

End-of-life issues in the ICU

Ian McLellan

Email: iandimclellan@btinternet.com

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Introduction

This paper is the first of two which will be written from the perspective of UK medical practice, ethics and the law. There will be national, cultural and religious differences between states in the world which will affect how these issues are seen and acted upon. Even within the UK there are differences in the legal systems, for example, between England and Scotland. End-of-life issues are evolving with speed as both patients and doctors note the changing healthcare scenarios.

This paper deals with issues involving adults in the main part. These issues are withholding and withdrawal of treatment, advance directives or statements, do not attempt resuscitation orders, the permanent vegetative state, the doctrine of double effect, body ownership and organ donation. A further paper will deal with assisted suicide and euthanasia as well as discuss the issue of doctors' involvement in judicial executions.

These are emotive issues which involve ethics and the law. As previously stated, different cultures will have differing views and acceptance/rejection of some of the concepts. What is necessary though is

open discussion of these issues and for them not to be kept hidden out of sight and mind.

Before dealing with these there are some basic terms to be discussed.

First of these is the geographical use of the word state which is interchangeable in practice with country rather than an area of a country.

What is the 'End-of-Life'?

The term 'end-of-life' can mean the immediate time preceding death and also the period leading up to this. This paper will deal largely with the latter. It may be a period of months, weeks or days.

A number of issues have developed over the last few decades which lead to a possible difficult interaction between patients and the healthcare professionals caring for them. One issue is the (increasing) ability of medical care to extend life with the use of machines/drugs *etc.* The other issue is the concept of patient autonomy, enabling them to decide what healthcare they will accept. These can lead to clashes as patients may decide not to accept treatment which could extend their life. One of the dilemmas for healthcare professionals is the extent to which they are extending life as opposed to prolonging the process of dying.

Patient autonomy has developed such that the idea has changed from 'doctor knows best' to 'doctor

McLellan I, MBBS, FRCA, M Phil (Medical Law)
Emeritus Consultant Anaesthetist,
University Hospitals of Leicester NHS Trust
Clinical Teacher, University of Leicester, UK

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presents treatment options and the patient decides which one to take'. The treatment options should be offered by the doctor and include what the disease course with no treatment is likely to be. The patient should have time to reflect and then decide in conjunction with their doctor which option to take.

Another issue can be cultural differences over 'what is death': from the classical cessation of heartbeat and respiration to brainstem death.

It is important to consider the sanctity of life. Should life be maintained at all costs – not only to the patient but their relatives, other patients and the clinical team caring for them? Doctors in the author's experience have a modified view of the sanctity of life such that they strive to maintain life but if it reaches a point where the situation is considered clinically hopeless, the disease process is allowed to conclude with the patient kept comfortable.

Capacity, Competence and Consent

Healthcare professionals are familiar with the need to gain a patient's consent for treatment but in a number of situations especially in end-of-life scenarios, the question of the patient's competency to be able to understand the implications of their consent arises. An issue with competence is the need to assess it and to provide an explanation of the treatment in terms that the patient can understand (if conscious). *Capacity* refers to the patient's ability to process the information about the treatment offered to him/her. Their ability to retain that information has also to be assessed. A patient who does not have capacity cannot be *competent* to give consent. Capacity is dependent on each individual treatment and a patient may have the capacity to make a decision about one but not about another treatment. This may depend on the implications of the treatment. A competent adult patient has the right to refuse treatment even if this may cause them some harm or even lead to their death. In these cases doctors do not have the right to force treatment on the patient.

Consent and Refusal of treatment

Consent needs to be obtained before treatment

commences as without it, any contact by the doctor with the patient could be battery.

