

The end of life issues - Part 2

Ian McLellan

Email: iandimcleveland@btinternet.com

Introduction

This paper is the second of two which will be written from the perspective of UK medical practice, ethics and the law. The issues covered in this paper mean that the national, cultural and religious differences within and between states in the world will affect how these issues are seen and acted upon. End-of-life issues covered in this paper are evolving with great speed. This is best shown by current public discussion over terminal care using the Liverpool Care Pathway (LCP). The issues discussed involving patients should be considered to be an adjunct and not an alternative to good palliative care. It is important that palliative care is fully supported as a way of improving the care to the patient who is dying so as to give him an improved quality of life.

The issues this paper deals with only adults. They are assisted suicide, euthanasia, terminal sedation techniques, care pathways as well as discussing the issue of doctor's involvement in judicial executions.

These are very 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. As with the issues discussed in the first paper, what is necessary 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 need to be re-visited.

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

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. This paper covers the situation in England (and Wales). As other countries within the UK have different legal systems, this paper may not apply to them and their law may change in a different direction than in England.¹

What is the End of Life?

As in the first paper, the end of life can mean the immediate time up to death occurring and also the period leading up to this. This paper will deal with both. It may be a period of months, weeks or days.

The definition of 'what is death' may vary from the classical *cessation of heartbeat and respiration to brain stem death* depending on cultural differences.

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 in as much that they strive to maintain life but if it reaches a point that the situation is considered clinically hopeless, the disease process is allowed to conclude with the patient kept comfortable. However, there are groups of patients and their relatives who believe that sanctity of life is absolute. This can bring them into conflict with medical staff in an end-of-life situation.

Also there is a possible clash between medical staff and the patient. At the end of life terminal care can be extended to keep the patient comfortable, pain and distress free. A number of patients feel though that they wish to control the time and method of

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their death rather than leave it to the medical staff and wish to take the options of assisted suicide and euthanasia. They may wish to take this option before they become physically unable to commit suicide. This does not rest easily with medical staff as the patient may wish action to be taken to die weeks or months before death would have occurred if the disease process had been allowed to progress naturally. Arguments develop over the patient's competence and capacity to make decisions such as these.

Assisted suicide

Assisted suicide is when a person who so wishes is helped to use means which cause them to die or attempt to die. The assistance may be in the form of information, counselling, travel arrangements and the supply of drugs and/or apparatus.

Suicide itself is no longer a criminal offence in England since 1961 when the law was changed under the Suicide Act.² The same act covered assisting suicide which is a criminal offence with a maximum sentence of 14 years in prison. With the rise of patient autonomy, some patients wish to end their life at a time and place of their own choosing, to die with dignity before body functions start to fail. If they have problems of managing the movements required to take medicines or to get possession of the necessary drugs, they may need assistance if they are going to commit suicide. As it is illegal in the UK, some patients travel to the European states where assisting suicide is legal. At present the only state which allows assisted suicide for non-nationals and non-residents is Switzerland. The other states which allow it for their residents are Belgium, The Netherlands and Luxembourg.

The question arose that 'was it assistance to accompany on or organise the transport to Switzerland'. In England there had been no prosecutions for this but there were requests for clarity as some patients going to Switzerland noted that they were going while they were still capable of making arrangements and travel without needing assistance because they were concerned that if they waited until they needed assistance anyone helping them to go would face prosecution. The Director

of Public Prosecutions drew up a list of public interest factors to weigh for and against a decision to prosecute for assisting suicide.³

The factors against prosecution include that the victim had clear wish to commit suicide and they had indicated that and asked personally for that assistance from the suspect. They had a terminal illness, a severe incurable disability or a severe degenerative condition with no hope of recovery. The suspect was wholly motivated by compassion, was a close friend, partner or relative and gave only limited assistance.

Euthanasia

Euthanasia is a term used for several different ways that a patient's life is ended by another person or persons. There is an implied beneficence in the action. The main distinction is between voluntary euthanasia and involuntary euthanasia. Voluntary euthanasia is as far as this paper is concerned is the intentional ending of life at the person's request and is also referred to as 'mercy killing'. Involuntary euthanasia is the ending of life *without the person's request and/or even their knowledge* and is not under discussion as all parties would require the patient to have been competent when they made the decision. This paper will therefore discuss the issues of voluntary euthanasia. Other terms used are active and passive euthanasia, active is taking positive steps to end life and passive is used in a number of medical scenarios such as withholding or withdrawing life sustaining medical treatment. As far as this paper is concerned passive euthanasia involves standard medical decisions and actions which were discussed in the first paper and is not covered further.

