Euthanasia in chronic severe disablement

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One of the major dilemmas for the clinician caring for people with chronic disabling conditions is how to provide not only a good quality of life but also the best quality of dying. It is my view that the clinician should provide the opportunity for living before giving the opportunity to die. By this I mean that the clinician has the responsibility to ensure that efforts have been made to improve the quality of life by controlling clinical situations and providing psychological and emotional support. Once the decision has been made by patient, family and clinical team that it is inappropriate that life should continue, then the quality of the dying process should be of the highest standard. The present attitude of ending the patient’s life by withdrawal of nutrition and fluids is highly unsatisfactory, if not inhumane, and the option of euthanasia would be by far a more satisfactory solution.

In addition, a more satisfactory procedure than application to the High Court for a directive on withdrawal of tube feeding needs to be found. This method is very stressful for family and staff already in distress and is an extremely expensive approach. An independent ethical panel to ensure that the decision to end the patient’s life is clinically appropriate, is being carried out purely for the best interests of the patient and is not influenced by the other considerations.

Chronically disabling conditions are common. The OPCS survey of disability in Great Britain (1988)¹ found that 135/1000 of the population had limiting long-standing disability, with the prevalence rate rising from 21/1000 for those 16–19 years of age, through 106/1000 for those 50–54 years, to 779/1000 for those 85 years and over. The Royal College of Physicians’ Report (1986)², reviewing the literature further, analysed the clinical disorders producing disability and reported that, in a population of 250,000 people, the number who would be severely or very severely disabled would be 860 with arthritis, 115 with respiratory conditions, 340 with stroke, 55 with Parkinsonism and 80 with multiple sclerosis. The Medical Disability Society (1988)³ reported that there are between 250–375 people in a population of 250,000 with severe or very severe forms of brain damage.

With so many severely disabled people involved, the vulnerability of disabled persons to the disruption of their own self-image, along with the negative concepts to disability by the able-bodied population, makes consideration of ethical issues, including euthanasia, particularly relevant.
Terminology

One of the difficulties of discussing the subject of chronic severe disablement is that it covers such a wide range of disorders and attitudes. *Chronic* can include degenerative disorders (such as Huntington’s disease or motor neurone disease), conditions which are static for many decades (such as head injury or arthritis), or conditions with a fluctuating pattern (such as multiple sclerosis). Each pattern places a different emphasis on ethical decisions. This is further complicated in that the word ‘chronic’ is often used nihilistically, meaning ‘nothing further can be done’.

*Severe* is an even more subjective term. The person with paraplegia who is able to tour the world, hold down a job and run a home can be regarded as severely disabled. But severe disability can also be used to describe the patient in late stage multiple sclerosis or Huntington’s disease who is totally dependent for all activities and care needs, through to the vegetative patient unaware of the environment yet with the possibility of living for decades.

*Disablement* is used as a catchall term to cover *impairment*, *disability* and *handicap*. A severely impaired (e.g. amputee, hemiplegic or blind) person may not be severely *disabled* and certainly not necessarily severely *handicapped*. Since handicap (social functioning) depends on attitude of mind and motivation, rather than on the severity of the impairment or disability, then the quality of life affected by the impairment and disability is more related to mental state, mood, attitude, personality, ‘drive’ and the environment in which the patient lives. Thus a well motivated person with a constructive personality who is suffering from a ‘locked-in syndrome’, where there is total paralysis except for the ability to move the eyes, may have a better quality of life than a professional ballerina with chronic arthritis of the knee who is devastated at no longer being able to dance.

This preamble is important in recognising the ethical dilemmas faced by the long-term care physician. The severity of the disability as perceived by the observer may have little correlation with the opinion expressed by the disabled person.

The embarrassment demonstrated by able bodied people in trying to communicate with a severely neurologically disabled person is often expressed as a feeling that the disabled person would be better off dead. The present attitude to ‘value for money’ and that financial resources should only be used for demonstrable clinical gain, further leaves the disabled person dependent not only on the help but also the good-will of able bodied people. This leads to a lack of self image, depression and expression of dissatisfaction with life.