Part of the process of gaining consent must be an explanation of what treatment is advised, what the alternatives are, including no treatment. It is necessary to ensure that the patient understands and if there is a language barrier an appropriate way of translating needs to be used. These could include family members, translators or written information sheets. The patient should (except in an emergency situation) have time to reflect and consider what treatment pathway they wish to follow. They may therefore refuse to consent to the suggested treatment even if this causes harm to themselves or results in death. A review of 'Consent in 2012' is in *Anaesthesia News* for July 2012.¹

Withholding and Withdrawing treatment

Part of the ethical and legal process of treating patients at the end of life is the need to decide about withholding or withdrawing treatment. Treatment should have a point; to cure the patient, to provide palliative care or to provide relief of distress and pain. When death is imminent in the immediate future, it is reasonable not to prolong the time taken to die by continuing treatment which is futile and withdrawal is indicated. It may be prudent in these circumstances to withhold treatment and not start fresh treatment. Although there is no difference in English law between withholding and withdrawing, it is more difficult in practice to withdraw rather than to withhold. This is because there has been a treatment pathway wherein other healthcare professions as well as relatives may have been involved.

Futility refers to treatment that may not produce not only the required result but also quality results so that the patient does not gain usefully.² However, several points about what should be considered futile are more in the realm of the patient's view of their life and future rather than the doctor's. As such, whenever possible, the patient should be involved in any discussion about withholding or withdrawing treatment, else family and friends

should be approached to get the patient's views and life values. The idea of futility and withdrawal of treatment does not sit easily with some relatives and even as this paper is being written, there is a case in court where the family disputes the possibility of useful recovery with doctors who wish to withdraw treatment.³

Advance directives or statements

These are often referred to as '*Living Wills*' but are more than an end-of-life issue. They are designed so that the competent patient can consent to or refuse treatment in advance if they subsequently become incompetent. Although treatment can be consented to, it cannot be demanded.

Although already present in Common Law, these were made statutory in the Mental Capacity Act 2005.⁴ They were also recognised as valid by the General Medical Council, UK.

Advance directives should be reviewed at frequent intervals to ensure that the patient's situation has not changed or new treatments become available. It is possible to appoint a proxy when the patient becomes incompetent to give consent for health-care by using the Continuing Power of Attorney. However, assigning a proxy needs to be carried out when the patient is competent.⁵

Do Not Attempt Resuscitation Orders (DNAR)

Do Not Attempt Resuscitation Orders are often referred to as DNR (Do Not Resuscitate). These are made in circumstances when the outcome expected for the patient is limited or the patient is nearing the point of death or they have made an advance directive for that circumstance. If the patient is competent, DNAR orders should be made by a senior doctor in collaboration with the patient. They should be well labelled in the notes and communicated to all the relevant clinical staff. If incompetent, they should be made in the '*best interests*' of the patient. If the patient has made a valid advance directive, that should be followed. If further treatment is an option, it is reasonable for the doctor to discuss it with the patient who may then change their directives if they so wish.

DNAR orders should be reviewed regularly during the illness's course as there may be a change of mind by the patient or a change of circumstances or treatment. If resuscitation is 'likely' to be needed say in Cardiology or Cardiac Surgery this should be discussed with a patient who has made a DNAR advance directive *before* they enter the treatment course.

The Permanent vegetative state

This is the state which occurs when the cerebral cortex is severely injured or is destroyed leaving the brainstem intact. These patients are insensate but have their circulation and respiration preserved. It usually occurs in an incident where the cortex is deprived of oxygen. So long as these patients receive adequate nutrition, hydration and nursing care the outlook is that their lifespan could be many years or even decades. As the patients are in hospital, the question arises whether treatment should be withdrawn and if so, when? In a landmark case⁴ it was found that continuing treatment was not in the best interests of patients in a permanent vegetative state as they are insensate. Nutrition and hydration given by artificial means such as nasogastric tube, percutaneous endoscopic gastrostomy (PEG) or intravenously is a form of medical treatment. As such it can be withdrawn if the clinical staff foresees no future. As the end result of withdrawal of treatment is death, it is mandatory at present that each case be considered by the courts. This condition must be differentiated from that known as the minimally conscious state where there is some sensate activity. In some cultures it is not such an issue as the care is provided by the family at home.