It must be pointed out that euthanasia is not an alternative pathway to palliative care but may be the patient's choice.

Euthanasia as an active way of intentionally ending life is a criminal offence and classed as murder. The verdict of murder has a non-discretionary life sentence. There are a number of partial defences to murder and in the often complex cases of mercy killing, the partial defence is killing while their mental responsibility is impaired for the act.⁴ This defence

if successful leads to a verdict of manslaughter which allows the judge to use discretion to impose a range of sentences from life imprisonment to a non-custodial sentence.

Why is there an ethical discussion over euthanasia? A number of patients are in severe pain and distress and do not want their life to continue. This may occur even if they are being treated by an excellent palliative care service. They would like their doctor [or another trained person] to end their life for them at a time and place of their choosing. They may make repeated requests over a period of months or years and their relative looking after them may with great compassion decide to carry out their wishes. Although this is legally murder there is in most people's mind a difference between this situation where a person is acting with compassion and where a violent murder for personal gain takes place.

Euthanasia is legal in the Netherlands, Belgium and Luxembourg. The patient must be competent to make the decision for voluntary euthanasia to be legal. As stated previously it is not legal in the UK and it seems unlikely that the law will change.

Terminal sedation

Terminal sedation is the medical practice of relieving pain and distress in the last period of life before death by using a continuous infusion of an analgesic and/or a sedative drug. The period of time may be days or hours and the rate of the infusion can be increased. It has other names such as palliative sedation or deep continuous sedation. The patient is kept well sedated and may have artificial means of hydration or nutrition removed.

As the intent is not to kill the patient but to relieve pain and distress it is not euthanasia and this is an example at one end of the range of care of the doctrine of 'double effect'.⁵

Care pathways – The Liverpool care pathway (LCP)

The Liverpool Care Pathway⁶ is a well-recognised model of care for the patient in the last few days/hours of life and is aimed at improving that care. It is well recognised and it is recommended in the

National Institute for Clinical Excellence's guidance on palliative care for patients with cancer as well as its Quality Standard (2011). It was developed by the Specialist Palliative Care team at the Royal Liverpool and Broadgreen Hospitals NHS Trust and the Marie Curie Hospice, Liverpool.

The pathway depends on the recognition that the patient is dying and treatment and interventions should be reviewed. It may be necessary to start new treatments, stop others or continue as at present. Although formal consent to use the pathway is not needed, it is required to discuss it if possible with the patient and the relative or carer. This is significant as it is about claimed inadequate communication that disputes have arisen and will continue to arise in the future. This is particularly true if as part of the pathway artificial nutrition and hydration are withdrawn. Although the patient should be kept pain and distress free, deep and continuous sedation is not part of the pathway and so it differs from terminal sedation.

As with many things in medicine, if the unexpected occurs and the patient improves the LCP can be stopped. There is therefore a need for patient reviews during its course.

Execution

Most of the world's population live in states where execution is a possible sentence. One of the techniques used for execution is lethal injection. This is in fact made up of three drugs, an anaesthetic induction agent or similar followed by a muscle relaxant and then a drug to stop the heart. Questions were raised about the adequacy of the anaesthesia and the possibility some prisoners were aware of the effects of the muscle relaxant. As a result of these concerns executions stopped in a number of USA states as doctors were asked to observe in one case and possibly help with the execution and in this instance they refused to assist.

There are arguments against having anything to do with executions and also for assisting. In the former, doctors may feel it is against their ethical standards. In the latter, the argument for giving assistance, it is necessary to consider that there are two basic

ways this can be done. Firstly, to train non-clinical staff and secondly for the doctor to take part in the executions itself. In both these two scenarios the argument for being involved is that either training or participation improves the skills required for the technique of the process and it is carried out efficiently and would thereby be less distressing for the prisoner.

Conclusion

This paper covers a number of contentious issues of medical treatment, ethics and the law. Each clinician needs to consider these and to come to a point of view. These views will be diverse and personal. It is up to all clinicians to conclude what their own position is. It is one of the fastest moving areas of medical law and ethics and again I re-emphasise that it is important these are discussed openly, calmly and without emotion. It is also important when

considering these issues to understand that these end-of-life issues should be considered only when the patient requests a different path more than the high standard palliative care which they should be receiving.

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