The ethical problems in chronic disablement are, therefore, not so much to do with the *severity* of physical disablement but with the ability...
to accept the handicap resulting from the impairment or disability and the influence of society's, usually negative, attitude to disablement. This, however, does give the opportunity, if not the duty, to take every effort to provide facilities to improve the quality of life of even the most severely disabled person. It is ethically essential to give the opportunity to live (in all meanings of the word) before providing the facilities to die.

Clinical ethical issues

Why should a severely disabled person wish to end his or her life? First it is important to emphasise that such expressions of desperation are rare, and usually the reason for the decision is made for very good, though often manageable, reasons.

Severe chronic pain would seem to be the most obvious reason to request euthanasia. Whilst it is not always as easy to control pain as is often stated, pain is often unnecessary because it has not been investigated sufficiently. Analgesia is only one approach to the problem, with much attention required for correct postural control with special seating, good nutrition, overcoming the sensation of general ill health and fatigue, management of depression and splinting of joints. The dilemma arises when there is a need to respond to the patient with intractable pain who requests physician aided termination of life.

Distress at the severity of the disability is another important concern. Ironically, it is often the less severely disabled person who expresses dissatisfaction with life. Very severely disabled people, especially those with brain damage, often do not have the insight into their condition to appreciate their loss. Dissatisfaction with life's lot is, of course, not confined to the disabled population. The request to die may simply be a cry for help.

The third element is the perception of being a burden on other people. There is no doubt that severe disability affects a family as well as the individual. Many families go to enormous lengths to support their severely disabled relative. Others do not have the social, emotional or financial resources to do so. This inevitably places pressure, either overtly or covertly, on disabled persons to recognise that they are a burden. How they respond to this will largely depend on their personality and strength of the family unit.

Whilst these pressures are understandable they are no different from any other clinical situation—they are symptoms for which the cause needs diagnosis and an appropriate treatment started. In chronic disability this is likely to require a combination of social, psychological and recreational, as well as clinical, solutions.
So what are the situations and issues which arise in the clinical management of people with chronic severe disabilities? There are two main situations which arise:

**The patient who is severely physically disabled but mentally competent and who does not want to continue to live**

This situation is really no different from the able-bodied person who does not want to continue living, and probably equally as rare. These patients have the absolute right to make decisions about whether they accept treatment or not. The clinician, however, has the responsibility and opportunity to discuss with them the reasons for their decision, to explain the options open to them and to explain the consequences. In addition, the clinician has the responsibility to ensure that patients are not making the decision to forgo treatment under duress or because they have a treatable condition which is influencing their judgement (e.g. endogenous depression or an acute illness which is making them feel unwell).

Even when the decision has been made to discontinue or withhold treatment, the clinical team are still not in a position to withdraw from the care of the person. They continue to have the responsibility to ensure that the patient is comfortable, does not develop any unnecessary complications, is free from unnecessary distress and remains dignified during the inevitable deterioration into the terminal phase and eventual death. The frustration of helplessness felt by the staff during these phases receives very little attention.

**Mentally incompetent patients**

Most situations concerning decision making about euthanasia or treatment issues will involve the incompetent patient.

The mentally incompetent patient should have the same rights as the competent person. The decision about whether the patient is incompetent is not always as easy in the clinical situation as it is in the philosopher’s chair. This dilemma has been expressed in the Law Commission’s *Report on Mental Incapacity*. They give two criteria for the definition of mental incapacity: that the person is ‘unable to communicate a decision on the matter because he or she is unconscious or for any other reason’; or that the person is ‘unable by reason of mental disability to make a decision on the matter in question’. The difficulty arises when attempts are made to define the ability to ‘make a decision’. The Law Commission attempted to clarify this by suggesting two sub-sets – one based on the inability to
understand relevant information and the other on the inability to make a ‘true choice’. The decision about these issues is far from clear in the practical situation.

Quality of life is a complex concept especially since it is so difficult to measure - what is a poor quality of life for one person may not be for another. Quality of life is subjective and, therefore, no matter what our views are about the level of the quality of someone else’s life, the only test is what that person feels. In my experience of working with severely disabled people, I have been surprised by their acceptance of, and ability to cope with, conditions I would have thought to be almost intolerable. Overt depression is not an obvious feature of severely disabled people provided that they have been given the opportunity to function optimally within the limits of their disabilities and in an environment suited to their needs.