The Doctrine of Double effect

Clinical staff in an end-of-life situations will want to relieve the patient's pain and distress. The drugs which help to do this often have effects on respiration and circulation which may speed the path to death. The doctrine works on the principle that the intention of the staff is to relieve the patient's symptoms and as such they should give the necessary doses of drugs such as morphine to do so. They should recognise that the side effects of these drugs may lead to an earlier death but as the physician's *intention*

is to relieve pain and suffering, rather than an earlier death, this use is acceptable. To give the same drugs with the intention of bringing about an earlier death would be against the law. The important issue is the *intent* of the staff.

Body ownership

Previously in this paper the issue of patient autonomy has been discussed alongside the concept of advance directives. Some patients make arrangement for their funeral or cremation while others do not. Who owns the body or its parts once life is extinct is a fundamental issue. In fact there is no ownership of a deceased's body, only a right of disposal. That right may rest with the relatives, persons appointed by the patient prior to death, the hospital or state/national authorities.

Ownership of a body or its parts can be retained in the circumstances of processing to provide a museum or teaching specimen. In carrying out this process, the body or its parts can be considered to have been '*manufactured*'.

Organ donation

Organ donation is highly successful in maintaining not only life itself but also a better quality of life for the recipient. From previous sections it is obvious that the living competent donor has the absolute right to consent to donate an organ or part of it. Living donors must be advised of the risks of the procedure of donation and have time to reflect. Donation must be made from an altruistic motive both for related and non-related donors. Payment for donation, thereby putting '*a price on organs*' is against the law.

In the case of donors who are dead, they should have given previous consent by being on the donor register or making their wishes known. Once they are dead they do not have 'ownership' anymore and the wishes of any relatives are to be taken into account. This means that even if the dead person wanted his organs to be harvested and used, this will not happen if the relatives refuse or object to donation.

In the UK the system used for being on the donor register is the 'opt in'. This means that it has to be a positive act to go on the register. This is being considered for change to a presumed consent 'opt out' system in which all persons dying are considered to be donors unless they have opted out by a positive act. Many states of Europe have donor systems based on this concept and it has been stated that the British donor/transplant rate would rise if the law changes. Spain has a system which provides the highest donation rates in Europe and has indicated that their success is due to investment in transplant co-ordinators and counsellors in each hospital.⁶ There has also been a question raised in some states about the understanding of the 'opt out' system and therefore the adequacy of the presumed consent in as much as it may not be fully informed. The question was raised because the rate of refusal to donate in these states was low, in fact well below that which would be expected.⁷ In the UK, public consultation is taking place regarding a change in the law to presumed consent and also for giving those on the organ donor register priority to receive an organ, if needed. Of interest to healthcare professionals is a suggestion that the *possibility of elective ventilation be considered in certain dying patients to allow their organs to be harvested after death*.⁸

In both the 'opt in' and 'opt out' systems of donation there is a practical requirement for consent from relatives. Even in the 'opt out' system, no transplant team will take organs if the relatives object. It has been put forward that there could be a significant increase in availability of donated organs if this practice of heeding relatives' refusal ceased,⁹ when the potential donor has indicated their wishes by carrying a donor card/ being on the register. Shaw goes on to argue that failing to follow the donor's wishes "... is unethical, unprofessional and against the spirit of the law."¹⁰

The question of organ trafficking in cultures other than the UK has recently been revived as a newspaper report about organ trafficking in China has been published. Organ trafficking in China is against the law but the police there have recently

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arrested a number of people including doctors who were forcing healthy individuals to donate organs. There is an ethical issue for professionals to consider concerning the donation of organs from executed prisoners.¹¹

Conclusion

This paper has covered the background to a number of issues which occur at the end of life.

As stated at the beginning, it is important that these issues be tackled as medical advances lead to methods which can increase longevity and patient survival. We must not allow medical science to prolong the dying process alone rather than prolonging life and wellbeing. It is necessary to ensure patient knowledge, consent and involvement in the decision making process.

Medical law and ethics textbooks such as those referenced can be consulted for further reading^{12,13} in order to clarify these points as well as guidelines published by the medical organisations in each state.

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