as depression being less than optimally treated is also cited. These broader potential hazards have been viewed as so significant as to override individual circumstances and respect for autonomy, as the case of Dianne Pretty illustrated (<http://www.publications.parliament.uk/pa/ld200102/ldjudgmt/jd011129/pretty-1.htm>). This involved a patient with severe motor neurone disease who unsuccessfully sought a ruling from the English and European courts that her husband would not be prosecuted if he were to help her take an overdose when she was no longer able to do this unassisted. Recent examples of members of the medical profession choosing to end their lives in Switzerland [19], emphasises an issue which cannot, however, be indefinitely ignored by either the profession, the law or the representative government. Whilst such a public course of action could be viewed as a political statement rather than absolute necessity, it could be argued that forcing these individuals to end their lives prematurely on foreign soil, given that such facilities are not available in this country, is a denial of individual human rights. Although debate on euthanasia makes reference to the advances in palliative care that have been achieved, it is clear that for certain individuals in certain circumstances, a slow death either in a hospice or at home does not equate with a good death. It is of note that the Royal College of Physicians has revoked formal opposition to 'assisted dying', declaring that this is a matter for society to decide upon, and the GMC has adopted a similar position whilst reminding physicians to adhere to the law.

Conclusions

End-of-life decision making in the UK embraces a spectrum of opinion and practice that is governed more by guidelines from the professional bodies than by specific statute. Common law and case law do establish certain principles for the care of the incompetent adult, and these will be marginally refined by the Mental Capacity Act. The Human Rights Act allows application to the

courtson the right-to-life principle, but this does not often override the right to be free from inhuman treatment. Provision of a dignified death remains a complex area from a legal perspective, particularly at a time when there is broad pressure to legalise assisted dying. It remains likely therefore that decision making in intensive care will continue to be scrutinised and generate ethical and legal debate alongside questions as to optimal treatment of the critically ill from a purely medical perspective.

References

1. Anonymous (2001) The Bristol Royal Infirmary Inquiry. Central Office of Information, London
2. Redfern M (2001) The Royal Liverpool Children's Inquiry report. Stationery Office, London
3. General Medical Council (2002) Withholding and withdrawing life-prolonging treatment; good practice in decision-making. General Medical Council
4. Dyer C (2006) Trusts can take cost into account when deciding drug treatment. *BMJ* 332:928
5. Fisher MM, Raper RF (2005) Courts, doctors and end-of-life care. *Intensive Care Med* 31:762–764
6. Woodcock T, Wheeler R (2005) *Glass v United Kingdom and Burke v General Medical Council*. Judicial interpretations of European Convention rights for patients in the United Kingdom facing decisions about life-sustaining treatment limitations. *Intensive Care Med* 31:885
7. Department of Health (2001) Good practice in consent. HSC 2001/023. Department of Health
8. General Medical Council (1998) Seeking patients' consent: the ethical considerations. General Medical Council
9. Bell MDD (2003) Consent and intensive care—new directives, persistent challenges. *Care Crit Ill* 19:187–190
10. Ridley SA (2002) Uncertainty and scoring systems. *Anaesthesia* 57:761–767
11. Bhagwanjee S, Muckart DJJ, Jeena PM, Moodley P (1997) Does HIV status influence the outcome of patients admitted to a surgical intensive care unit? A prospective double blind study. *BMJ* 314:1077–1084
12. Poulton B, Ridley S, Mackenzie-Ross R, Rizvi S (2005) Variation in end-of-life decision-making between critical care consultants. *Anaesthesia* 60:1101–1105
13. Sprung CL, Cohen SL, Sjokvist P, Baras M, Bulow HH, Hovilehto S, Ledoux D, Lippert A, Maia P, Phelan D, Schobersberger W, Wennberg E, Woodcock T, Ethicus Study Group (2003) End of life practices in European intensive care units: the Ethicus Study. *JAMA* 290:790–797
14. Ravenscroft AJ, Bell MDD (2000) 'End-of-life' decision making within intensive care—objective, consistent, defensible? *J Med Ethics* 26:435–440
15. Beauchamp TL, Childress JF (1994) *Principles of biomedical ethics*, 4th edn. Oxford University Press, Oxford
16. British Medical Association. Withholding and withdrawing life-prolonging medical treatment (1999)
17. Inwald D, Vandyck W (2001) Paralyzing agents may be given up to but not at or beyond the point of extubation. *BMJ* 323:389–390
18. Dyer C (2006) UK House of Lords rejects physician assisted suicide. *BMJ* 332:1169
19. Anonymous (2006) Obituaries: Anne Turner. *BMJ* 332:306