One other aspect of this is that I have met several people who have stated, whilst able bodied, that they would not wish to continue living if they developed severe disabilities but who have changed their mind when they found themselves in such a situation. It is almost as though it were easier to understand what it must be like to be dead than have any concept of what it is like to be disabled.

This is particularly relevant since it has been stated that recovering, for instance from the vegetative state, to a severe level of dependency, is ‘worse than death’. These statements are made without any research evidence and often by people who have not been involved in the long term management of people with severe disabilities.

Even when the decision has been made that the patient is mentally incapacitated or incompetent, it can be very difficult to know what is in that person’s best interest. In any decision about clinical management there has to be a balance between the advantages and disadvantages of the treatment. It goes without saying that the overall benefit must be greater than the disadvantage or harm of the treatment. In complex disabilities this can be difficult, since incomparable benefits and side effects are being evaluated and we are dealing with degrees rather than absolutes.

Discussions about best interests have received much attention in cases involving the vegetative state. Here the issue is: ‘is it in the best interest of a patient who is unaware of his or her internal or external environment to continue tube feeding?’. The obvious answer may seem to be ‘no’ but it must be questioned whether the patient has any interest rather than a best or worse interest. If this is the case then the decisions are being made for the benefit of others, a dubious decision making process.

Even where the decision has been made to support the patient in life-limiting activities, the options open to the clinician are relatively limited. A do not resuscitate policy is reasonable when discussing cardiopulmonary
arrest, but is less helpful when considering other acute medical conditions. If a patient has received good care, then he or she should be in a good nutritional state and, therefore, resistant to infections. Even where infections do occur, withholding antibiotic treatment is just as likely to result in a live, but deteriorated patient, as in causing death. This can hardly be regarded as good clinical management.

The competent patient is likely to be too severely disabled to commit suicide and, therefore, any action by the clinician is assisted suicide. Where the patient is incompetent, then an action, or lack of action, requires a definitive decision by the clinician to assist in the ending of the life of the patient. Whatever semantics are used, withholding or withdrawing treatment will have the same outcome as euthanasia, i.e. the clinician will have taken a decision that the patient should die. This decision is difficult for many clinicians to come to terms with.

The only real option for the clinician, apart from euthanasia, is to withhold food and fluids. There are now several countries where it is accepted, usually after seeking legal declaration in a Court of Law, for feeding tubes to be removed from patients in the vegetative state. This creates several dilemmas for the clinician, even when he feels that the decision is an appropriate one. Whatever the legal view that tube feeding is treatment, there are many carers who regard feeding as care and, therefore, withdrawal of feeding causes them moral, ethical and practical problems.

Having decided that it is appropriate that the patient should die, then there is a reluctance to be seen to take an active part in the ending of the life. We cling to the concept that food is a treatment. Since the ‘treatment’ is futile, we can, therefore, stop the treatment and the patient will die due to the brain damage. To assuage our own emotional needs, we then decide to starve and dehydrate the patient over a period of 10–14 days until he or she dies of ‘natural’ causes. The argument, that since the patient cannot feel discomfort from this treatment, then the slow mode of death is acceptable, denies the respect we have for a dying person. Even a dead person is treated with respect and we would not carry out acts on a dead body simply because they would not be felt. Society is, therefore, in a dilemma—it is of the opinion that the patient should die, but it does not want a quick death because that would be seen as euthanasia.

The decision to withdraw or withhold feeding in the vegetative patient is difficult, but the situation becomes more difficult when dealing with the patient who is aware but profoundly disabled. This can be seen, for instance, in deciding whether to place a gastrostomy tube in a patient with Huntington’s disease, where the condition is deteriorating and the patient is cognitively impaired, and dysphagic. In this situation certain questions have to be asked:
1. If the tube is not placed, what will the consequences be to the patient?
   a. Will the patient be able to get sufficient food or fluids if additional care is taken and more time is available to feed the patient?
   b. Is the patient choking at frequent intervals.
   c. Is the patient losing weight rapidly?
   d. Is the patient developing pressure sores?
   e. Will the patient become dehydrated?

2. What is the progression of the disorder the patient is suffering from?
   a. Is the patient suffering from a rapidly deteriorating condition?
   b. Will tube feeding merely delay the natural terminal stages of the illness?

3. What effect will tube feeding have on the quality of life of the patient?
   a. Will it enable the patient to have less distressing bouts of choking?
   b. Will it enable the patient to feel better?
   c. Will it enable pressure sores to heal in a patient who is not in the terminal stages of illness?
   d. Will tube feeding merely prolong an already unhappy, unsatisfactory or distressing life?
   e. Will tube feeding merely prolong 'existence' in a patient who is unaware of his or her surroundings?
   f. Will tube feeding give the opportunity to see if optimal conditions will allow the patient to make some recovery?

There is growing support for the concept of advance directives in assisting with the decision making on behalf of incompetent patients. There is, indeed, much advantage as far as the clinician is concerned in accepting advance directives at face value. The difficult decision can be taken out of the hands of the clinical team, since they are simply obeying the wishes of the patient. It helps to overcome difficulties in the case of the incompetent patient, where there are differing views amongst members of the family or where the family have taken a position which is at variance to that of the clinical team. It also makes it easier for the decision to be made when there are differing opinions as to appropriate action amongst the members of the clinical team.

The strength of the advance directive is its ability to provide help to the clinician in the end-of-life treatment decisions. But, in chronic disability, we are often not dealing with terminal events and, therefore, the concerns become quality of life, or dying, issues—a much less objective field of clinical evaluation. The purpose of an advance directive is to give the incompetent patient the same rights of decision making as the competent patient, as discussed above. However, advance directives are often made without the opportunities for informed consent required for the competent patient. Concerns include:
Informed consent On what basis did the patient make the decision that he or she would not want to be treated? The decision not to accept treatment should be based on clear understanding of the situation. It is therefore essential that the patient really understood the disorder. This can be complicated in rarer conditions, such as vegetative state for instance, where the clinician giving the advice has very little experience, if any, of the condition and is, therefore, not knowledgeable enough to give informed guidance.

Opportunity to change mind In a patient who is mentally alert and who makes a decision not to receive treatment, there is always the opportunity for the clinician to sit down with the patient and discuss the reasons for the decision in the light of the particular clinical features of that patient. The clinician also has the opportunity of discussing with the patient why he or she does not want treatment. Is it fear of pain, of loss of dignity, concern for others, etc.? In these circumstances, the clinician is, therefore, in a better position to ensure that the patient has clearly thought out the decision. This possibility is removed when faced with an advance directive and an incompetent patient.

Potential for scientific development Competent patients have the advantage of making their decision based on up-to-date knowledge. Advance directives may be made many years prior to the time for their implementation, during which period new treatment or changes in quality of life opportunities may have occurred.

Clarity of the advance directive Advance directives are not always clear about the intention of the patient. For instance, I have seen a recent advance directive which stated that, if the person developed severe brain damage, she would not want to continue living. There was no statement as to whether this decision was to be made on the first day or after a period of several days/weeks/months to give the opportunity of recovery. The definition of severe brain damage gives great opportunities for widely differing opinions, even amongst clinicians experienced in the management of brain damage.

One major difficulty for the chronic care physician is 'who should make the decision that it is not in the patient's best interest to receive treatment?'. Whilst it is usually recommended that the family be involved in the discussion about the management of the incompetent patient, they do not have the legal authority for deciding what is in the best clinical interest of the patient. Since treatment requires a clinical decision, the family, whilst expressing opinions, do not have the final say in the treatment. When the issue is care, as opposed to treatment (though the
distinction is not always obvious), then the position of the clinician is less clear.

Whilst relatives may be in the best position to advise on the views that the patient would have expressed, there is always the concern that they may be transferring (consciously or otherwise) their own opinion of the situation. Inevitably, disabilities affect a family rather than just the individual and, therefore, there are dilemmas in deciding what emphasis to put on the relatives’ views. This is even more complicated when, not uncommonly, there are differing views within the family.

References